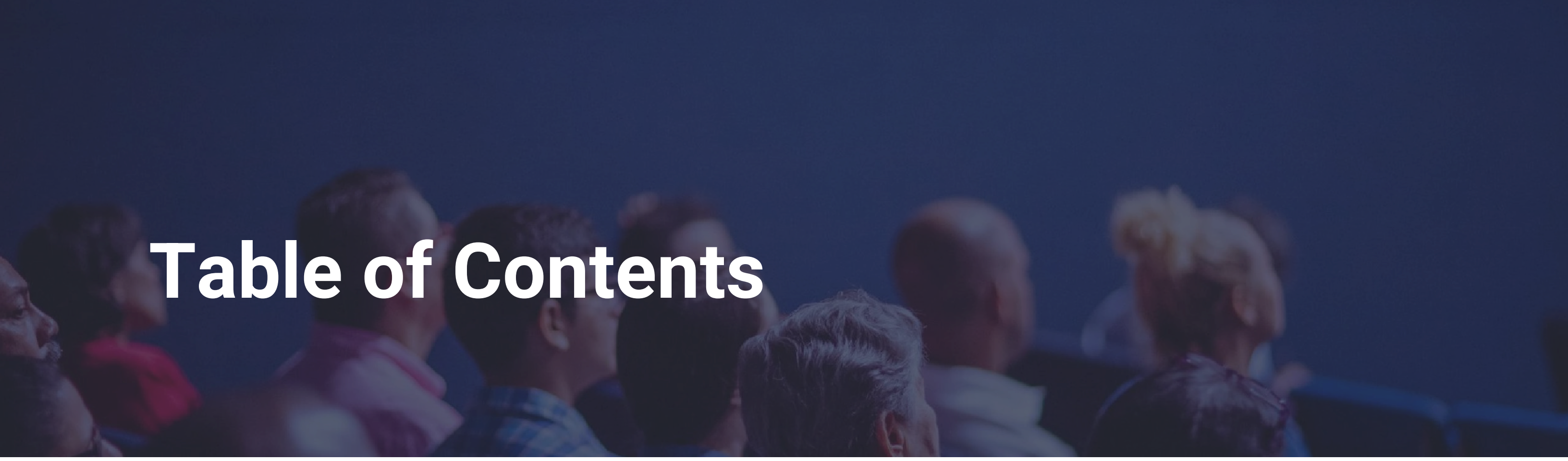
Family Forum and Family Representative Group Review

Final Report

April 2025



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Executive Summary

Genio was commissioned by HSE National Disability Services to independently review the functionality and sustainability of the Family Forums and FRGs. This final report draws on mixed-methods research, combining a survey with a 70% response rate (n=202 respondents) with focus groups and sensemaking sessions involving Family Representatives, Children's Disability Network Managers (CDNMs), Independent Facilitators, HSE Heads of Disability Services, and Lead Agency CEOs. 53 participants took part in the qualitative stage with participants from all 9 Community Health Organisations (CHOs).

Fundamental Issues of Functionality and Sustainability

The most significant finding is that the vast majority of Family Representatives and CDNMs perceive the forums as ineffective in improving service outcomes, with only 17 percent of Family Representatives and 14 percent of CDNMs rating them as effective or very effective. This is exacerbated by a **misalignment of understanding across stakeholders of the primary purpose:** nearly half of Family Representatives view it as a space for driving service improvements, compared to just 28 percent of CDNMs.

The disconnect in perceived actions arising from the forums is clear: 38 percent of Family Representatives said nothing had been actioned, compared to just 10 percent of CDNMs.

A further challenge is the inconsistent interpretation of roles and responsibilities, which is closely tied to the wider misalignment of understanding across stakeholders of the purpose.

Family Representatives, and CDNMs reported emotional strain, much of it stemming from unstructured, townhall-style meetings where forum discussions are perceived as grievance-focused and unresolved, compounding a sense of fatigue and disengagement.

Clarity around the escalation and outcomes of issues raised to the Governance Group remains inconsistent, with a significant number of Family Representatives unsure of processes or impact. Progress is often overshadowed by these ongoing challenges and remains isolated and unshared.

As forums have evolved differently across the country, their formats and functionality now vary. The review has captured this shift, with some moving away from townhall-style meetings toward more productive thematic, clinician attendance and networking-based models.

The research identified several emerging pockets of progress, including where:

- An area established **alternative mechanisms for escalating concerns** outside the remit of the CDNT (Children's Disability Network Team) and allowed Family Representatives to engage policymakers outside the forums. This led to more constructive Family Forums, where participants were kept focused on issues relevant to their CDNT.
- An area addressing emotionally charged forums through **training in constructive communication and de-escalation,** active listening strategies, and scenario-based roleplays.
- An area focused on **improving communications**, including newsletters, and asking family members about improvements they can make to their communications.
- One area has strengthened **co-design for service improvement** through small service-level working groups, and feeding the progress back into the family forum.

Reimagining Family Forums as Platforms for Service Innovation

The research highlights a lack of clarity around the purpose and roles within Family Forums, as well as significant inconsistencies in how they operate across the country. As there is broad agreement that the forums are not currently improving service outcomes, this shared concern points to the need for change. Family Forums could serve as inclusive spaces for constructive idea-sharing, while the FRGs could provide a more formal platform for co-design, ensuring that family voices help shape service improvements.

The short-term recommendations focus on establishing clarity of purpose and roles across Family Forums, FRGs, and Governance Groups, addressing immediate pressure points while strengthening psychological safety and communication. Standardised induction and training will reinforce role clarity and collaborative practice. Medium-term actions expand on this through practice-informed training and structured working groups for co-design. Long-term goals aim to embed co-design at every stage of service improvement, with regional alignment, consistent measurement, and national structures to support shared learning and scaling of service improvements.

The following table provides a concise overview of key actions to support the HSE in reimagining Family Forums and Family Representative Groups (FRGs) as platforms for service innovation. More detailed information is available in the report.

Timeline	Focus Area	Key Actions
Short Term (0-9 months)	Clarify Purpose and Remit	• Reposition Family Forums as thematic, solution-focused platforms for improving service outcomes. • Strengthen the FRG's role in driving service improvements by creating clear pathways for ideas from the Forums to be integrated into workplans. • Clearly define and communicate the roles of Family Forums, FRGs, and Governance Groups in relation to improving service outcomes. • Review, map, communicate and, where necessary, revise the complaints and grievance processes for families to ensure that issues which are outside the remit of the Family Forums can be effectively pursued through appropriate channels. • Train facilitators to redirect out-of-scope issues.
Short-term (0-9 months)	Role Clarity and Induction	• Deliver standardised inductions for all stakeholders (Family Reps, CDNMs, Governance Groups, Facilitators). • Define roles, expectations, and role boundaries. • Emphasise facilitator's role in maintaining focus on innovation and psychological safety. • Clarify time commitments and compensation for Family Representatives.
Medium term (3-9 months)	Training and Capacity- Building	• Roll out training in co-design, de-escalation, and psychological safety. • Use scenario-based learning to build collaboration skills

Timeline	Focus Area	Key Actions
Medium-term (3-9 months)	Service Innovation Process	• Co-develop annual service innovation plans (FRG + Operational Management Group O(MG)). • Prioritise proposals from Family Forums based on feasibility and impact (FRG + OMG). • Launch targeted working groups with clear Terms of Reference. • Compensate family participants and define expectations. • Embed feedback mechanisms.
Medium-term (3-9 months)	Measurment and Communication	• RHAs to define standard metrics to measure forum impact. • RHAs to track and share service improvement outcomes consistently. • Use newsletters, websites, and reporting to communicate progress. • RHAs to identify and prepare successful initiatives for regional scaling.
Longer-term (12 months+)	Embedding Co-Design	• Fully integrate co-design into all stages of service planning, delivery and evaluation.
Longer-term (12 months+)	National Scaling and Shared Learning	• Develop a national database of innovations. • Create a national learning network across RHAs. • Use family feedback and data to inform national improvements.

Introduction

The governance structures of children's disability services, set out in the Children's Disability Network Teams (CDNT) Governance Policy, include a Family Forum and Family Representative Group (FRG) aligned to each of the 93 CDNTs. This report presents the findings of an independent review carried out by Genio into the functionality and sustainability of Family Forums and FRGs within CDNTs.

This final report presents the unequivocal themes that emerged from a comprehensive mixed methods study. The research process included a national survey with a high response rate, a series of stakeholder focus groups, and a round of appreciative inquiry interviews. Crucially, the emerging findings were returned to participants across two dedicated sensemaking sessions, providing an opportunity to validate the insights, add nuance, and deepen the analysis through reflection and challenge.

The findings reveal persistent barriers to effective engagement, including a lack of clarity around the purpose and roles within forums, inconsistent practice across areas, and concerns about emotional burden. At the same time, the research identified a number of positive examples where forums have functioned more effectively, offering practical insights into what enables meaningful collaboration.

This report outlines those findings in detail and offers a set of short-, medium-, and long-term recommendations aimed at improving the functionality and sustainability of Family Forums and FRGs. It seeks to support a shift from grievance-driven spaces to more constructive, inclusive platforms for co-design and service innovation.

Background

The Promise of the Family Forums and Family Representative Groups

The Roadmap for Service Improvement 2023 – 2026 (HSE, 2023a) outlines Family Forums and FRGs as central to enhancing children's disability services in Ireland. The Roadmap recognises that the establishment of the Family Forums "is critical to ensuring that families' voices are heard and an authentic partnership with children's disability services is forged to inform service developments and improvements" (p. 6).

The CHO Governance of Children's Disability Network Services Policy (2021) outlines the terms of reference for the Family Forums as follows:

1. To involve families in the development of children's disability services in their local CDN 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 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.

The HSE's 2022 guide "Setting up and Sustaining the Family Forum - A Guide for CDNMs and Lead Agencies" adds that:

"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" (HSE, 2022, p 4).

The 2023 HSE policy “CHO Governance of Children’s Disability Network Team Services (Revision one)” outlines the primary goals of the forum as follows:

1. For the CDNM 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

2. 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

3. 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

4. To share information on:

- Service provision, governance and access
- Community supports
- Rights of the child and the family
- Other relevant topics of interest

5. To facilitate networking and sharing knowledge and experiences amongst families (HSE, 2023b).

Furthermore, the policy outlines the terms of reference of the FRGs as follows:

- For the two elected Family Representatives from each Family Forum in the CHO to learn and share feedback from the various different Family Forums.
- To select two Family Representative Group members to attend each CHO CDNT Governance Group meeting.
- To select two Representatives of the Family Representative Group to meet with the Operational Management Group as indicated by the CHO CDNT Governance Group, in order to seek input on service experiences and service development opportunities and agree action plans and timelines for same.
- To raise and collate issues, and suggestions/ideas for their resolution at appropriate levels of the governance structure.
- To develop a feedback template to support timely feedback to the family forums.

Embedding Family Representation into Governance Structures

HSE policy and guidelines demonstrate a strong commitment to incorporating Family Representatives into the governance structures of children's disability services and the decision-making processes. The FRG “comprises two representatives from each Family Forum in the CHO, to share feedback and learning, to provide for representation on the Children’s Disability Network Governance Group, and to meet with the OMG”.

Two Family Representatives from each FRG are elected to the Governance Group for Children's Disability Network Services. This Governance Group "provides a nationally standardised governance structure for children’s disability network services across the CHOs" (HSE, 2023, p. 7). According to HSE policy on the CHO Governance of Children’s Services, the inclusion of Family Representatives ensures:

- "There is a focus at all times on the needs of children and their families"
- "Bringing the view from the family perspective on all issues discussed"
- "Bringing a wide range of competencies and experience"
- "Bringing lived experience and themes expressed via Family Forums" (HSE, 2023, p. 7)

In addition to their role on the Governance Group, Family Representatives nominate two members from the FRG to attend meetings with the OMG. The OMG is "responsible for ensuring consistency in management and operation of all CDNTs across the CHO in line with the PDS principles and CDNT model of services and supports" (HSE, 2023, p. 4)

Translating Commitment into Action

While HSE policy and guidelines endorse family engagement, collaborative working, and co-design, translating these commitments into effective practice is a significant challenge.

A key issue is the lack of solid policy guidelines about how to meaningfully engage stakeholders. Beresford (2010) outlines a spectrum of service user involvement, from consultation to user-controlled organisations. Yet, consultation, often the most common form, is frequently reduced to a "tick box" exercise, leaving participants feeling their input has little tangible effect (Beresford, 2010, p. 497). For instance, Benz et al. (2024) stress that while the rationale behind co-design—the "why"—is well-established, there is a pressing need to focus on the "how," calling for more detailed methodologies to ensure its effective implementation. Without clear guidelines, co-design risks becoming a vague concept, as Blomkamp (2018) cautions, where "almost everyone seems to be doing it" but with little understanding of what the process truly entails (p. 4). Loeffler & Bovaird (2018) echo this, emphasising the need for more empirical research to examine how co-design is being applied, by whom, and what outcomes it is delivering.

Blomkamp (2018) outlines three key areas where co-design can deliver real benefits if properly implemented. First, the involvement of a diverse range of participants, including citizens, end users, stakeholders, professionals, and experts, throughout the design process ensures that both problem definition and solution generation are more likely to meet the needs of the public and government. Second, the integration of design thinking, originally used in the private sector, into the public sector is recognised as a way to improve service quality by incorporating user interests into the design process. Finally, co-design can strengthen relationships, build trust, and foster mutual understanding, which could address public disengagement and low levels of trust in government, thus building social capital (Blomkamp, 2018).

Organisational Preparedness for Family Representation on Governance Structures

While HSE policy focuses on embedding Family Representatives into the governance structures of children's disability services, there is a need to examine how this participation is actualised. It is important to distinguish between different types of citizen participation. Influential typologies of citizen participation outline a wide spectrum, ranging from non-participation to tokenism and ultimately to citizen-controlled governance (Arnstein, 1969; Pretty, 1995; Cornwall, 2008). “Participation through information sharing, for example, might limit more active engagement” (Cornwall, 2008, p. 271). Arnstein's (1969) "Ladder of Citizen Participation" illustrates this progression, highlighting how participation can range from manipulation and therapy (non-participation), through informing, consultation, and placation (degrees of tokenism), to partnership, delegated power, and citizen control (levels of citizen power). Pretty (1995) expands on this by categorising participation into seven types, from passive participation to self-mobilisation, emphasising the varying degrees of stakeholder influence.

The integration of Family Representatives into governance structures reflects a clear dedication to inclusive decision-making. Yet, a key challenge is the organisation's ability to adapt and provide the necessary groundwork to support these representatives in making a meaningful impact at the governance level. Pozniak (2021) raises a relevant question: "Is family engagement embedded in the wider infrastructure of organizations, and if so, how?" (p. 1). To foster meaningful engagement at an organisational level, Pozniak (2021) stresses the importance of openness to learning, relationship-building, and continual improvement through family insights (p. 7). Without this level of organisational support and acceptance of stakeholder engagement, issues can arise. For instance, Staley (2009) highlights the potential emotional burden on stakeholders if proper supports are not provided, noting that expecting them to manage without adequate support is “ethically unacceptable” (p. 59). One example in Staley's research involved a mental health project where a user researcher, overwhelmed by workload and lack of support, experienced a relapse (Staley, 2009, p. 60). This situation highlights the distress that can arise when participants recognise the limitations of their involvement or are exposed to negative media portrayals of their efforts (Staley, 2009).

Stakeholder engagement in the decision-making structures has significant consequences at an organisational level. Desai (2018) observes that "decision makers take risks to their organisation’s legitimacy into account, becoming less likely to engage collaboratively when stakeholders are relatively powerful or when past practices have directly been called into question" (p. 37).

Moreover, studies have found that when tensions arise in practice, collaboration is frequently scaled back or interpreted differently by stakeholders (Høvring et al., 2018). This indicates that without adequate support and a culture that embraces shared decision-making, the presence of Family Representatives on governance structures may not lead to the intended meaningful impact.

A Mixed Methods Study

This report presents on the findings triangulating insights from every stage of the mixed methods research in order to develop ways forward for the functionality and sustainability of the family forums and FRG. The first stage of the research, which included a survey with more than a 70% response rate (See figure 1) and focus groups with Family Representatives who have sat on Governance Groups, CDNMs, Independent Facilitators, Heads of Disability Services, and CEOs of Lead Agencies. This provided an initial understanding of the issues affecting Family Forums and FRGs.

The second phase of the research involved returning the interim findings to the participants in five participant groups sensemaking sessions to deepen the analysis and ensure a more nuanced perspective. The initial data was returned to the participants for them to challenge, add and deepen the findings and their analysis.

Lastly, five appreciative inquiry interviews were undertaken to explore pockets of progress where forums were functioning more effectively (n=7).

Survey design

The survey was designed based on a review of previous studies on engagement, participation, and co-designed services (Bovaird, 2007; Voorberg et al., 2015; Saini et al., 2021), as well as feedback from a piloting phase. Although not exhaustive, the literature review provided a solid foundation by considering lessons learned from earlier research. The survey aimed to address three key areas identified in the literature: conceptualisation of participant's expectations and motivations; interpretation of pathways and processes within the forums and FRGs; and outcomes that provide tangible evidence of the forums' and FRGs impact.

The survey included a mix of closed-ended questions for quantitative analysis and open-ended questions to capture qualitative insights from Family Representatives on the FRG, CDNMs and Independent facilitators.

Survey Distribution

The survey was administered electronically using Survey Monkey. Invitations were sent via email to all identified Family Representatives on the FRGs, CDNMs, and Independent Facilitators. Participation was voluntary, and confidentiality was assured to encourage honest and open responses. Reminder emails were sent two weeks after the initial invitation to enhance the response rate.

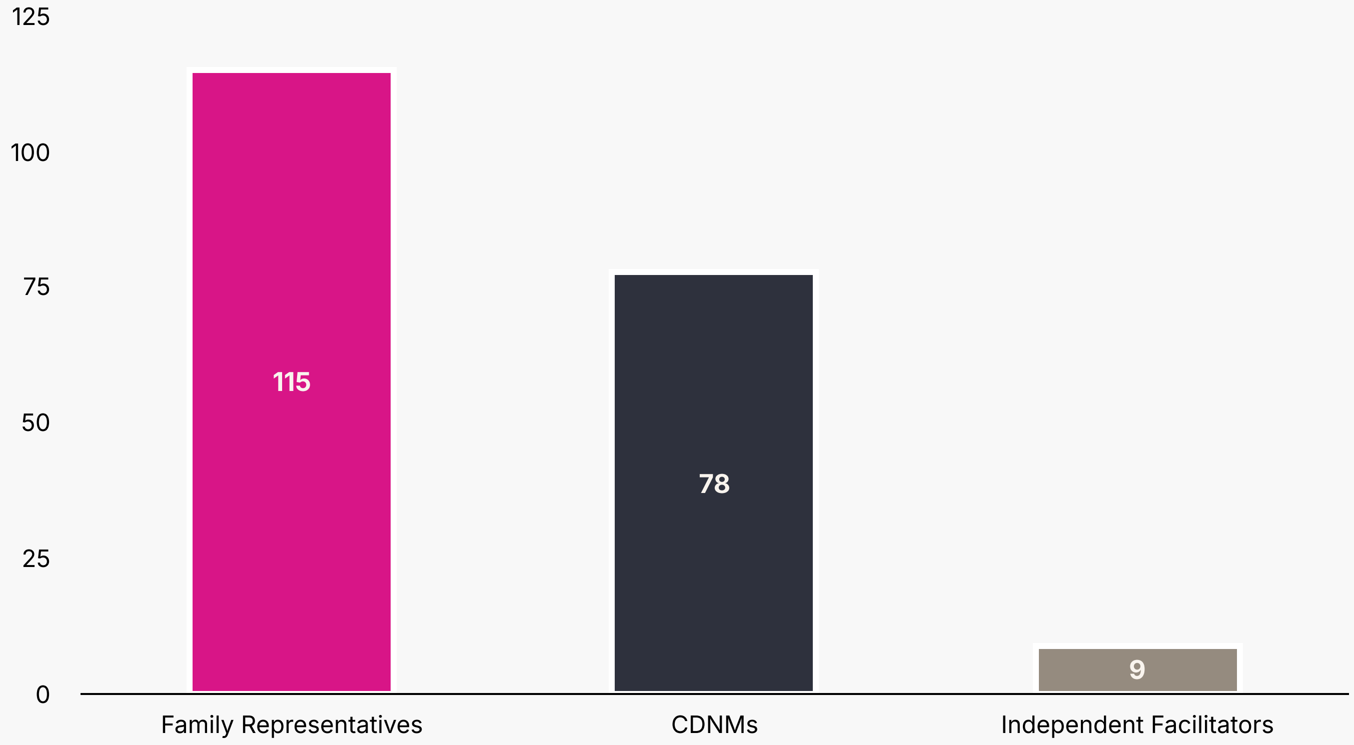
Response Rate and Participant Demographics

The survey achieved an estimated overall response rate of over 70%, with 202 respondents out of a total population of approximately 288 stakeholders. The respondents were broken down as follows:

- Children's Disability Network Managers (CDNMs): 78 respondents
- Independent Facilitators: 9 respondents
- Family Representatives on the FRG: 115 respondents

This high response rate indicates strong engagement from the stakeholders and provides a robust dataset for analysis.

Figure 1: Survey Respondents



Focus Groups: Initial understanding of Functionality and Sustainability of Family Forums and FRGs

To gain deeper insights beyond what the survey could capture, seven focus groups were conducted with key stakeholders including Family Representatives who have sat on Governance Groups (n=14), CDNMs (n=8), Independent Facilitators (n=5), Heads of Disability Services (n=5), and CEOs of Lead Agencies (n=5). The focus groups aimed to delve into participant's conceptualisations, motivations, and expectations regarding the Family Forums and FRGs, as well as to explore interpretations of the pathways and processes. Each focus group facilitated open discussions, allowing participants to share experiences and perceptions in a collaborative environment. This qualitative approach provided rich, detailed data that complemented the survey findings.

Sensemaking Sessions: Adding Nuance and Validation

The key themes from the interim report were presented to participants, highlighting several critical issues. In addition to validating the interim report’s findings, the sense-making sessions encouraged participants to challenge any findings they felt did not represent their experiences. Several themes emerged, adding depth and nuance to the initial findings.

Appreciative Inquiry: Validating the Research through a Strengths-Based Lens

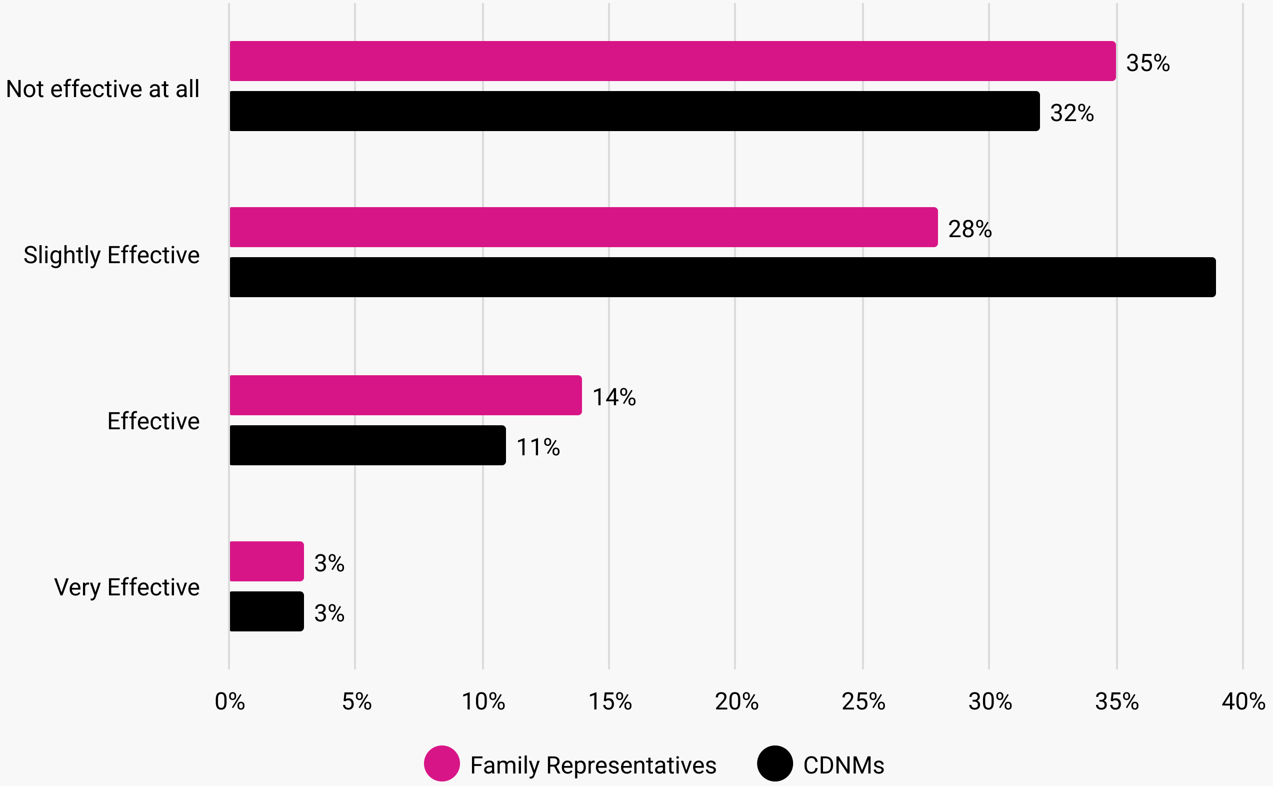
While the survey, focus groups and sensemaking sessions revealed widespread concerns and inconsistencies, they also surfaced a small number of promising examples where forums were functioning more effectively. Appreciative Inquiry built on these earlier stages by honing in on these pockets of progress to explore what was working well. Five Appreciative Inquiry interviews were conducted with key stakeholders, including a family representative, two independent facilitators, a CDNM, and a focus group involving a CDNM, a clinician and a family member. These discussions created a space to better understand the specific conditions and practices that enabled meaningful engagement and collaboration, offering valuable insights that could inform broader improvements.

Findings Part One: Service Outcomes

Service Outcomes

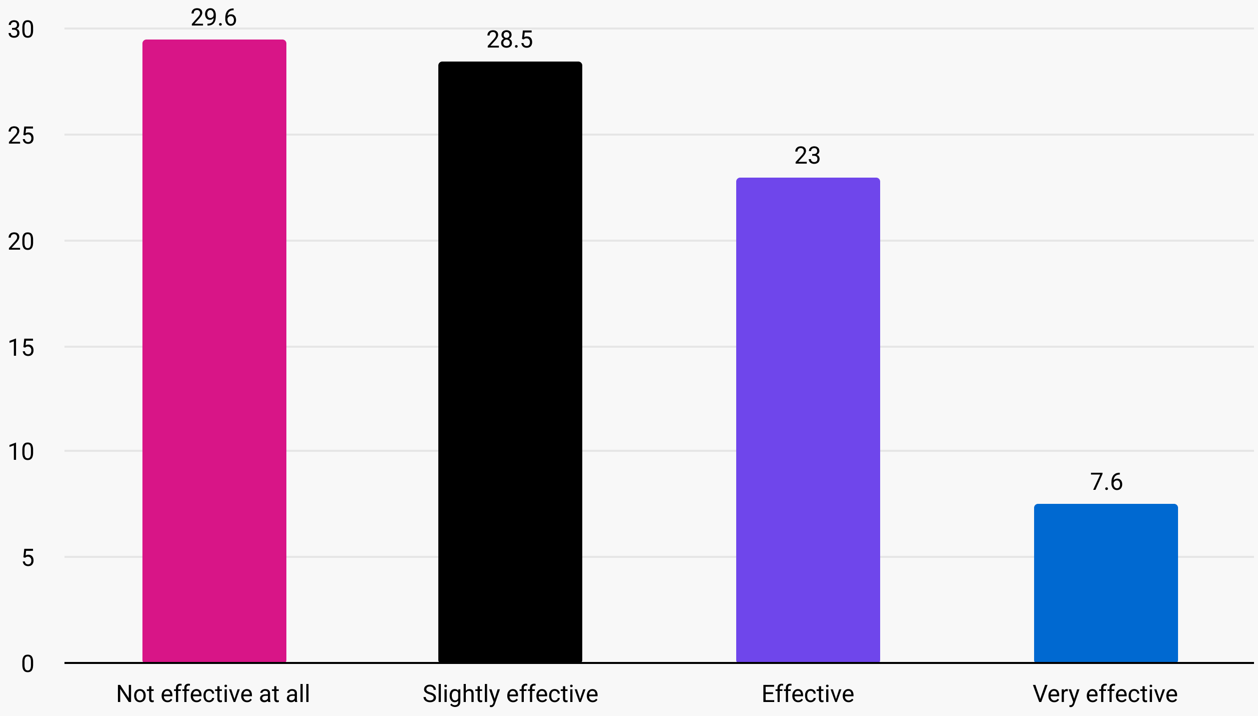
There is a widespread perception that Family Forums are not leading to improved service outcomes for children. When asked how effective they feel the Family Forums are in achieving better outcomes for children and their families only 17% of Family Representatives believe they are effective or very effective and only 14% of CDNMs believe they are effective or very effective.

Figure 2: CDNM and Family Representative's perception of the effectiveness of the family forums



When asked about the effectiveness of the Family Representative Group (FRG) in improving service outcomes, one-third of Family Representatives rated their FRG as effective or very effective. In contrast, two-thirds rated their FRG as only slightly effective, not effective at all, or said they didn't know.

Figure 3: Family Representatives perceptions of the effectiveness of the Family Representative Groups in improving service outcomes



There was unequivocal agreement across all stakeholder groups that, despite the time, effort and resources invested in establishing Family Forums and FRGs, they are not leading to improved service outcomes. As one Independent Facilitator observed, “there is a lot of interest and a high level of commitment from the parents that I’ve met on the FRGs I work with. There is a high level of frustration among the parents on one of the FRGs I work with at the lack of progress in improvements to services. In spite of this many are still persisting in their roles.”

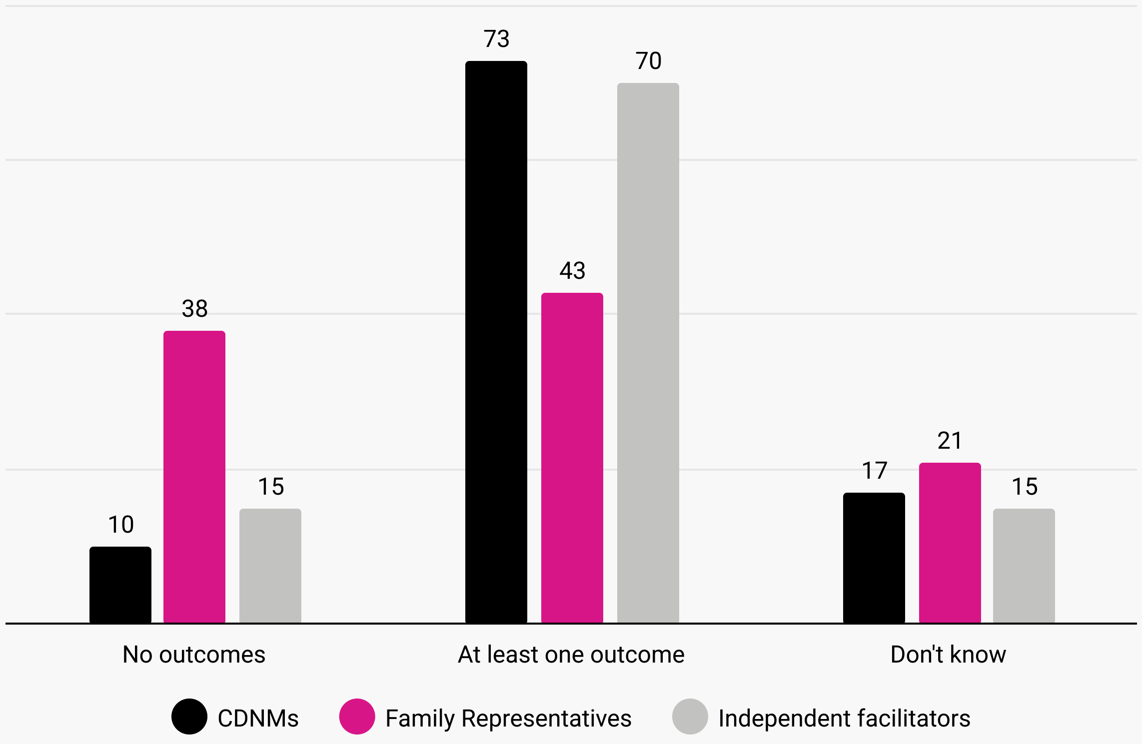
Family Representatives expressed a desire to be part of shaping better, more consistent services. One parent spoke about the importance of families contributing to policy development alongside professionals. For instance, one Family Representative explained the development of a motor management policy whereby “experts will be getting together… the policy will be put together based on expertise from qualified people… there’s going to be parents involved and families involved.” They saw this collaborative approach as a way to ensure that innovation is informed by both clinical knowledge and lived experience: “It’s a policy about motor management… it’ll inform best practice… and it will be one sounding board that everybody who’s involved in your child’s care… will pick from and they’ll all work off that.”

Participants across all groups have noted that discussions often become dominated by frustrations with the broader system, leaving little space for acknowledging progress or sharing effective practices. As one Head of Service observed:

"I think sometimes there's such a focus and defensiveness on the big picture that people aren’t appreciating the small wins and actually even focusing on the benefits that have taken place. It’s really hard to get them vocalised, and one of the pieces that has come back in our area is that where people do make progress, there's huge peer pressure. I notice a big difference in meeting people independently versus meeting them as a group—people are afraid to talk about things that have worked because others are experiencing difficulty, so the good stuff isn’t really getting to the surface at all."

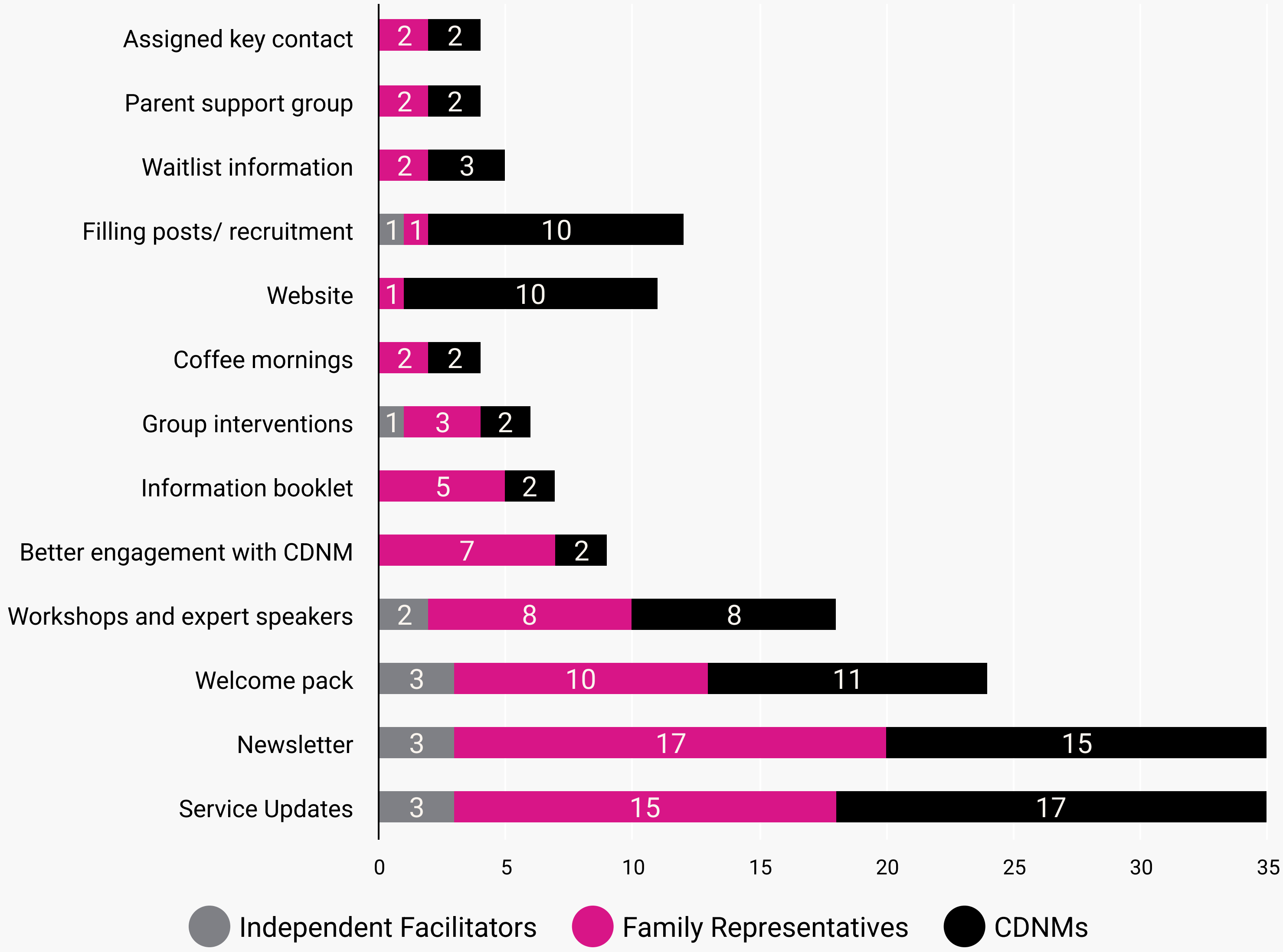
There is a perception that the negativity present in some forums makes it difficult to focus on any progress that is made. The survey revealed the perceptions of the kinds of actions achieved through the Family Forums captures a significant misalignment between Family Representatives and CDNMs. When asked to describe any issues that arose in the Family Forums that have been actioned, 38% of Family Representatives reported that nothing has been actioned. In contrast, a much smaller portion, 10% of CDNMs said that nothing has been actioned from the Family Forums, suggesting a disconnect between these two groups in terms of perceived outcomes and actions from the forums.

Figure 4: Perceptions of actions arising from the Family Forums



The survey indicates that the most significant impact of the forums has been improvements in the communication, between families, CDNMs and services and greater transparency and openness about the status of services in the local areas. This has been achieved through service updates, the development of newsletters, information booklets, introduction packs, websites, and posters. For instance, the introduction of newsletters and posters has been highlighted as a key step in keeping families updated on service modules and available facilities. One Family Representative noted the "use of social stories to address changes, redevelopment of info pack, introduction of newsletter and posters". However, while these have been developed at a local level, there is a lack of national co-ordination, leading to duplication of effort and mounting frustrations about time wasting.

Figure 5: Types of actions arising from the Family Forums



Findings Part Two: Clarity of Purpose

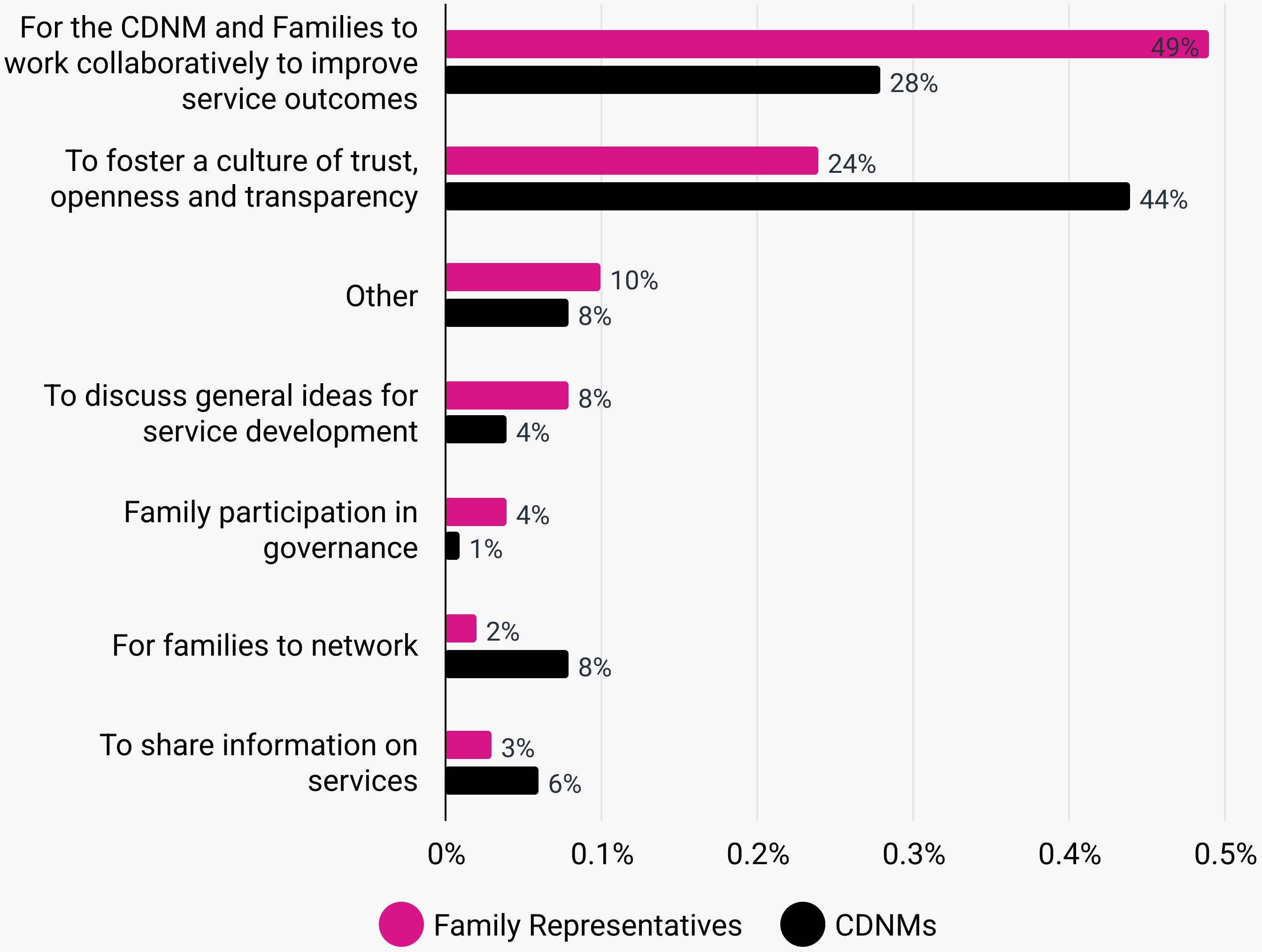
Clarity of Purpose: The Family Forums

The call for clearer purpose and role definition in Family Forums and FRGs was voiced by CDNMs, Family Representatives, Facilitators, Heads of Service Disability and Lead agency CEO's, with the significant majority advocating for a more structured approach to the forums. All stages of the research confirmed a misalignment of understanding across stakeholders of the primary purpose of the family forums, and therefore a misalignment in expectations.

The survey reveals this notable difference in the understanding of the primary purpose of Family Forums between Family Representatives and CDNMs. Specifically two significant divergences were:

- Fostering collaboration to improve outcomes for children: Almost half of the Family Representatives 49% viewed this as the primary purpose of the forums. However, only 28% of CDNM members shared this opinion, reflecting a significant difference in perspective.
- Fostering a culture of trust, openness, and transparency: When asked what the main focus of the forums should be, 24% of Family Representatives agreed with this purpose. In contrast, a larger percentage of CDNMs 44% believed that building trust, openness, and transparency should be the forum's central focus.

Figure 6: CDNM and Family Representative Perception of the Primary Purpose of the Family Forums



Inconsistencies Across Family Representative Groups

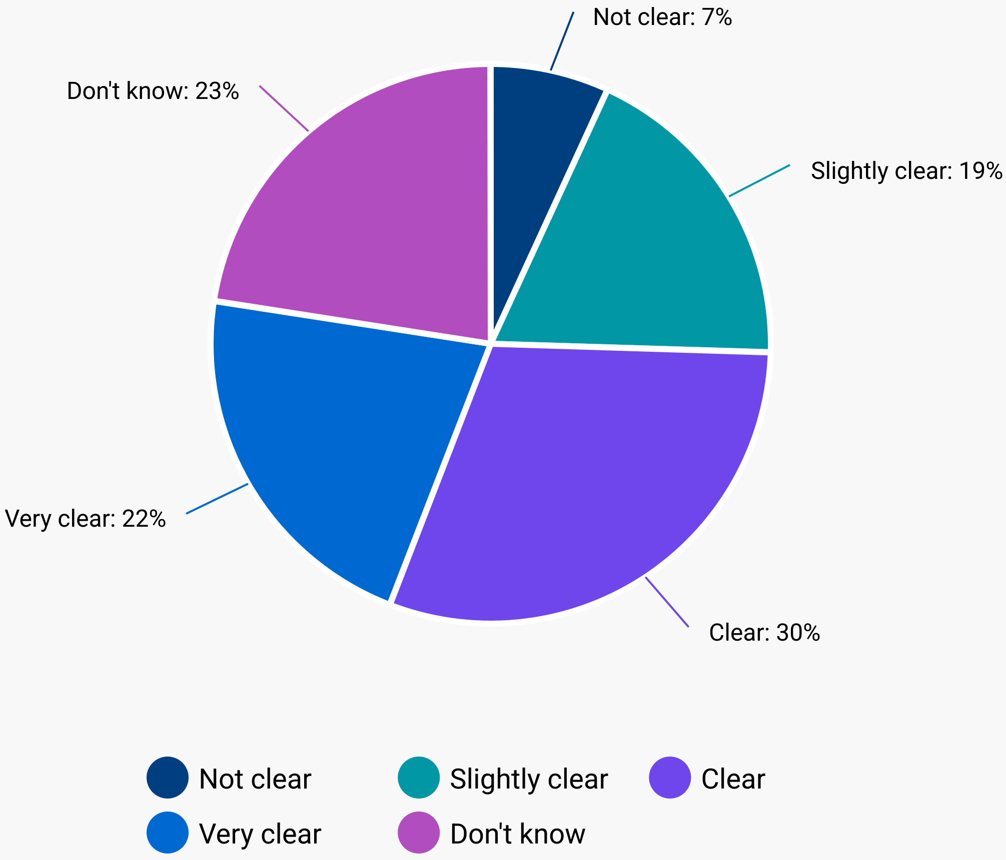
The FRG is intended to be the linchpin connecting Family Forums with higher-level decision-making bodies like the OMG and the Governance Group. For this to happen, there are extensive calls for a stronger purpose for the FRG itself, and clarity around escalation processes and feedback loops from the Family Forums up to the OMG, Governance Group and back down.

One Family Representative emphasised the need for a "clearer definition of the role of reps and if we are really working on co-design." An independent facilitator echoed this, calling for "better induction and more clarity on the role of the Family Rep at forum, FRG, and Operational Governance Groups," and advocating for "better contracting arrangements between CDNT, Heads of Service, CDNMs, and reps." A Family Representative identified:

“One huge issue though that needs looking at, is the support of parent reps. In a management structure, everyone has someone above them who supports but the Family Reps are very left out on who we have as a group. Who do we contact if we just need support on FRG level? This has been a very grey area which left some reps very vulnerable and needs to be looked at”.

Inconsistencies in the way FRGs are running and functioning were a significant concern shared across all groups. These discrepancies are reflected in the survey findings. Feedback from Family Representatives on the functionality of the FRG was mixed. When asked if the meetings were clear and easy to follow, just over half (52%) of representatives felt they were clear or very clear. However, the remaining 48% said the were only slightly clear, unclear or did not know, illustrating a divide in the clarity of how the FRGs are run.

Figure 7: Clarity of the Family Representative Group meetings



Local Variation

The findings highlight variations in how Family Forums are run across the country, with local areas adopting their own approaches. The variation has led to the perception of a postcode lottery, whereby some areas are advancing, whereas others are stuck in a confrontational style of Family Forum outlined below.

Currently, there is little if any mechanism for sharing localised improvements and lessons on a broader scale, leading to calls for scaling of effective practices nationally and preventing duplication of effort. As a CEO of a Lead Agency explained: “there is a lot of positives and a lot of progress has been made … and hopefully this will help in trying to capture some of that with taking all of the learning nationally, even what we’ve discussed here in the shared learning, to help refine it again for the next part in the journey”.

Townhall Forums

In some areas, Family Forums have taken on a "town hall meeting" style, where service updates are delivered in open, often uncontrolled environments. As one CDNM described: “It’s like a town hall meeting... and you’ve families on the waiting list sitting there who are not getting that level of service, and they find that very distressing.”

Without clear structure or focus, the forums have become emotionally charged and confrontational. These townhall-style meetings have proven counterproductive, creating a space where, as one Family Representative noted, the CDNT is "forced to justify lack of services and put the workers on the ground facing the lion's den.". This confrontational atmosphere has had a negative impact on families, CDNMs, and Family Representatives alike, with CDNMs describing the experience as "extremely stressful" and even "traumatic."

The emotional toll on CDNMs and Family Representatives is substantial, with one CDNM sharing: "My experience of Family Forums has been a trial by parents (who are sad, angry, frustrated), and it is a very uncomfortable position to be in." Constant exposure to collective frustration has led to work-related stress and anxiety. Family Representatives also report high levels of stress, with one stating: "Some of our meetings have been very uncomfortable with a lot of anger in the room." Another expressed frustration at being used as a buffer in these tense moments: "I feel like I’m going out to calm the anger... and the CDNM would point to me even when asked a difficult question."

Local Variation

Thematic Forums

Many areas have made a huge effort to move away from confrontational, “townhall” style forums. One of the key reasons for this divergence is to try to engage more families in areas with low attendance. A CDNM explained that;

“Bringing in an external speaker definitely helps. It is a lot of effort for a very small number of families. Our numbers have dropped from 50+ to average under 30 people (can include 2 from 1 family). Out of an overall caseload of 750, it is a fraction of the families. I think we need to engage families in a different way, make it easier for them to access the team while they are waiting, more clinics, CDNM attends parent coffee mornings, opportunities to meet CDNM at other events, newsletters etc”.

In some areas, Family Forums have taken a thematic approach, offering targeted discussions on relevant issues to better address family’s specific needs. One CDNM described how these forums are organised around specific topics, noting, “we’ve had themes in our Family Forums. We’ve invited SENOs (Special Educational Needs Organiser) to come in and do talks... we had one of the OTs (Occupational Therapist) lead a discussion on sensory issues… which was especially useful in September, a busy time for families”.

These thematic forums alternate between morning and evening sessions each quarter to accommodate families' schedules. There are also calls to offer online access to these kinds of forums to encourage better attendance. The flexibility could allow for a broader range of participation, with the content tailored to current challenges families may be facing.

Despite the positive feedback for this approach, there have been challenges in securing the necessary support needed to run these forums. As the Family Representative explained, “We’ve had to think about what themes we want for Family Forums... but when we went back to management and asked for a Therapist to talk about a topic, they said, ‘Oh no, that’s in the universal support.”

Local Variation

Clinicians Attending the Family Forums

In a small minority of areas, Family Forums are evolving into spaces where clinicians actively engage with families. Whilst uncommon, these forums allow clinicians to sit with families and provide direct support. One Family Representative noted, “all the therapists, or at least 90% of them actually attend the Family Forums. They sit at the tables with the families, they talk to them, which has been an absolute game-changer”. A CEO of a lead agency described them as “a welcome place where people can come in and seek genuine answers for questions that they may have”.

One independent facilitator explained how their region shifted to a model where the CDNM and a social worker are always present, along with other staff. This multidisciplinary approach has proven beneficial, particularly when supporting families who are in distress or attending for the first time. The facilitator noted, "We were able to do a little workshop at the end for families to fill out forms, apply for different things, and advise them on schemes like the nappy scheme for children”.

These more focused sessions, with the presence of key staff, provide practical information and support, reducing the pressure on the Family Representatives and the CDNM. For instance, in one region, families have lead calls for clinicians to attend forums and presentations on topics decided by families, for example, access to assistive technology. These forums often include workshops on specific topics, such as a behaviour therapist’s session, in which a Family Representative described as “gold,” especially for families awaiting services. Feedback from families helps shape future workshops, with one Family Representative stating, “Parents got to input what worked and didn’t work in workshops, and this feedback was all actioned”.

The success of this approach led to plans to extend it across the region, demonstrating the benefits of structured, professional-led forums over the confrontational townhall style.
While this model was highly regarded in the silos where it exists, engagement from therapists remains challenging, as an independent facilitator noted, “We’ve tried to involve social work and psychology, but they don’t feel ownership or confidence to come on board.”

Local Variation

Networking Events

Within the survey when asked what parts of Family Forums interest families the most, 59% of Family Representatives, 56% of CDNMs and all of independent facilitators chose networking as one of the areas of interest.

In some areas the Family Forums have largely become networking events where parents can meet others for peer interaction. One Family Representative explained the value for families who “crave the sense of community as parenting a child with additional needs can be very isolating. Families mostly come however for information on how to help their child, waitlists, who to turn to”.

These networking events include coffee mornings, which provide a more relaxed, informal setting. These kinds of forums were seen as useful in areas with high levels of parents that do not speak English as a first language and also for parents who are uncomfortable speaking in larger groups. Translators were an additional resource in these areas, to include parents who are new to the country and who don’t speak English. Peer support and networking was also seen as beneficial for parents of children on the waiting list to receive peer information on local supports and networks.

Findings Part Three: Role Clarity

Role Ambiguity

This lack of clarity extends beyond the purpose of the forums and into the roles of those involved. The research revealed a wide variation in how these roles are interpreted and performed. There was unequivocal agreement across all groups that the Family Representative role lacked clear parameters and boundaries, as the demands of the role change and grow.

CDNMs also voiced concern about the unclear purpose of the forums and the lack of defined role boundaries, which not only limits their effectiveness but also creates unrealistic expectations about what is within their remit to act on. As one CDNM explained, “respite, alternative respite, schools, everything, everything is thrown at us and it’s very hard then just to get them to understand what is the boundaries, what is it that we do and what is that we don’t do from these meetings.”

The research also identified significant variations in the execution of the role of the independent facilitators. One Independent Facilitator described the absence of coordination or shared standards across the system:

“There is no real clarity at the moment or there’s no interdepartmental working to bring it all together. It’s not being coordinated… There are different ways in which we do it, so there’s no standardisation yet, which means that there’s no clarity.”

This lack of consistency in facilitation has, in some cases, negatively affected the quality and tone of engagement. A CDNM reflected on how differing facilitation styles can influence the dynamic within forums: “the independent [facilitator], some have been good and some have not been, some have actually exacerbated parents or riled parents up.”

Duty of Care for Family Representatives

Across all groups, there are increasing demands for formal induction, training and support for Family Representatives. One Head of Service Disability noted inconsistencies across regions. It was their perception that "there seemed to be no support from national office in terms of training for the Family Reps, training in terms of their expectations." This lack of guidance has led to differing expectations. With the perceived absence of national direction, regions are taking matters into their own hands, with one Head of Service explaining, "We're actually having to do a role clarity day ourselves here locally".

Without clear guidelines outlining the parameters of their role, Family Representatives often dedicate significant time beyond the forums themselves. One Family Representative noted the extensive time commitments, saying, "there are a lot of meetings and planning outside of the Family Forum itself... in the run-up to the Family Forums, there could be two or three organising meetings... it is quite time-consuming." Tasks such as arranging guest speakers and coordinating forum details have fallen heavily on representatives, leaving them feeling overwhelmed. As the Family Representative shared, "the job seems to be getting bigger, and the meetings come thick and fast." The lack of visible outcomes from this effort is particularly discouraging, with the representative adding, "You don't mind if you see a bit of change... but our last Governance Group meeting... was a bit of a downer."

A lack of boundaries further adds to the emotional strain, as representatives are often contacted outside formal meetings. One noted, "people will send you messages on social media later on... coming into your private life." The sense of obligation to respond, especially when families are desperate for help, contributes to burnout: "You feel you can't not answer them... but it does wear you down."

Duty of Care for CDNMs

Without clear parameters on the purpose, roles and remit of the Family Forums the welfare of those tasked with running the townhall style forums has emerged as a significant concern across all stakeholder groups.

A key finding of the research was the impact of Family Forums on the dignity and wellbeing of CDNMs. Many described the forums as stressful and emotionally draining, exacerbated by staff shortages and long waiting lists. CDNMs expressed frustration at being held accountable for systemic failures beyond their control. One CDNM described the overwhelming strain: “This is only one tiny piece of a CDNM’s job actually, and we’re doing way more than we should be, and it’s in the context of everything else. So this actually is the breaking point, I think, for all of us.” A Head of Service acknowledged the severity of the situation, stating: “They can’t continue to be subjected to the abuse… when they're trying to run a professional service.”

The Need for Alternative, Effective Advocacy and Complaints Mechanisms

The findings reveal significant misalignments between the issues arising at the townhall style forums and the CDNM's remit, pointing to a need for structured advocacy and complaints pathways when issues arise that are outside the CDNT scope .

The perception of many participants is that the CDNMs are being held accountable for issues that are beyond their control. For instance, complaints about the Progressing Disability Services (PDS) model have been dominant at many of the forums, with families campaigning for one-to-one services. CDNMs have reported that they find themselves in an impossible position, expected to address issues like waiting lists, recruitment, and interdepartmental coordination, which are beyond their control. As one Family Representative put it, "put parents in front of decision-makers, not put parents in front of CDNMs where nothing can change".
An independent facilitator noted, CDNMs "have to defend the indefensible" and are expected to comment on services like CAMHS or primary care, even though "the reality is that they cannot influence that." Likewise, a CDNM explained:

"Unless there is a meaningful way for families to contribute to actual service development the whole process is meaningless and increases distrust amongst families… Many of the issues families have are with Education and other services none of which we can address. Other suggestions require additional resources which we cannot provide. The ongoing issues with moratoria and recruitment embargos are at core ridiculous and very hard to explain and/or justify for parents."

There is widespread recognition of the need for alternative advocacy and complaints mechanisms that involve those with decision-making power. A CDNM explained: "I think it's important for the people higher up in management to hear what it is like for those families, what the challenges are. Something in that format, like a smaller outside group, could allow them to put forward their concerns in a broader context." Likewise, a Family Representative expressed their frustration about the lack of influence:

"I often leave feeling completely despondent that there will be any way of effecting changes in the system, because it is not clear how we have any influence with decision makers and those who control resources".

Findings Part Four: The Governance Group and OMG

Family Representatives on the Governance Group

The findings from both the survey and focus groups point unequivocally to a disconnect between Family Representative's expectations and the remit of the Governance Groups. The findings highlight the need for better alignment and communication about the role and limitations of the Governance Groups. Clearer role definitions and comprehensive induction processes could help manage expectations by providing Family Representatives with a better understanding of the Governance Group's remit, including the constraints they operate within.

Across all stakeholder groups there is a clear recognition of the skill and expertise of some Family Representatives on the Governance Group. Many Family Representatives have professional backgrounds in the private sector and corporate environments. However, in some Governance Groups this has resulted in tensions. A Head of Service explained, the gap between the Family Representatives' expectations for swift action and the reality of slow-moving processes creates a "mismatch around the role, purpose, and function" of the Governance Group.

Furthermore, the conduct of some Governance Groups has been heavily scrutinised by many Family Representatives. Specific concerns include the last-minute cancellation of meetings and the circulation of large documents without allowing enough time for proper review. One Family Representative expressed their frustration, explaining: "In terms of governance, our meetings were cancelled twice at short notice because somebody couldn't make it, and there was no one else available. That's kind of like a slap in the face, because if you were working in a corporate environment, that wouldn't happen. If we have a governance meeting, it has to happen."

The conduct of some Family Representatives sitting on the Governance Group was also criticised. There were fears around confidentiality. Heads of service feeling that the organisation was "vulnerable" and calls for a code of conduct. "We're really quite vulnerable as a large organisation because we have no contract with the families. So, they can take anything that they get their hands on and circulate it with people's names on it. There is no governance of the family reps, and that has to come from national".

Escalation to the Governance Group

The research captures a broader issue: an implementation gap between the concerns raised in the Family Forums and FRGs and their escalation to the Governance Group. Several Family Representatives and CDNMs explained this gap in detail. For instance, one respondent shared that “When an issue has been brought up they weren't giving much time to discuss the issue until they were brushed off”. Similarly, other respondents expressed similar views about the Governance Group's perceived dismissive attitude, with one Family Representative feeling that their contributions were "dismissed and not taken seriously," reducing their role to mere "lip service."

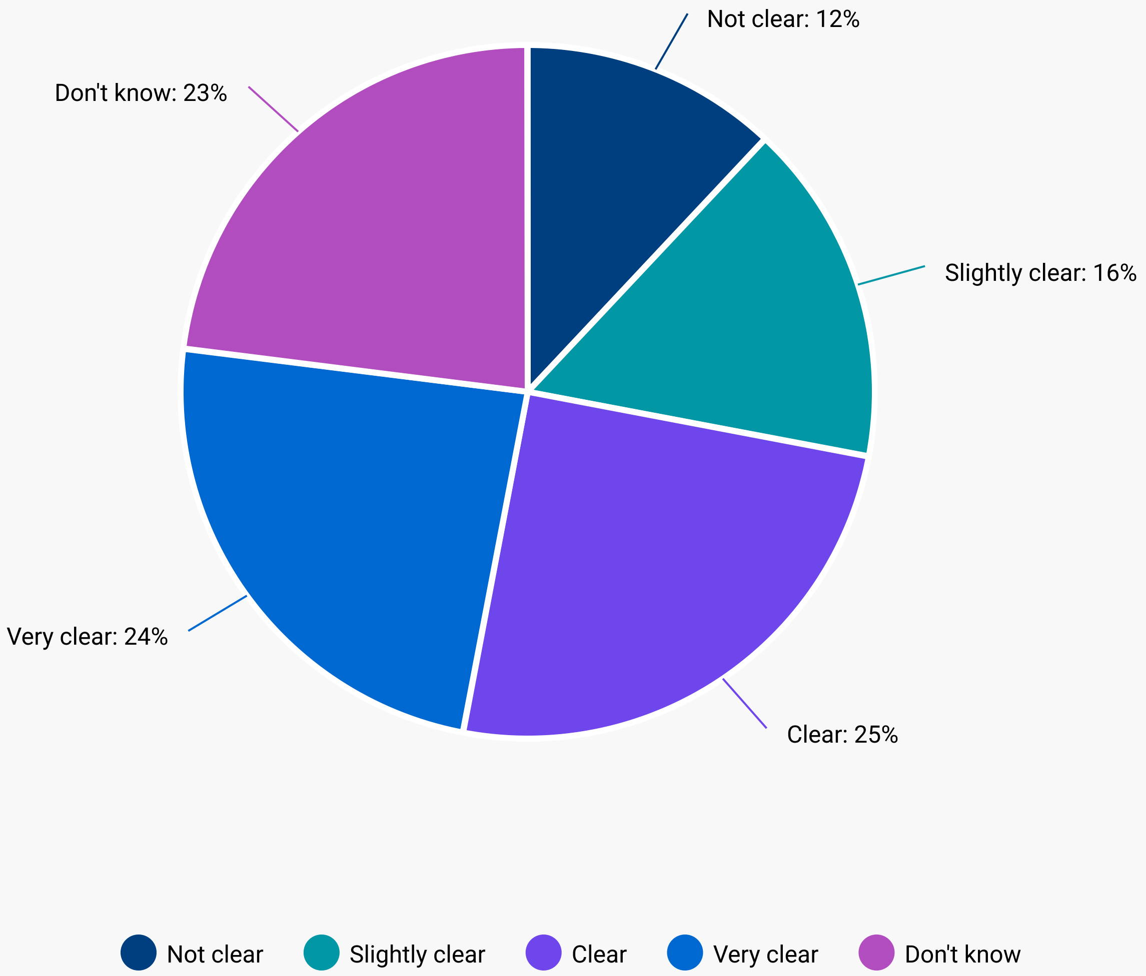
“It feels very much like any issues we have raised have been dismissed and not taken seriously, like a pat on the head to be there, but nothing more. Not once did I feel validated in my role, nor that we were seen as having value, beyond lip service and it was business as usual behind the scenes that we were not included in”.

One CDNM suggested the need for a more structured approach to communication between the FRG and the Governance Group, they complained that “the Governance Group actually has to function first. Then there should be a written format by which FRG can put issues to the Governance Group and time slots at GG meeting to present their issue and discuss it”.

Escalating issues to the Governance Group

The survey findings indicate that almost half of Family Representatives (49%) were clear or very clear about which issues were going to be escalated to the Governance Group, leaving a majority who are only slightly clear, unclear or do not know.

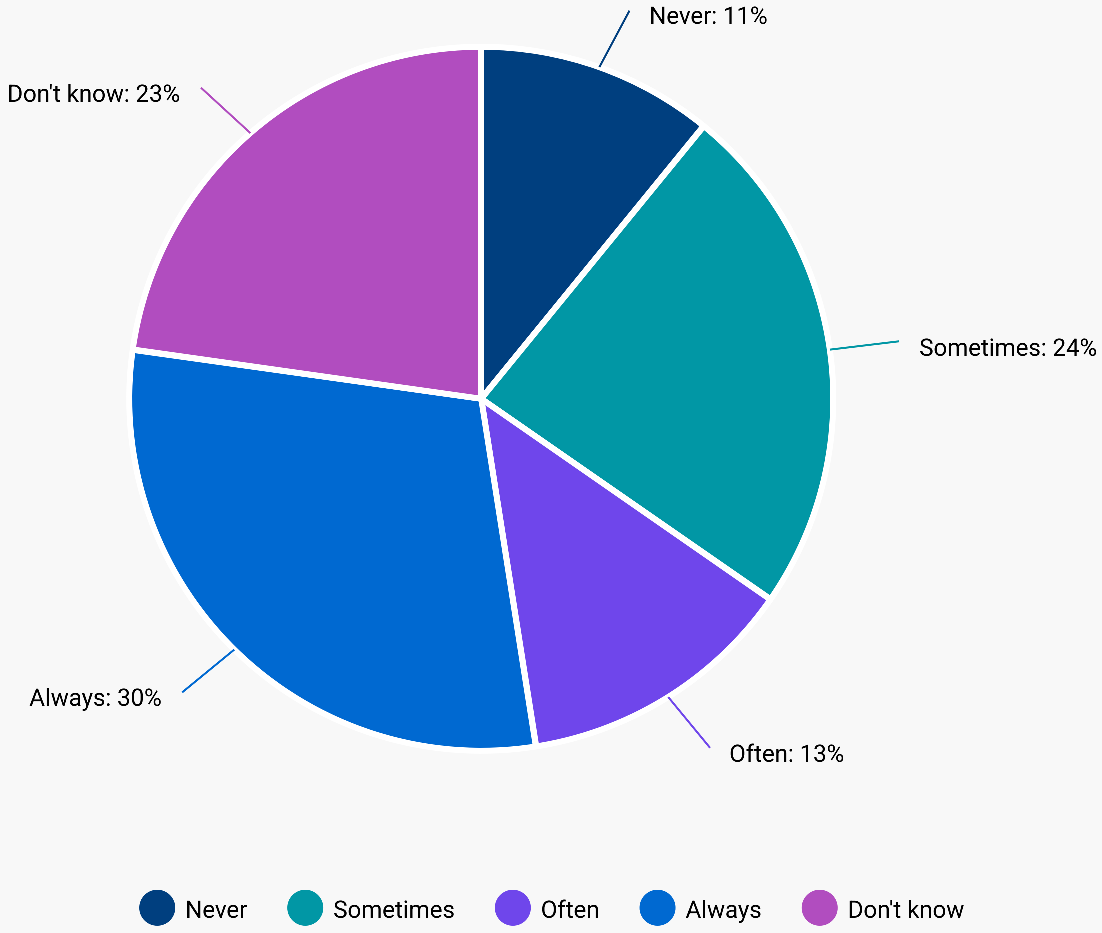
Figure 8: Family Representative's clarity about which issues will go to the Governance Group



Clarity about Issues Raised at the Governance Group

A concerning 58% of Family Representatives feel that the outcomes of the issues raised at the Governance Group is only sometimes clear, never clear or they did not know. This indicates that there are ineffective feedback loops.

Figure 9: Family Representative's clarity about the outcome of issues raised to the Governance Group



Communication Between the FRG and the OMG

Many Family Representatives expressed a lack of awareness or communication between their FRG and the OMG, with comments like "no idea, no communication" and reports of representatives not being included after elections. Conversely, some shared positive experiences, noting that collaboration with OMG representatives led to successful outcomes, such as developing a welcome pack, highlighting the benefits of increased cooperation.

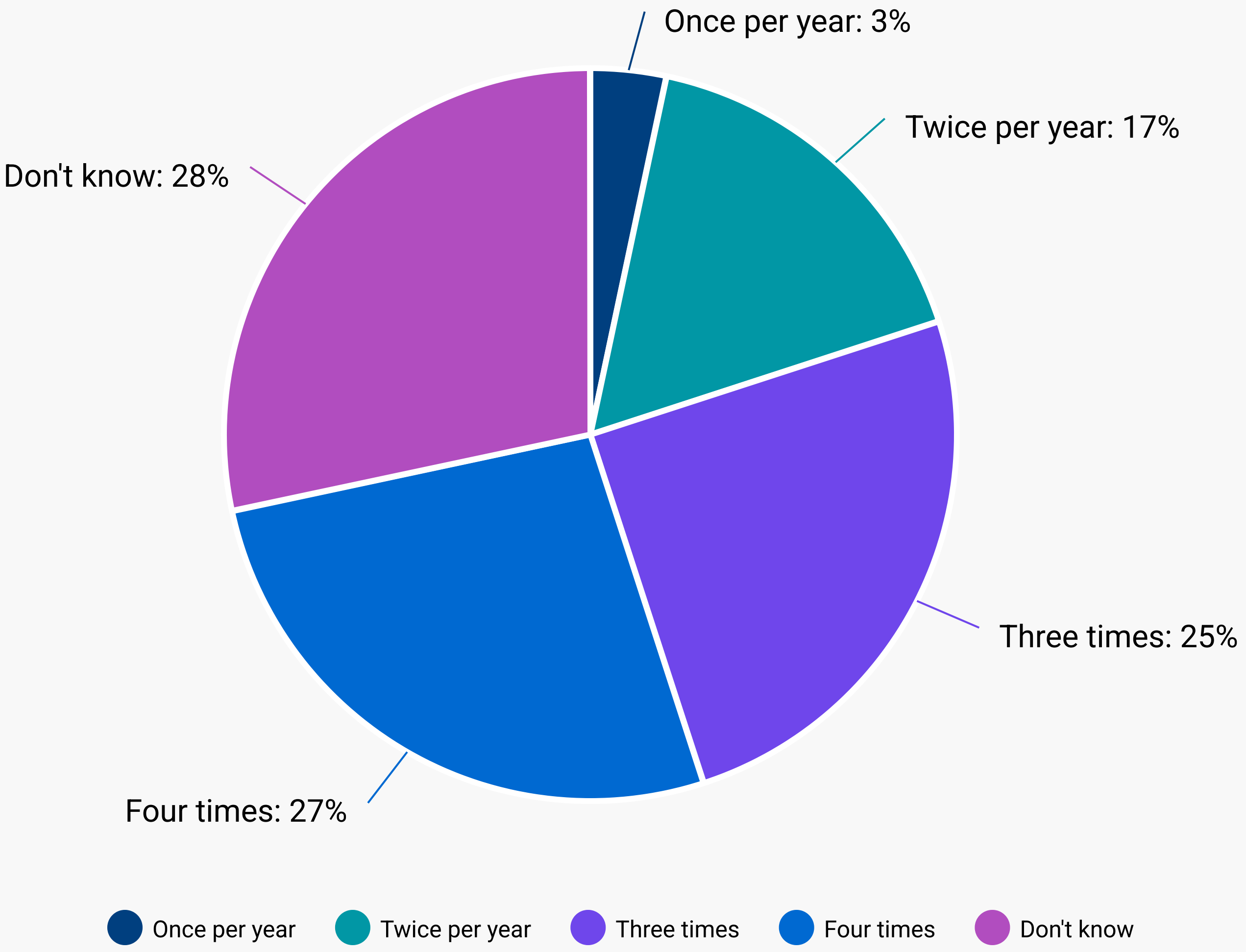
When CDNMs were asked how often the OMG creates action plans based on FRG feedback, nearly a majority said either sometimes, often or always. Despite these challenges, some CDNMs reported that increased engagement with FRGs improved relationships and trust. For instance, one CDNM said "Continued and open discussion regarding what families on the ground in the network really want to hear about and focus on. We have a very clear and open relationship with our family reps".

Family Representatives were far more likely to say that the issues that they raise are never actioned by the OMG. However, a significant portion said that they didn't know, indication in gap in feedback loops.

Frequency of Contact Between the FRG and OMG

A significant portion of Family Representatives were uncertain about the frequency of contact between the FRG and the OMG. 28% indicated they did not know, and 17% stated their FRG does not meet with the OMG. Among those aware of the contact frequency, responses varied, with some reporting quarterly meetings and others less frequent interactions.

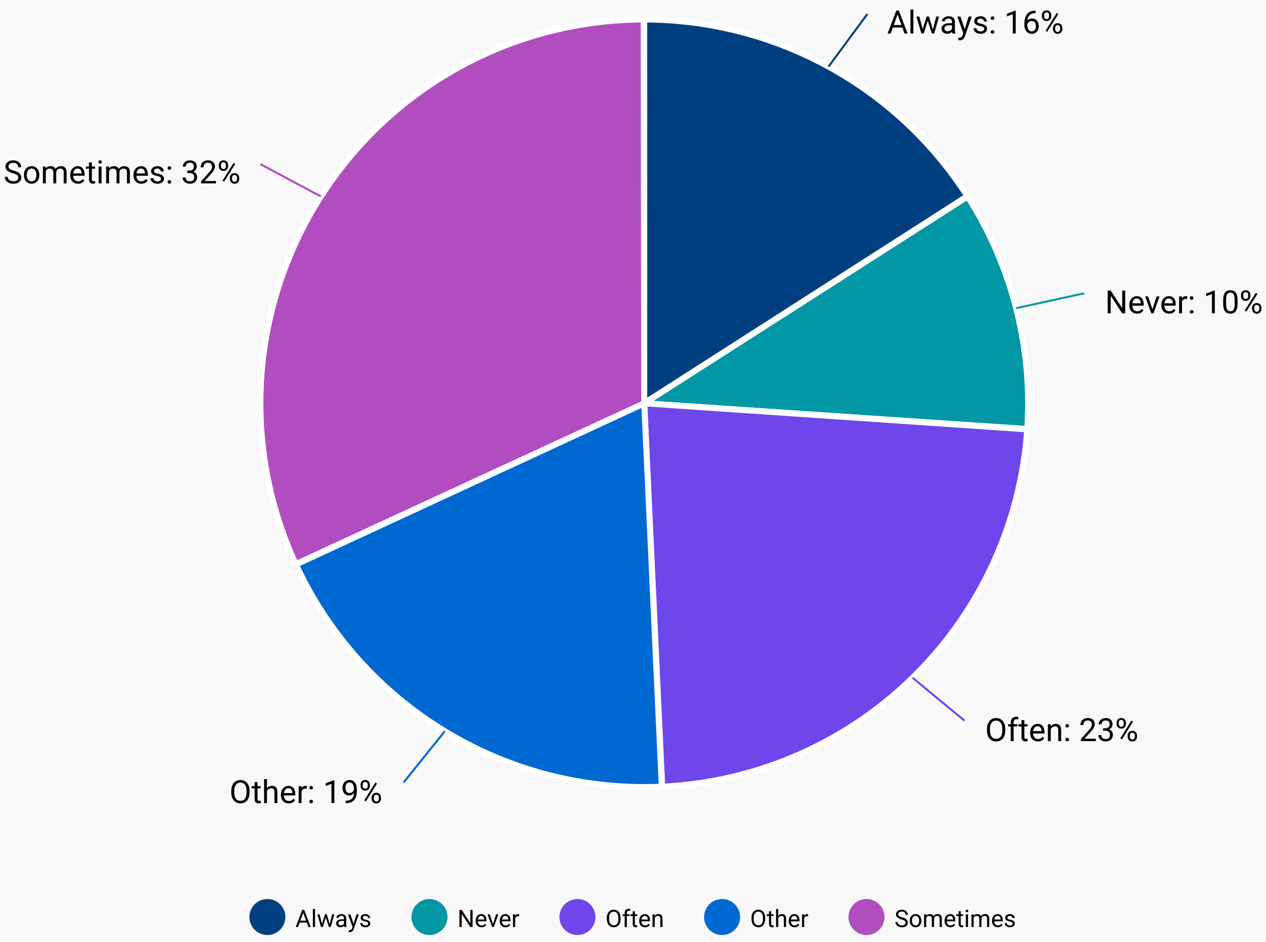
Figure 10: How often the Family Representative Groups are in touch with the Operational Management Group



OMG Responsiveness to Issues Raised

When asked if their OMG develops action plans with timelines based on issues raised by Family Representatives, a significant majority of CDNMs said always (16%), sometimes (32%) or often. Only 10% said that their OMG never makes plans.

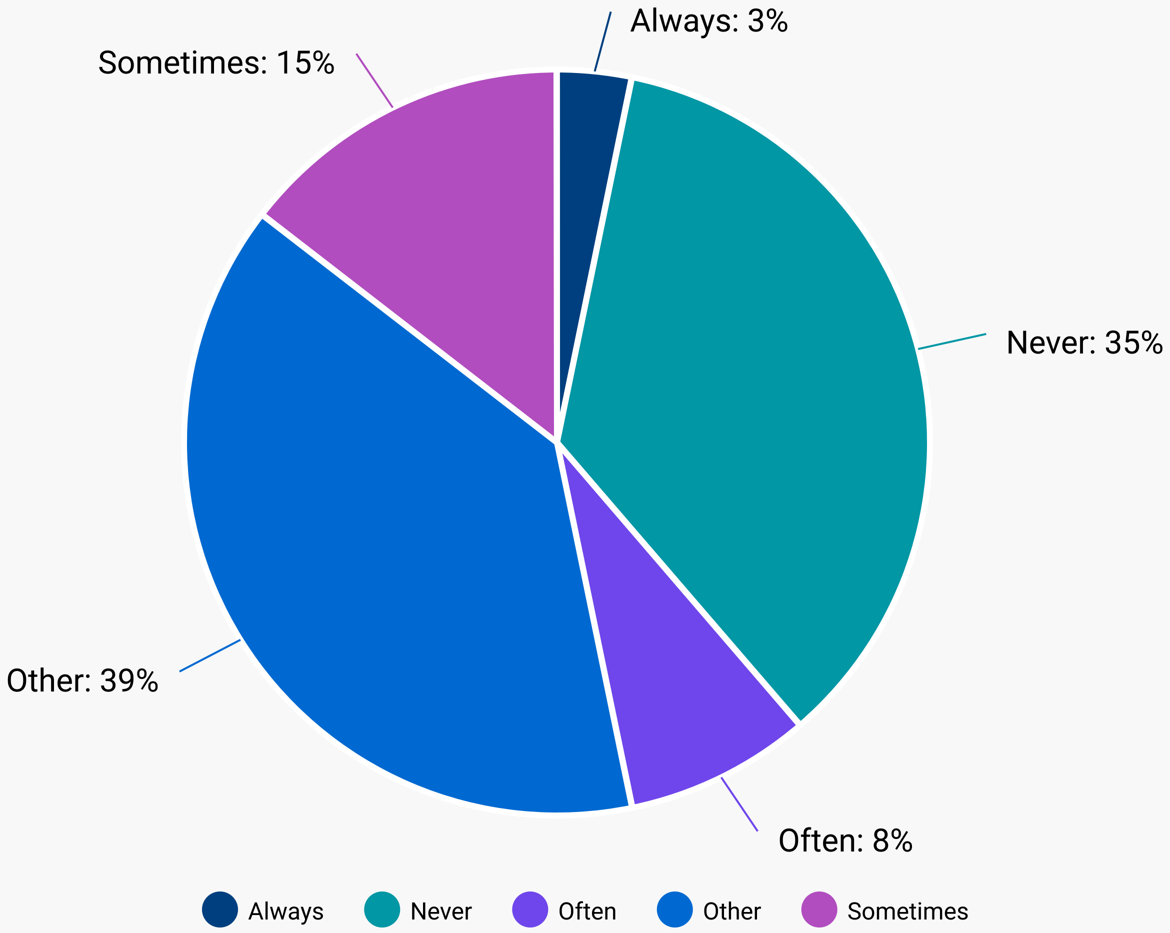
Figure 11: Perceptions of OMG Action Planning in Response to Family Representative Issues



Family Representative's View of the OMG Responsiveness

However, when asked whether the OMG has developed action plans with clear timelines and provided feedback based on the issues they raised, Family Representatives were more likely to report that the OMG has never actioned any of their issues (35%). An additional 39% selected "other," with the vast majority clarifying that they were unaware, highlighting a significant gap in the feedback loop.

Figure 12: Perception of Family Representatives if the OMG develops actions based on the issues they raise



Appreciative Inquiry: Validating the Research through a Strengths-Based Lens

Concrete Examples

The Appreciative Inquiry stage of the research focused on uncovering what works well within the existing system. Rooted in a strengths-based approach, this stage of the research aimed to build upon what is already effective. The following four examples emerged from this stage, illustrating concrete strengths and opportunities identified through participants' insights and experiences. While these may be isolated examples, they offer valuable insights that are important to share, highlighting potential practices and principles that could be adapted or scaled more broadly across the system.

1**. Alternative Advocacy Mechanisms** in one where family representatives worked with their CDNM to advocate for policy changes by engaging politicians, policymakers and decision-makers directly. This approach led to more constructive Family Forums, as participants were kept informed about progress at the decision-making level, and could focus on issues related to their CDNT.

2**. Building Safeguards** explores how trauma-informed approaches, structured facilitation, and smaller group discussions have created safer spaces for engagement.

3. **Improved Communication on Service Delivery** this concrete example examines how targeted communication efforts, such as newsletters, information booklets, and workshops, have addressed longstanding gaps in transparency and responsiveness. By demonstrating quick, tangible outcomes, these initiatives have helped build trust and opened possibilities for deeper engagement.

4. **Co-Design for Service Improvement** this concrete example illustrates how targeted working groups and the recognition of the value of lived experience have enabled targeted, solution-focused collaboration. These initiatives, though limited in scale, represent significant steps towards embedding co-design practices and engaging with families as active participants in improving services.

Concrete Example One: Alternative Advocacy and Complaints Mechanisms

Alternative Advocacy and Complaints Mechanisms

This concrete example illustrates a more effective advocacy model providing insights into the impact of having functional advocacy and complaints mechanisms outside of the forums. In one area, Family Representatives and CDNMs worked together to address policy issues, taking their concerns beyond the forums and directly engaging with politicians and policymakers. This external advocacy was seen as contributing to more constructive Family Forums, as participants were kept informed about progress at the decision-making level, and could focus on issues related to their CDNT.

Trust and transparency between the Family Representatives and the CDNM were necessary for this collaboration. The family representative reflected on the approach taken: “Our CDNM welcomed us with open arms; we were made to feel like part of a movement. We met with the CDNM from the get-go, it’s not us vs. them. We’d rather come at this with a collaborative approach.” Another representative described the ongoing engagement: “We asked her what kinds of topics we can help her with… we meet with her monthly. She’s very open about what issues she’s facing. We started off with a huge level of trust and co-operation.”

A family representative involved in this initiative described how they identified bigger, systemic issues to tackle: “we knew that recruitment was the biggest issue our local area was facing, so we got invited into a meeting with a Minister, and everyone got a say.”

Alternative Advocacy and Complaints Mechanisms

Such structured advocacy efforts led to real policy change, demonstrating the potential for alternative mechanisms that ensure accountability and action. “We met with political parties and emphasised the need for regular meetings. Every six weeks, we wanted to be in the room with HSE representatives, CDNMs, local politicians, and us parent reps. Because of that, we kept the HSE accountable and kept the process running. Again, no one was antagonistic.”

This direct engagement with decision-makers ensured that concerns were addressed at the appropriate level rather than being lost in the frustration of forums where no one had the authority to act on them. This model of engagement highlights the importance of defining the role of Family Forums clearly. While they remain valuable spaces for service-level discussions, issues that fall outside the CDNT’s remit should be channelled through mechanisms that ensure decision-makers are present. Establishing structured advocacy routes can help direct concerns to the appropriate bodies while relieving the pressure currently felt by CDNMs and Family Representatives within the forums. Strengthening these alternative pathways will lead to more constructive engagement and improve the overall effectiveness of family advocacy.

Townhall Style Forums	Alternative Advocacy and Complaints Mechanisms
Large, open-ended discussions with no clear structure. Emotional intensity often escalates, leading to frustration	The family forms are more constructive spaces because the big issues are being addressed elsewhere.
CDNMs feel unfairly held accountable for system-wide failures	CDNMs work collaboratively with the family representatives to instigate change
Meetings often feel adversarial and reinforce mistrust	The feeling that nobody is hiding behind a smokescreens

Concrete Example Two: Building Safeguards

Building Safeguards Through Training

One area, recognising the potential for confrontation at the family forums introduced training for CDNT staff to prepare them to better manage the emotional intensity of the forums. An independent facilitator worked closely with the team to ensure that CDNMs had an opportunity to reflect on their concerns in advance. This preparation created a reflective space where staff could openly discuss anxieties, identify skills they already use in one-on-one settings, and adapt them for group discussions. A series of workshops were introduced to help participants develop a greater understanding of anger and frustration, recognising these as underlying emotions that often shape discussions within Family Forums.

The workshops also focused on the differences between individual and group needs, reinforcing that the forums should be solution-focused rather than dominated by personal grievances. De-escalation techniques, active listening strategies, and scenario-based roleplays were incorporated to equip staff with the skills needed to handle difficult conversations without becoming defensive.

A key component of this workshop should be helping staff recognise and acknowledge the gap between family expectations and the operational realities of service provision. An independent facilitator explained:

“I did an entire session on expectations, the difference between the family and the team expectations, because there’s a huge chasm in between, that isn’t necessarily a bad thing, once you have an awareness of it, if you don’t have an awareness of it that’s where you get stuck in conflict, where you can’t bridge it.”

Building Safeguards Through Training

Structural changes were also implemented during the forums themselves. One of the most significant adjustments was moving away from large, town hall-style meetings, which often created overwhelming and confrontational environments, and instead introducing smaller, structured discussions. Breaking the forums into small groups allowed for more balanced and manageable conversations, reducing the likelihood of any one issue dominating the agenda. One Family Representative reflected on this approach, saying:

"We suggested that the large groups could be broken up into small groups, probably the same discussions, but in a smaller group, there is less chance of it escalating and becoming one agenda. A better way to hear everyone’s voice. Then each group has a spokesperson to report back to the full group, and it is a more measured conversation with hopefully better outcomes. And if someone in attendance has major issues that need addressing, there should be a facility to give them a day and time that someone from the CDNT will call them. Diffuse the situation.”

Further safeguards were put in place to support both families and CDNMs during the forums. Volunteer professionals, including social workers and psychologists, were brought in to provide emotional support where necessary. Pre-meetings and debrief sessions for Family Representatives ensured that they were not left to process difficult encounters on their own. The creation of a more supportive atmosphere was another key component of the trauma-informed approach. Meetings were held in neutral, comfortable spaces, with refreshments provided to help reduce tension and foster a sense of safety. However, careful consideration was given to resource allocation, as some families expressed concern about meetings being held in high-end venues, such as hotels, at a time when services were already under financial strain. Striking the right balance between creating a welcoming environment and maintaining financial accountability was essential in maintaining trust.

Building Safeguards Through Training

Townhall Style Forums	Building Safeguards Through Training
Large, open-ended discussions with no clear structure	Smaller, structured discussions with clear objectives
Emotional intensity often escalates, leading to frustration	Facilitated discussions focus on active listening, solution-focused forums
CDNMs feel unfairly held accountable for system-wide failures	Other clinicians are present at the forums, the CDNM is more supported
Families use the forum to voice grievances rather than collaborate	A focus of diffusing the situation, and dealing with individual grievances seperately
Meetings often feel adversarial and reinforce mistrust	Meetings foster trust, collaboration, and shared problem-solving

Concrete Example Three: Clear Communication and Expectations

Clear Communications and Expectations

One area took a structured and responsive approach to Family Forums by setting clear goals and expectations, focusing on thematic issues. The first forums followed a town hall-style format, but feedback indicated that this approach was overwhelming and often ineffective. In response, the organisers shifted towards a planned and structured model, ensuring that the CDNM, Family Representatives, and an independent facilitator met in the weeks leading up to each forum to prepare the structure and topics. Setting clear expectations for families before each forum also became a key strategy. Before each session, families received letters detailing the agenda, topics, and speakers, allowing them to prepare in advance. Families also had the opportunity to engage with representatives from local partnerships that run parent groups, strengthening connections to community resources.

The forums have shifted toward a more participatory approach where families are actively invited to provide input on what is working, what is missing, and what changes they would like to see within the service. As one CDNM described, “part of the family forums is meant to be about how parents would like to input into the service. Last week I brought up all the universal groups we run , we have pretty poor attendance, so I asked: what ones do you think are useful and worth keeping? What would you like that you don’t see here? And, acknowledging that parents are really busy, what time, place, and where would suit them best?”

One example of real-time responsiveness involved a request from parents at the forums for personalised waitlist updates. Within days, parents who attended the forums received direct updates on where their child stood on the waiting list. At the next meeting, an admin staff member was available to answer specific queries about individual waitlist positions, ensuring a practical and immediate response to family concerns.

To enhance continuous feedback, forums now include an end-of-meeting survey to assess whether families found the session useful and to gather suggestions for improvement.

Clear Communications and Expectations

Townhall Style Forums	Clear Communication and Expectations
Misaligned expectationsued meetings	The themes are communicated to parents in advance of the forums
Families expect immediate answers and accountability from CDNMs	CDNMs work collaboratively with the family representatives to instigate change
Families use the forum to voice grievances rather than collaborate	Workshops and presentations improve information sharing

Concrete Example Four: Co-design Working Groups to Improve Service Outcomes

Co-design working groups to improve service outcomes

In one area, focusing on collaborating with families to improve service outcomes transformed how Family Forums functioned. Previously, forums were described as distressing and grievance-focused. As one CDNM recalled, they often centred on “what’s going wrong.” In response, the CDNM and Family Representatives redesigned the format, focusing the forums on updates about service improvement: “I rethought the format... with the Parent Reps, and we redesigned our next Family Forum with a focus on solutions and gleaning learning in order to make service improvement and quality improvements.”

This shift led to the creation of working groups within the service, each tasked with improving specific service pathways, with parents actively involved in shaping the design. “We’re going to start working on a number of pathways... and we’d like to have parent representation on each of those working groups. We can bring all the research, but we need the lived experience,” explained the CDNM. This approach gave Family Forums a more constructive tone, as updates from these groups showed real progress. “It leaves that space of ‘services are shambles’ and goes into a productive space... they have something tangible to work on that actually has an impact.”

One working group focused on fussy eating, bringing together clinicians from different disciplines and a parent who was described as a “perfect pairing.” A clinician reflected: “what she gave was so much richer than what we’d get without her there.” The group model expanded quickly, with three additional working groups launched. Parents were invited to join based on interest, and clear terms of reference helped define objectives, time commitments, and boundaries. A clinician suggested that “the parent being there keeps us accountable. Nobody wants to look bad in front of the parent… we don’t want to let a parent down,” one CDNM said.

Co-design working groups to improve service outcomes

Parents participating on the working groups recongnised the benefits, with one suggesting that, “engaging parents with very clear ground rules as to what is to be achieved will enhance the service no end… the role was laid out very clearly.” Clinicians also saw the benefits: “Parents supporting each other and listening to each other... was really well developed in this group. Being able to say to parents, ‘we’ve had parent feedback, we’ve done the research,’ builds trust... The therapeutic relationship is really significant, and I think that parents believing us is very important.”

Recognition was important too. One parent said, “It was great for my CV... but also great, as a parent, to contribute.” Clinicians echoed this, noting that “information coming from a parent with experience is more powerful than hearing from a clinician.” Some suggested paying parents for their time as a way to acknowledge their contributions and support ongoing involvement.

The five workshops developed by the group were complemented by one-on-one sessions and followed by structured feedback through parent focus groups. A six-week follow-up with an assistant psychologist helped gather reflections and identify further improvements.
The success of this model led to its wider adoption. As one clinician reflected, “It gave us a lot more confidence... we could say ‘parents helped us put this together’... It gave us more impetus and power from the get-go.” A CDNM added, “I’ve learned a lot... even just after a couple of engagements with families, that ‘oh god, we’re really pitching this at the wrong level.’”

Townhall Style Forums	C-design to improve service outcomes
Open-ended discussions with no clear structure	Intentional and structured engagement, which is fed back to the participants at the forums
No input into service outcomes	Respecting and using parent experience to improve services
General discussion without actionable results	Working towards tangible service outcomes

Ways Forward: Reimagining Family Forums as Platforms for Service Innovation

Introduction

The independent review of Family Forums and FRGs highlights an urgent need to reimagine these structures as platforms for service innovation, rather than grievance-focused spaces. Despite the time and effort invested by families and CDNMs, only a small minority of respondents view the forums as effective in improving service outcomes. Just 17% of Family Representatives and 14% of CDNMs rated the forums as effective or very effective. At the same time, nearly half of Family Representatives identified improving service outcomes as the primary purpose of the forums, pointing to a clear misalignment between intent and impact. This disconnect is further compounded by widespread variation in how the forums operate, unclear role boundaries, and the absence of safe, structured and impactful mechanisms for advocacy and complaints. Many Family Representatives and CDNMs described the forums as emotionally challenging, with reports of distress, frustration, and deteriorating trust.

The recommendations that follow respond directly to the findings of the review. They are not a series of isolated actions, but a cohesive framework for reform. Each recommendation is rooted in the evidence and designed to tackle the challenges identified. These include inconsistent implementation across regions, unclear roles and remits, a lack of structured pathways for advocacy and complaints, and a forum environment that is often experienced as emotionally challenging by both families and CDNMs.

While some actions can and should be implemented straight away; such as clarifying the purpose of the forums and mapping alternative complaints mechanisms, all actions are focused on building the long-term sustainability of Family Forums, strengthening the role of the FRG, and embedding meaningful family representation in governance structures.

The initial emphasis is on establishing clarity of purpose, role definition, and safe processes for families to contribute constructively to improve service outcomes. These efforts will support a shift from reactive to proactive, co-designed service improvements. In doing so, the forums can evolve into effective, trusted platforms where families' voices are heard and an authentic partnership with children's disability services is forged to inform service developments and improvements" (HSE, 2023a, p.6).

Short-Term Actions (0-9 Months)

I Clarity of Purpose

These actions aim to address immediate pressure points, build psychological safety, and create foundational clarity across structures. The findings highlight a need for clear, consistent communication about the purpose of the Family Forums, the FRGs, the Governance Groups and OMG, including what falls outside of their remit.

Issues that fall outside the CDNT's remit should be channelled through mechanisms that ensure appropriate resolution. Establishing structured advocacy routes can help direct concerns to the appropriate bodies while relieving the pressure currently felt by CDNMs and Family Representatives within the forums. Strengthening these alternative pathways will lead to more constructive engagement and improve the overall effectiveness of family advocacy.

Clarity the Purpose of the Family Forums

- Reposition Family Forums as a dynamic platform where families can participate in thematic, solution focused service improvement forums and propose ideas and suggestions for service innovations.
- Clarify and widely communicate the reimagining of the Family Forums as structured platforms where families can contribute ideas or proposals for service improvements, and innovation.
- Showcase positive service developments and outcomes, shifting the focus from grievances to progress.
- Ensure regular updates are provided to attendees on how family contributions have influenced service planning or delivery.
- Provide thematic forums that respond to the expressed needs of the families.
- Provide safe space for families to learn about services, including clinician presence at the forum.

Short-Term Actions (0-9 Months)

Clarify the Purpose of the FRG

- Establish a stronger focus on service innovation at the FRG level, with forums feeding directly into this process.
- Create a mechanism for ideas and proposals raised at Family Forums to be brought to the FRG for discussion, refinement, and potential integration into work plans (see medium term actions).
- To raise proposal for discussion and refinement at appropriate levels of the OMG and governance structure to develop a feedback mechanism for feedback to the family forums .

Clarify the Purpose of the Governance Group

- Draft a document setting out the core role of the Governance Group in supporting, responding to, and actioning insights from the reimagined Forums and FRGs.
- Include the role of the Family Representatives on the Governance Group, and the feedback loops between the Governance Groups and the FRG.
- Widely disseminate and clearly communicate to all relevant stakeholders, including the Governance Groups, the OMG, the FRGs, Service Providers and elsewhere, where relevant.
- Reserve a standing agenda item for discussion of key themes, and ideas for service improvements raised at Family Forums and FRGs.
- Use this slot to track the status of proposals and provide an opportunity for follow-up or scaling.

Short-Term Actions (0-9 Months)

Map or Establish Pathways for Complaints and Advocacy Outside the Scope of the CDNT

- There is a clear need for consistent communication about what falls within the remit of CDNMs, CDNTs, and other areas. Clarifying these boundaries will support more focus on improving service outcomes.
- Map existing complaints and advocacy mechanisms, and establish new ones where needed, to ensure that concerns and issues are escalated to the appropriate channels. Clearly communicate the limits of the CDNT’s remit, helping all stakeholders understand where certain issues should be raised.
- Ensure independent facilitators are trained to identify when concerns should be redirected and are confident in guiding families toward the appropriate mechanism, whether that’s a formal complaints procedure or an advocacy channel.

Short-Term Actions (0-9 Months)

II Role Clarity

To ensure forums stay aligned with their primary purpose, all stakeholders should have a consistent understanding of their roles, boundaries, and contributions. Standardised induction, training and clear role definitions, will support more effective collaboration, reduce confusion, and build trust across the system.

Central to this structure is the Independent Facilitator, whose role is not only to guide the process but also to uphold psychological safety, maintain focus on service improvement, and ensure respectful engagement. This includes proactively redirecting issues that fall outside the remit of the forums to the appropriate advocacy or complaints mechanisms.

Standardised Induction

- Provide standardised induction for Family Representatives, CDNMs, and Independent Facilitators, and all members of the Governance Groups.
- Establish clear role definitions and expectations for all stakeholders in the Family Forums and/or FRG as listed below:

• Independent Facilitator

Responsible for ensuring discussions stay focused on service innovation and development. Accountable to senior managers in the RHAs. Key responsibilities should include a focus on service improvement, upholding the Code of Conduct, ensuring psychological safety, directing complaints and advocacy to appropriate channels.

• Family Representative

Represents the collective voice of families, contributing to co-design and service improvement. The expected time commitment should be clearly communicated from the outset, including hours required for preparation, meetings, and follow-up actions. Key roles should include identifying areas for service improvements, and have an opportunity to participate in working groups for service improvements, engaging in governance structures, and providing feedback loops. Should receive clear role definitions, induction, and appropriate support where required. Consideration should be given to compensating their contributions.

Short-Term Actions (0-9 Months)

- ## CDNMs

The CDNM’s role in Family Forums should be clearly defined, ensuring that they are not positioned as the primary point of accountability for systemic issues beyond their control. A key element of this is enhancing the support provided by the Independent Facilitator. Provides professional insight and helps focus forums on realistic, service-level improvements. Collaborates on setting agendas, supports working groups, and prioritises service pathways. Not the point of accountability for system-wide issues and should be supported by strong facilitation.

- ## Clinicians

Participate in co-design with families. Support thematic working groups, clarify service limitations, and help translate family feedback into actionable service improvements. Ensure transparency and continuity in communication with families.

- ## Governance Group Members

Governance Group members should receive a clear and consistent induction that defines the group’s core remit, with a focus on strategic oversight. This should include an outline of the group's limitations, clarifying what falls outside its scope and where such issues should be escalated or addressed. The induction should provide concrete examples to guide decision-making and ensure alignment across levels. It should also set out the specific roles and responsibilities of all members, alongside an agreed code of conduct, privacy expectations, and principles of co-working. Central to this is a strong emphasis on the value of lived experience in shaping decisions and driving meaningful change.

- ## The Regional Health Authority (RHA) senior management

Provides oversight, strategic alignment, and accountability. Endorses work plans, ensures adequate resources, monitors facilitator performance, and promotes consistency and scaling service innovations across regions.

Medium-Term Actions (3-9 Months)

Provide Comprehensive Training Informed by Practice

- Roll out training on constructive engagement and co-working for Family Representatives, CDNMs, and Independent Facilitators focusing on collaborative problem-solving, partnership working and co-design.
- Offer workshops on psychological safety, de-escalation, and active listening to help participants navigate emotionally charged discussions and maintain respectful dialogue.
- Embed scenario-based learning and roleplays to improve practical communication and collaboration skills in real-life situations.

III Improving and Measuring Service Outcomes

To ensure that Family Forums and FRGs are consistently aligned with their intended goal of improving service outcomes, it is crucial to define and communicate the scope of their work clearly. The central aim is to co-design service improvements through working groups at the service level.

FRG Improving Service Outcomes

- Develop an annual work plan for service innovation, arising from the Family Forums and co-produced by the FRG and OMG, and endorsed by RHAs and lead agencies.
- Once ideas have been gathered through the Family Forums, these will be escalated to the FRG for further review.
- Prioritise areas for co-design, using a structured process that balances potential impact with feasibility.
- Create a joint working group between the OMG and FRG to finalise the priority areas for co-design over 3, 6, and 12-month timelines. The FRG and OMG plays a key role in evaluating the feasibility of proposed ideas, taking into account the resources, timelines, and broader impact of implementing them.
- Develop a phased implementation work plan and integrated feedback loop across these timeframes.

Medium-Term Actions (3-9 Months)

Working Groups at the Service Level

- Establish targeted working groups with clearly defined roles and Terms of Reference to deliver on specific service improvement goals.
- Recruit and compensate parents involved in working groups, with clear expectations regarding time commitment and contribution.
- Integrate feedback loops, including focus groups, surveys, and engagement tools, to ensure family perspectives are continuously informing service development.

The Regional Health Authority's Role (RHA) in Measuring and Showcasing Service Improvements

- RHAs should lead on establishing standardised indicators to measure the impact of Family Forums and FRGs.
- Define specific, measurable goals for the forums. Regularly track and communicate outputs, service improvements or other progress to all stakeholders to maintain focus on outputs.
- Develop a uniform method for measuring and documenting service improvements across all forums and FRGs to allow stakeholders to track improvements.
- Support local areas in tracking progress on prioritised issues, and consolidate data at the regional level for consistent evaluation.
- Implement structured reporting systems to regularly feed outcomes back to families, service providers, and governance groups.
- Share region-wide service improvements through accessible formats such as websites, or newsletters to highlight the value of family participation and service co-design.
- Identify successful initiatives emerging from forums and explore opportunities for replication or scaling across other areas within the RHA.

Medium-Term Actions (3-9 Months)

Capture and Scale Innovations Nationally

- Develop a national database of service innovations
- Establish a national learning network to share insights across RHAs
- Use trends and feedback to inform systemic service improvement
- Require lead agencies and senior management to assess and scale successful local initiatives.

Longer-Term Actions (12 Months+)

IV Embedding Co-Design for Service Improvements

To support long-term sustainability and drive meaningful change, co-design must be embedded at every stage of service improvement. While local areas have begun to pilot innovative practices, these efforts remain fragmented and are rarely shared or scaled. Without mechanisms to measure, communicate, and build on local successes, opportunities for wider impact are being lost.

These longer-term actions aim to systematise innovation, promote alignment across regions, and create national infrastructure to support shared learning, evaluation, and replication**.**

Embed Co-design

- Integrate co-design into all stages of service improvement (design, implementation, evaluation)
- Create cross-sectoral working groups (e.g. CAMHS, Primary Care) where appropriate

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