

Family Forum and Family Representative Group Review

Interim Report



November 2024



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Executive Summary

This study provides a comprehensive review of the functionality and sustainability of Family Forums and Family Representative Groups (FRGs). Using a mixed-methods approach, the research triangulates data from:

- A survey with a <70% response rate (n=202)
- Focus groups with Family Representatives who have sat on Governance Groups (n=14), Children's Disability Network Managers (CDNMs) (n=8), Independent Facilitators (n=5), Heads of Disability Services (n=5), and CEOs of Lead Agencies (n=5).
- A literature review on co-design and stakeholder engagement

The goal of this mixed-methods approach is to understand stakeholder's expectations, their interpretation of governance structures and processes, and outcomes of the Family Forums and Family Representative Group. The study offers evidence-based recommendations for enhancing family engagement in service development and improvement, while embedding family engagement into governance structures.

Fundamental Issues of Functionality and Sustainability

There is a significant disparity between stakeholders regarding the primary purpose of Family Forums. Family Representatives often view forums as a platform for collaboration to improve service outcomes for children, while CDNMs see them more as a means to foster trust, openness, and transparency.

Families often expect CDNMs and Children's Disability Network Teams (CDNTs) to address issues beyond their control, such as waiting lists and interdepartmental coordination. This often leads to anger and frustration. There is a call across all stakeholder groups for a less siloed approach to the forums, involving other sectors like CAMHS and primary care in the forums to address the holistic needs of children.

In the absence of a clear communicated and widely disseminated purpose, forums have evolved differently across regions, leading to inconsistent experiences for families. Formats range from confrontational "town hall" meetings to thematic workshops and networking events. Some areas have moved away from the confrontational style meetings to try to engage more families, where there is low attendance.

The lack of structure and clarity has resulted in emotionally charged environments, causing stress and burnout among CDNMs and Family Representatives. Without clear parameters on the purpose, roles and remit of the Family Forums the safety and welfare of those tasked with running the townhall style forums has emerged as a significant concern across all stakeholder groups.

Stakeholders emphasise the importance of setting clear, measurable goals and regularly tracking progress on service outcomes that arise from the Forums. Currently, the majority of Family Representatives and CDNMs believe that the forums are not effectively achieving better service outcomes. Where impact is noted, it primarily involves enhancements in communication, such as newsletters and information packs. However, these developments fall short of co-design or improving service outcomes for children.

Organisational Preparedness to Embed Family Representation

The FRG is intended to be the linchpin connecting Family Forums with higher-level decision-making bodies like the Operational Management Group (OMG) and the Governance Group. For this to happen, there is a broad consensus that there is a need for a clearer definition of the role of the Family Representative, the FRG, a strong purpose for the FRG itself, and clarity around escalation processes and feedback loops from the Family Forums up to OMG, Governance Group and back down. The FRGs vary in how they operate, leading to mixed perceptions of their effectiveness. There is often a lack of clarity and communication between the FRGs, OMGs, and Governance Groups, hindering the escalation of issues and feedback loops.

Family Representatives have not been provided with formal induction, training and support, leading to inconsistencies and no parameters around their roles. They invest significant time and face emotional strain without clear boundaries or support mechanisms. The research identifies a need for clear role definitions and guidelines to manage expectations, create greater role parameters and move towards embedding family representation into the governance structures.

Ways forward

The study offers evidence-based ways forward directly drawn from the findings. At the most fundamental level, there is a need to articulate and disseminate a shared purpose and vision for the Family Forums. Clearly defining the roles and remit of CDNMs, CDNTs, and Family Representatives is a crucial step identified in the findings. This clarity could help manage expectations, enable transparent accountability processes, and ensure that each stakeholder understands their specific contributions to service improvement.

One of the critical findings of this study is the perceived lack of tangible service improvements resulting from Family Forums. To address this gap, it is essential to transition from tokenistic engagement to genuine co-design practices. Setting nationally standardised, measurable service improvement objectives is a constructive way forward identified in the findings. Establishing specific, trackable goals for forums and regularly communicating progress to stakeholders can highlight both short-term and long-term developments. This could include short term, and longer term, incremental steps towards service co-design.

The findings identify a need for national co-ordination and sharing of localised progress. Facilitating national sharing of progress would promote consistency, avoid duplication and scale effective localised practices nationally.

Nationally standardising induction, training and support for Family Representatives would address a significant gap identified in the findings. Support could include implementing induction programs, more information on governance processes, defining roles, and offering ongoing support to address emotional well-being.

Embedding family representation into the governance structures by strengthening the link between FRGs, OMGs, and Governance Groups with clear escalation processes and feedback mechanisms can improve communication and action on issues raised at the forums.

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 purpose of Family Forums, as outlined in the HSE’s 2022 guide “Setting up and Sustaining the Family Forum - A Guide for CDNMs and Lead Agencies” further supports this vision. The guide highlights the importance of family engagement and participation, with a focus on co-designing service developments and improvements.

“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 CDNМ 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).

The 2023 HSE policy “CHO Governance of Children’s Disability Network Team Services (Revision one)” provide a more structured outline of the Family Forum and FRG's purpose, reinforcing its role in promoting collaboration and transparency between families and CDNMs. The primary goals of the forum include:

1. For the CDNМ 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 CDNМ 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 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, 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 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.

Methodology

This study employed a mixed-methods approach to triangulate data from: a survey, focus groups, and a literature review on co-design and stakeholder engagement. This methodology allowed for an in-depth exploration of participant's expectations, experiences, and perceptions regarding the Family Forums and FRGs.

Ethics

Ethical approval for the study was granted by the Trinity Business School, Trinity College Dublin. All participants gave informed consent prior to taking part in the research. The interviews were recorded. All potentially identifiable information was removed and anonymised to ensure the confidentiality of participants.

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 participants 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.

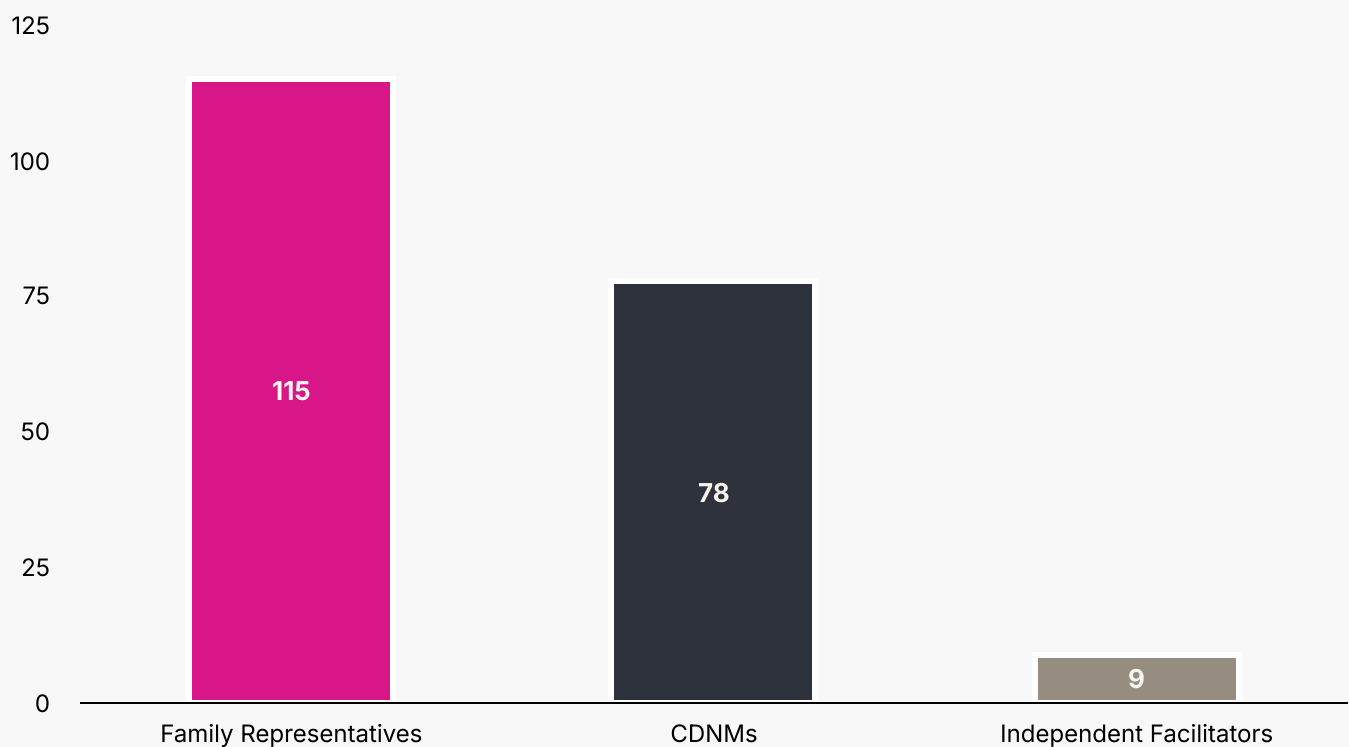
Response Rate and Participant Demographics

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



Data Collection and Analysis

Responses were collected over a four-week period. Quantitative data from closed-ended questions were analysed using descriptive statistics to identify patterns and trends within and across the groups. Qualitative data from open-ended questions were analysed thematically:

- **Coding:** Responses were systematically coded to identify recurring themes related to expectations, experiences, processes, and outcomes.
- **Cross-Group Comparison:** Thematic analysis allowed for comparison of perspectives between the different stakeholder groups, highlighting areas of consensus and divergence.

Focus Groups

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 participants 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.

Data analysis

Data from the survey and focus groups were analysed qualitatively and quantitatively. Survey responses were analysed using Microsoft Excel to identify patterns and trends across the key areas of conceptualisation, interpretation, and outcomes. Open-ended survey responses and focus group transcripts were thematically analysed to extract deeper insights into participant's experiences and perceptions. This involved coding the data for recurring themes and examining the relationships between different concepts. By integrating insights from the survey, focus groups, and literature review, the study aimed to provide a comprehensive understanding of the effectiveness of Family Forums and FRGs, allowing for validation of findings across different methods.

Findings Part One: Fundamental Issues of Functionality and Sustainability

Clarity of Purpose: The Family Forums

The call for clearer purpose and role definition in Family Forums has been 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.

Participants highlighted the need for purpose-driven forums which are focused on measurable service improvements. The findings emphasise the importance of setting clear, measurable objectives for Family Forums, along with regularly tracking and communicating progress.

A key step forward is refining the focus of the forums, towards a shared purpose and vision, as outlined in HSE policy (HSE, 2022). Many Family Representatives criticised the current guidelines as "vague," "woolly," and "nonsensical", leading participants across all stakeholder groups to perceive the Family Forums as tokenistic.

There have been reports of parent's attendance based on the belief that they'll receive a service. For instance, a CDNМ described a mismatch between the family expectations and what can be delivered through the Family Forums, leading to frustrations and even abuse.

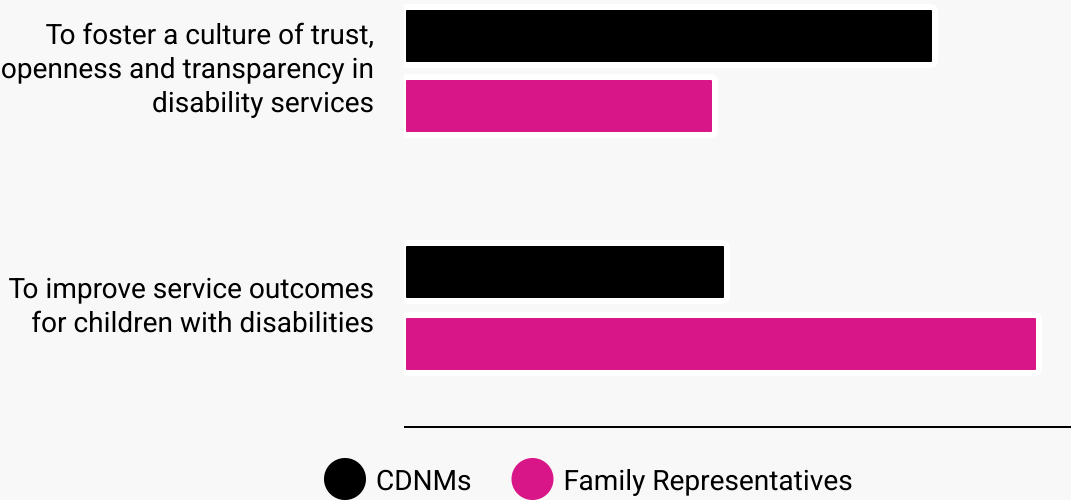
One CDNМ explained: "you've all these desperate parents expecting some sort of a welcome session, rather than the Family Forum – so, really not getting the purpose and function of it. And yes, I've been abused in Family Forums, and in the same Family Forums, parents have left very distressed".

Likewise, many Family Representatives recognised that "expectations have set people up for failure", suggesting a "need for clearer description of what the Family Forum is and its objectives. Clearer defined role of Family Forum reps".

This lack of clarity of purpose is captured in the survey findings, which reveals starkly differing perspectives on the forum’s primary focus. The survey reveals this notable difference in perceptions regarding 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%, n=56) viewed this as the primary purpose of the forums. However, only 25% (n=20) of CDNMs 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% (n=28) of Family Representatives agreed with this purpose. In contrast, a larger percentage of CDNMs members (41%, n=32) believed that building trust, openness, and transparency should be the forums' central focus.

Figure 2: CDNMs and Family Representative Perception of the Primary Purpose of the Family Forums



The findings reveal significant misalignments between family expectations and the CDNMs' remit, leading to frustration from unmet expectations and misplaced accountability on CDNMs.

The perception of many CDNMs is that they 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. Many Family Representatives and CDNMs described the emotions, the fear, stress of the Family Forums, with some describing them as traumatic. For instance, a CDNMs explained: "the fear of it being splashed all over social media scares me and team members each time we do it" Another CDNMs explained "[I] find them to be stressful and at times quite traumatic...it often feels like a townhall meeting where the CDNMs is being 'held accountable' for systems failures".

CDNMs often find themselves in an impossible position, expected to address issues like waiting lists, recruitment, and interdepartmental coordination, which are beyond their control. As one independent facilitator noted, "They 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 CDNMs 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. While families have great ideas for service development, they are outside of the CDNT's ability to provide due to many reasons and families feel the HSE has failed them yet again. 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."

The broader focus of the forums, has led many stakeholder groups to call for a more integrated approach to the forums, involving multiple sectors. There have been calls across stakeholder groups to "integrate the forum as opposed to being siloed", with agencies like CAMHS and primary care taking an active role in the Family Forums. For instance, a CDNMs called for "service user engagement for children's services within CHNs (Community Health Networks). And that it needs to be a much more integrated piece, and it's not just about CDNTs – because we have children who moved across services or utilities two different services, likes CAMHS". Furthermore, there were also calls to draw on the expertise from other areas in the HSE. For instance, one head of service asserted the "need to be getting support and guidance from that new arm of the HSE, which is patient engagement".

Clarity of purpose: Ways forward arising from the data

Communicate a Clear Purpose and Refine the Focus of the Forums

The findings highlight a need for articulation and dissemination of a direction at a national level. Providing clear and precise direction could help focus discussions and prevent them from diverging into general town hall-style meetings, keeping them aligned with the intended objectives to “promote family engagement, participation, and contribution to and co-design service developments and improvements” (HSE, 2022).

Co-ordination and Sharing of Improvements

The lessons learned from developments in local forums should be drawn upon to refine the forums focus. This will ensure that discussions and activities are purpose-driven and aligned with measurable service improvements. A co-ordination mechanism could be developed, such as a quarterly process, for disseminating local successes and lessons learned to other regions. This will enable national coordination and the scaling of effective practices across the country.

Enhance National Communication on Roles and Responsibilities and Establish Specific Service Improvement Goals

The findings highlight a need for clear, consistent communication about what falls within the remit of CDNMs, Children's Disability Network Teams (CDNTs), and other service providers. Ensuring that Family Representatives and stakeholders understand the boundaries and responsibilities of each role would facilitate better collaboration and prevent misunderstandings. Additionally, the setting of realistic and achievable goals for service improvements within the scope of the FRGs and CDNMs/CDNTs. Clearly outlining what can and cannot be addressed will help manage expectations effectively.

Adopt an Integrated Approach Involving Other Sectors and Link with Other HSE Engagement Initiatives

Rather than maintaining a siloed model, engagement should span across relevant sectors such as CAMHS and primary care within Family Forums. This approach would view the child as a whole, acknowledging the interconnected aspects of their health, development, well-being and transition into adulthood. Additionally, linking Family Forums with other HSE engagement and participation initiatives can strengthen support networks and ensure a cohesive, child-centered approach.

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 prevent 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 CDNMs 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 CDNMs 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 CDNMs 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 CDN M 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, CDN M attends parent coffee mornings, opportunities to meet CDN M 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 CDN M 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

Clinician/ Multi-disciplinary Forums

In a small minority of areas, Family Forums are evolving into therapy-focused settings where therapists actively engage with families. Whilst uncommon, these forums allow therapists 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 CDN 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 CDN. For instance, in one region, families have lead calls for clinicians to attend forums and presentation 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 addition 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 parent’s 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.

Duty of Care for Family Representatives and 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. Family Representatives and CDNMs have described the emotional toll of the role. For instance, a Family Representative explained: "sometimes I go into the forums and I feel like I'm being screamed at by the parents... I'm the buffer between the HSE, I'm trying to calm the room, I'm taking on that responsibility." This individual described staying behind after forums to counsel others, which affected not only their own well-being but also their family life. The representative suggested that offering "an option for counselling services or someone to check in with us" could make a significant difference.

There are growing calls for therapists to be present to help families attending the forums to cope with the emotional toll of navigating the system. One Family Representative highlighted this need, stating, "most forums don't have a social worker or psychologists present – and that is what parents really need. Parents are traumatised by the system; they feel scared, abandoned, broken, exhausted, depressed". An independent facilitator further emphasised the importance of adopting a trauma-informed approach, suggesting that "Family Forums are trauma informed and adopt a trauma aware approach," ensuring that the emotional complexities faced by families are acknowledged and addressed. Additionally, they recommended "training provided/offered for Family Reps around groups and group dynamics" to help them to navigate the more difficult interactions. A CDNМ also felt that the Family Representatives should have more support between meetings "FFs are a great idea for involving the families who receive a service but the expectations and return for the reps is quite out of sync - the reps need a point of contact for support and guidance as developments occur between sessions."

The psychological safety of CDNMs has emerged as a significant concern. A Head of Disability Service expressed alarm at "the stress levels for staff, and the health and safety impacts in relation to staff trying to undertake." Another noted the severe impact on psychological well-being: "The psychological safety of staff has to be a consideration... I cannot stand over what my guys have gone through – it's horrific. I find myself awake at night, thinking, 'That Family Forum is tomorrow, I wonder if (the CDNМ) is okay.' It's horrific.". Likewise, a CDNМ described the forums as unsafe, explaining "I really feel that the Family Forum in the context of putting a CDNМ out on a regular basis out to the unknown, is very, very unsafe and it is not fair for CDNMs.

Duty of Care for Family Representatives and CDNMs

The emotional toll placed on Family Representatives and CDNMs has been described as overwhelming, and even dangerous. Both have described how they are being thrust into high-pressure, townhall-style forums where they are expected to manage deeply distressing situations without the support they desperately need. One representative recalled a night when “two red-flag cases” arose, including “a serious risk to life”. While the CDN and Manager took immediate steps to address the situation for the at-risk individuals on that particular evening, there was no follow up support for those present on the night. The Family Representative explained “It was very distressing... we asked if we could consider bringing in somebody like a Social Worker or Therapist, but we were told ‘No, can’t be available.’”

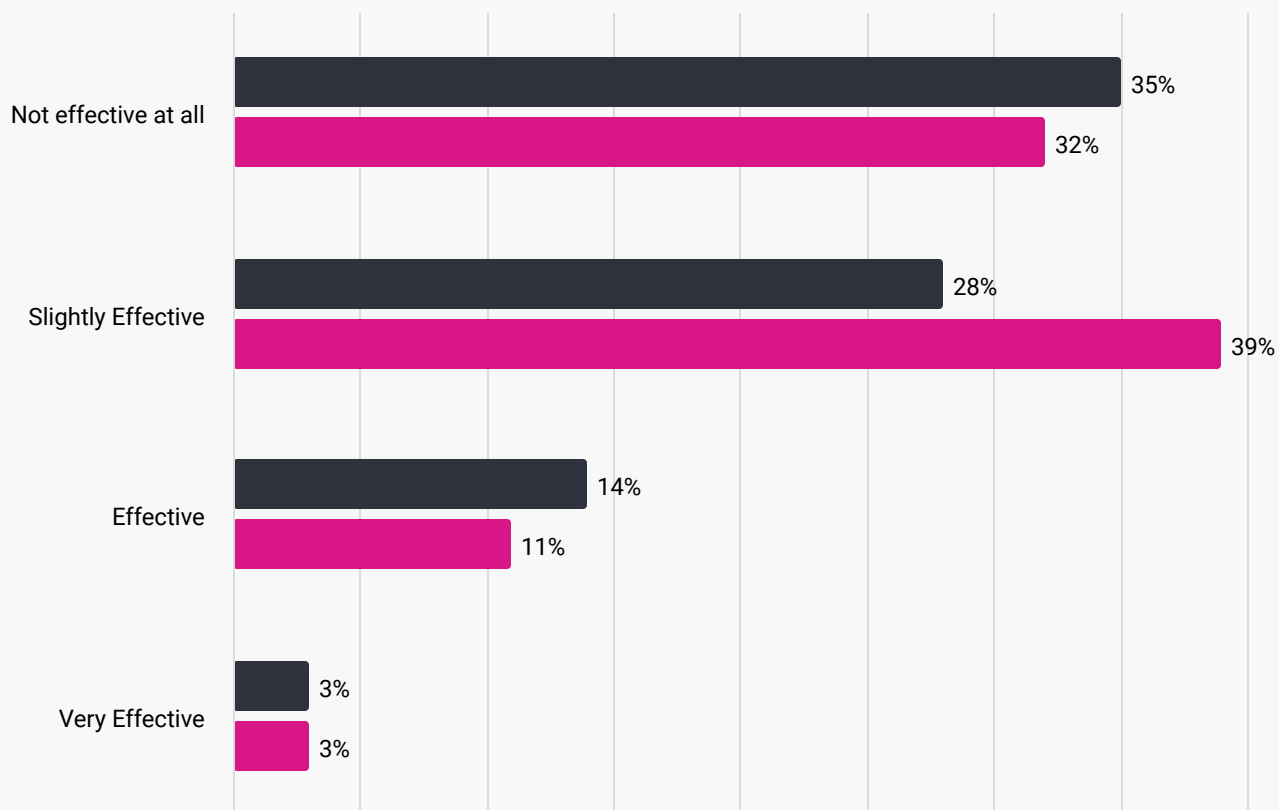
The issue was escalated by a Family Representative at the Governance Group, specifically requesting a Social Worker be available at each Family Forum to provide ongoing support for families in need. However, this request was declined and were told that the CDN’s presence should be sufficient to handle such issues. The Family Representative expressed frustration, emphasising that having an individual to provide trauma informed support, including aftercare would have been “an incredible help”.

This request was denied despite Social Workers and other therapists attending Family Forums in other parts of the country, again reinforcing the inconsistencies in the ways in which the forums are run.

Measuring Outcomes

The vast majority of Family Representatives and CDNMs believe that the Family Forums are not achieving better service outcomes for children with disabilities. 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.

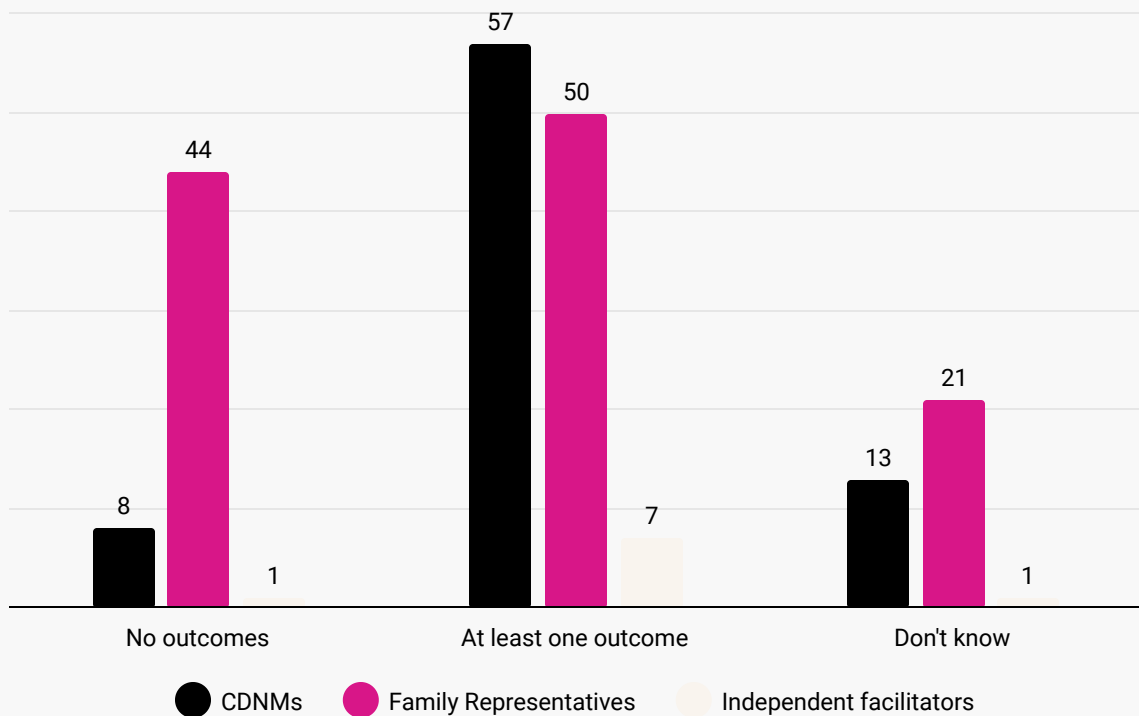
Figure 3: CDN and Family Representative's perception of the effectiveness of the family forums



Furthermore, the perceptions of the kinds of outcomes 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 there are no actions arising from the Family Forums, suggesting a disconnect between these two groups in terms of perceived outcomes and actions from the forums.

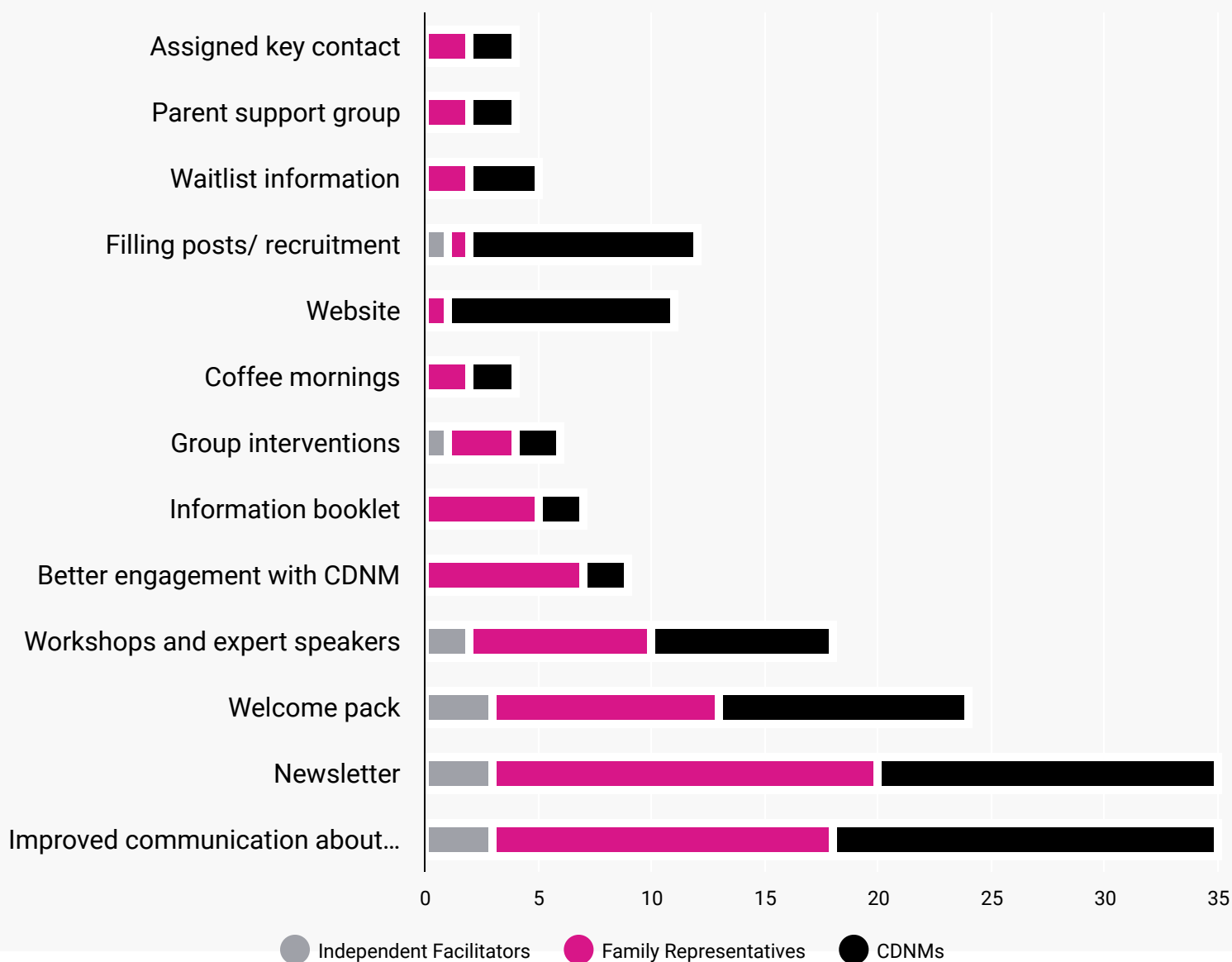
Dissatisfaction with the PDS model and calls for more one-to-one therapies are perceived to be dismissed at the forum level, adding to the frustrations. For instance, one family representative complained “at the moment families, family representatives, frontline staff, CDNMs, unions, regulatory bodies, politicians and the High Courts are all complaining about PDS but it isn’t being listened to”. A CDNМ explained the disconnect between family calls to move away from the PDS model, and what’s within the CDNМ’s capacity to change: “family forums are not a productive way of co-designing service provision with families. They have been very contentious at times and difficult for CDNMs and families in attendance. Rightly, the families are asking for more services for their children and specifically input from the therapy disciplines in the traditional sense not under the PDS model”.

Figure 4: Perceptions of outcomes and 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 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 outcomes and actions arising from the Family Forums



The vast majority of the outputs captured in the survey fall short of the promise to “co-design service developments and improvements” (HSE, 2022). The perceived lack of tangible service improvements has led to mounting frustrations over unmet expectations leaving Family Representatives feeling that “it absolutely has not run in the way it was initially portrayed... it has absolutely not shaped any services, it has absolutely not in any way improved outcomes for families”. A Head of Disability Service explained that “the purpose of a Family Forum and what they actually have turned into are two vastly different things. So, the purpose is of course a service improvement platform but it's very difficult to be up there as a CDNМ trying to foster collaboration if you've been attacked”.

Family Representatives stress the need for forums to focus on service improvements for children, the recruitment and retention of staff, with tangible outcomes that can be tracked over time. A Family Representative stressed, “There has to be a clear goal outlining the purpose(s) of these forums and what we are doing to achieve those goals. Parents need to see progress”.

The perceived lack of tangible service improvement leads to many participants calling the forums tokenistic. The unmet expectations, and lack of tangible outcomes appears to contribute to the low numbers attending the Family Forums. As one Family Representative explained; “It's really hard to know what the purpose is and if they are of any value. Most people come once for an update and don't attend again”. To combat this, clearer communication about the purpose and value of the forums was identified as key to addressing the perceived lack of tangible outcomes. Many families suggested providing regular updates on the outcomes of previous meetings to ensure that families are aware of any progress.

Expectations versus the pace of the system

Participants across the board have expressed anger and frustration at the pace of change and the lack of joined up thinking in the HSE system. An independent facilitator recognised that parental “frustration is being bogged down in bureaucracy, but the HSE seem to accept the bureaucracy and defend it as opposed to being honest and transparent about what they're going to do”.

While some areas have managed to develop resources, others have been stalled because of the pace of the system. For instance, another independent facilitator explained: “we're getting updates after updates after updates on the website. Something as simple as a website, which should be commissioned outside of the HSE and get somebody in to do it, but the HSE in the guise of their Senior Managers will not commit to that and they're saying ‘Oh yeah, we're working on it, we have a working group here and a working group there’ and nothing is happening. I'm doing this for a year and a half now in my areas, and nothing has changed”.

Measuring Outcomes Summary: Ways Forward arising from the data

Set Clear, Measurable Objectives for Family Forums & 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.

Standardise the Measurement and Documentation of Outcomes: Develop a uniform method for measuring and documenting service improvements across all forums and FRGs to allow stakeholders to track improvements.

Findings Part Two: Organisational Preparedness to Embed Family Representation

The Family Representative Role

Across all groups, there are increasing demands for formal 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."

The Family Representative Group

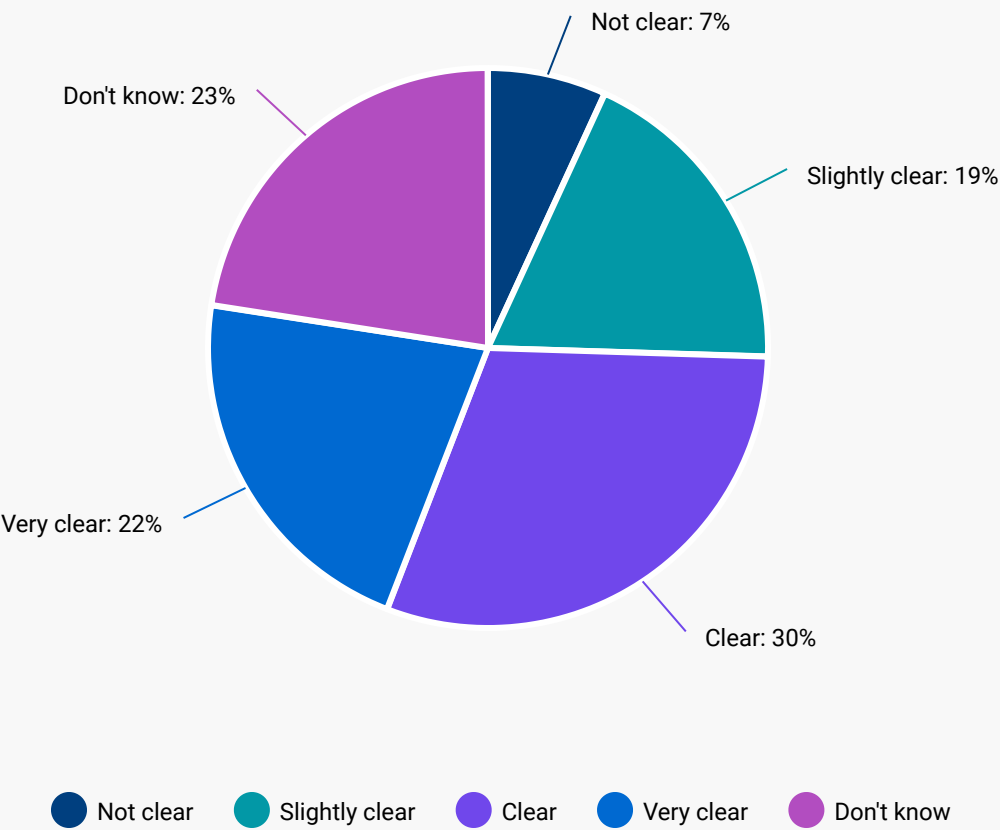
The FRG is intended to be the linchpin connecting Family Forums with higher-level decision-making bodies like the OMG and the Governance Group. For this to happen, there are extensive calls for clearer role definitions of the role of the Family Representative, the FRG, a strong purpose for the FRG itself, 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".

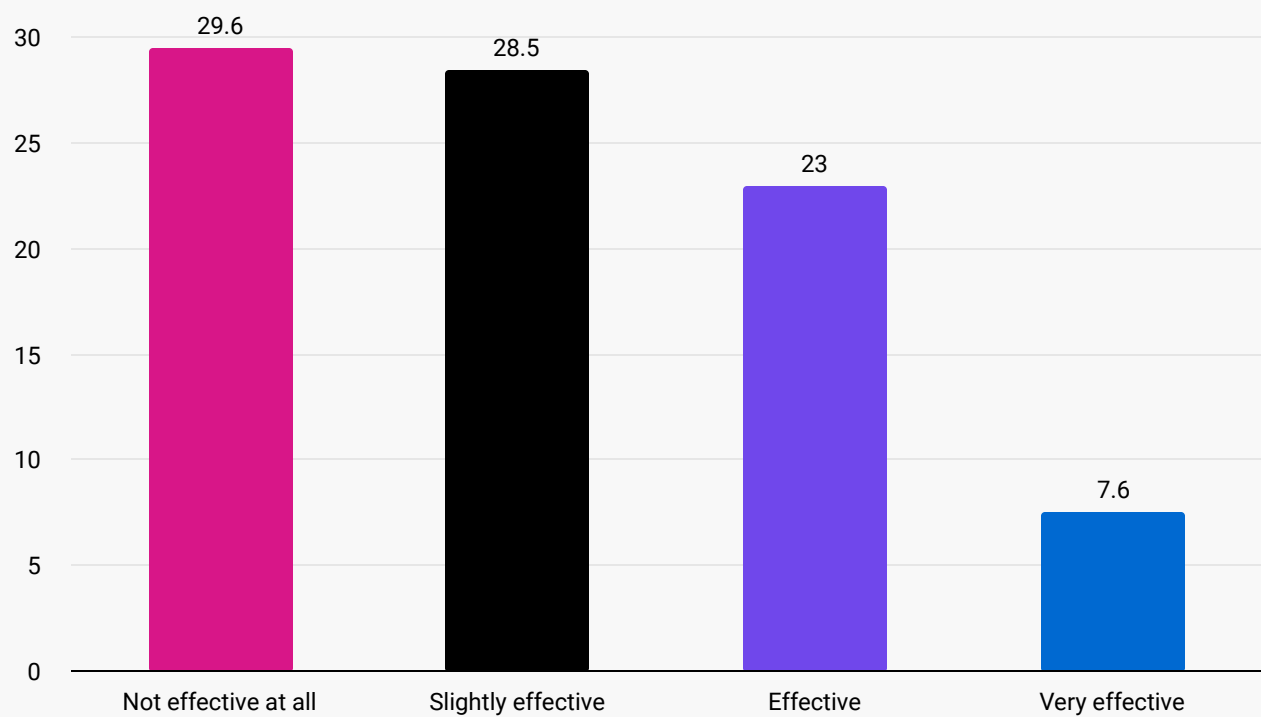
Inconsistencies in the way FRGs are running and functioning were a significant concern shared across all groups. These discrepancies are reflected in the survey findings. Feedback from Family Representatives on the functionality of the FRG was mixed. When asked if the meetings were clear and easy to follow, just over half (53%) of representatives felt they were either clear or very clear. However, just over a quarter (26%) felt the discussions were either only slightly clear or unclear altogether with 21% responding with 'don't know'.

Figure 6: Clarity of the Family Representative Group meetings



While 53% of Family Representatives found FRG meetings clear, this clarity does not translate into tangible service improvements. Only 30% of representatives believe the FRGs are effective at achieving better service outcomes for children, while 58% said the meetings are either not effective or only slightly effective.

Figure 7: Effectiveness of the Family Representative Groups at achieving better service outcomes



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, "they run rings around you, basically, in relation to our systems and processes in the HSE". The Head of Service went on to explain that 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 "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".

Inaction on issues raised by Family Representatives

The findings reveal the growing frustration among Family Representatives when Governance Groups do not meet their expectations, particularly when key decision-makers are present at meetings. Furthermore, a CEO of a lead agency empathised with this frustration, stating: “I can empathise how frustrating it must have been, but we all know that things can be very slow, particularly when you’re dealing with other care groups as well. One of the challenges was that primary care and mental health didn’t really attend the Governance Groups meetings. I think they were only maybe at one, so that target, that audience or that key decision-maker wasn’t there all of the time either, so that would have been really frustrating from a parent perspective”. This lack of attendance from critical stakeholders hinders progress and leaves Family Representatives feeling that their time and efforts are undervalued.

An illustrative example of issues raised at the forums not being actioned involves a basic yet critical communication concern. During the first Family Forum meeting, parents discovered that there was no direct phone line to reach their CDNTs. Despite multiple CDNTs operating out of the same building, all calls were routed through a central phone system where messages often went unchecked. A Family Representative recounted:

“At the first meeting, it came out that parents were ringing the CDNT, but there was no direct phone line. So there’s a number of CDNTs working out of the same building, and none of them have a direct line. It all goes into a central phone, and if you leave a message, there’s nobody checking the messages. We were horrified—we were like, ‘What? We don’t have a direct phone line? Can that be fixed?’ That’s something really practical, really easy to fix. I elevated it; I spoke about it even at governance level as an example of how things aren’t changing—just one small example, something that would really help parents. Small things that aren’t about therapists and government—they’re structural organisational issues. And even the most basic thing was a problem”.

Despite the issue being a seemingly straightforward issue to address, it was unresolved. This lack of action highlights a disconnect between the concerns raised by Family Representatives and the responsiveness of the CDNT to address practical concerns within their remit.

Embedding Family Representation into Governance Structures: Ways Forward arising from the data

Create a Stronger Sense of Purpose for the FRG: Define and disseminate a clear purpose for the FRG, outlining its objectives and how it fits into the broader system of service improvements. Develop guidelines for structuring the FRG in an impactful way. Establish Clear Boundaries for the Family Representative Role: including a realistic assessment of the time commitment required.

Provide guidelines on what is expected of Family Representatives, along with protocols for managing issues such as boundaries, abuse, harassment, or inappropriate behaviour experienced while in the role.

Standardised Induction, Training, and Ongoing Support for Family Representatives: Implement a standardised induction and training program for all Family Representatives, ensuring that they are fully equipped to fulfil their role. This should include induction and training on governance processes, their responsibilities, and how to navigate the system effectively.

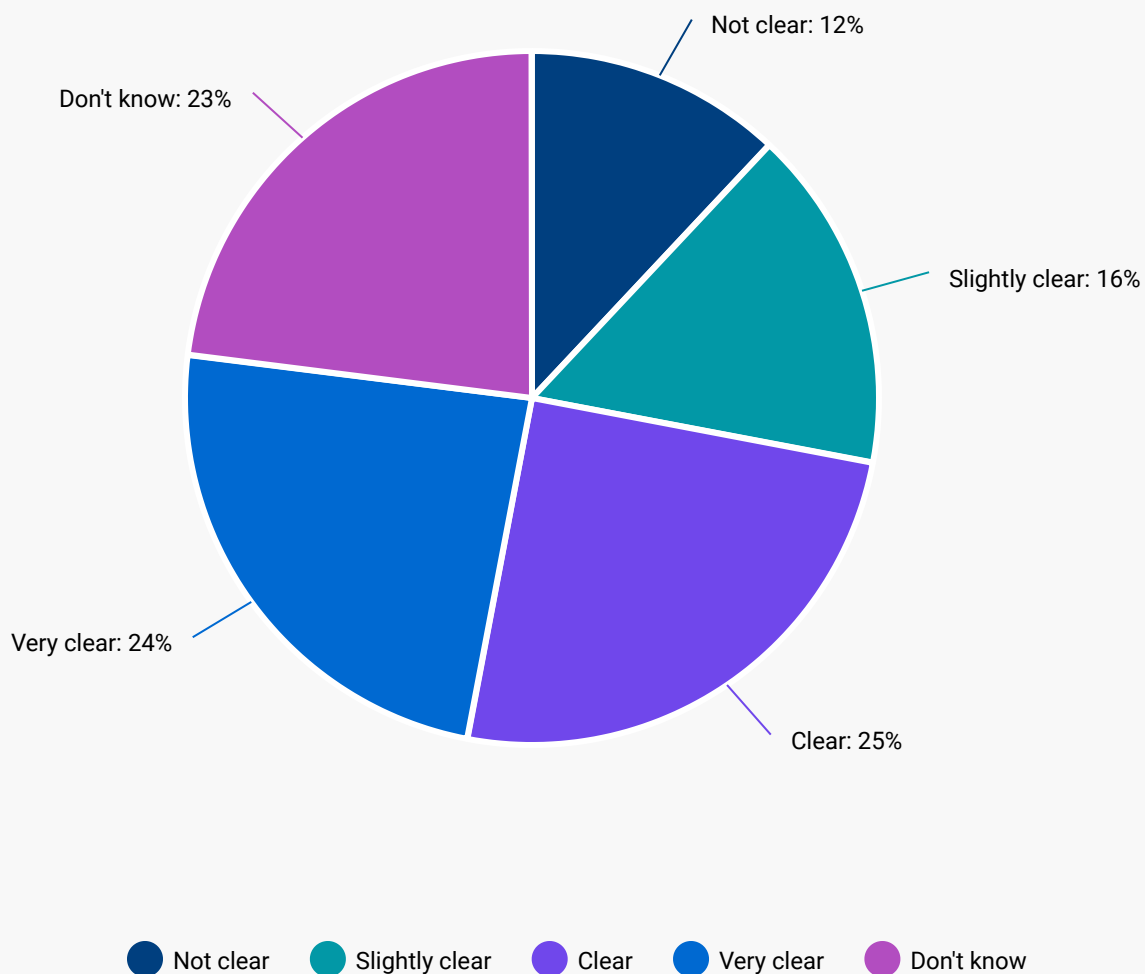
Clarity Around Escalation Processes and Feedback Loops: Establish clear and transparent processes for escalating issues raised in Family Forums, Family Representative groups, up to the OMG and Governance Group, with a structured feedback loop to ensure concerns are addressed and communicated back to families in a timely manner.

Support and Trauma-Informed Approach: Offer support to both Family Representatives and CDNMs, ensuring that they have access to counselling and relevant therapists as needed. Implement a trauma-informed approach for those who require it, recognising the emotional toll that navigating complex systems can have. This support will help maintain the well-being of all stakeholders involved in the forums.

Escalating issues to the governance group

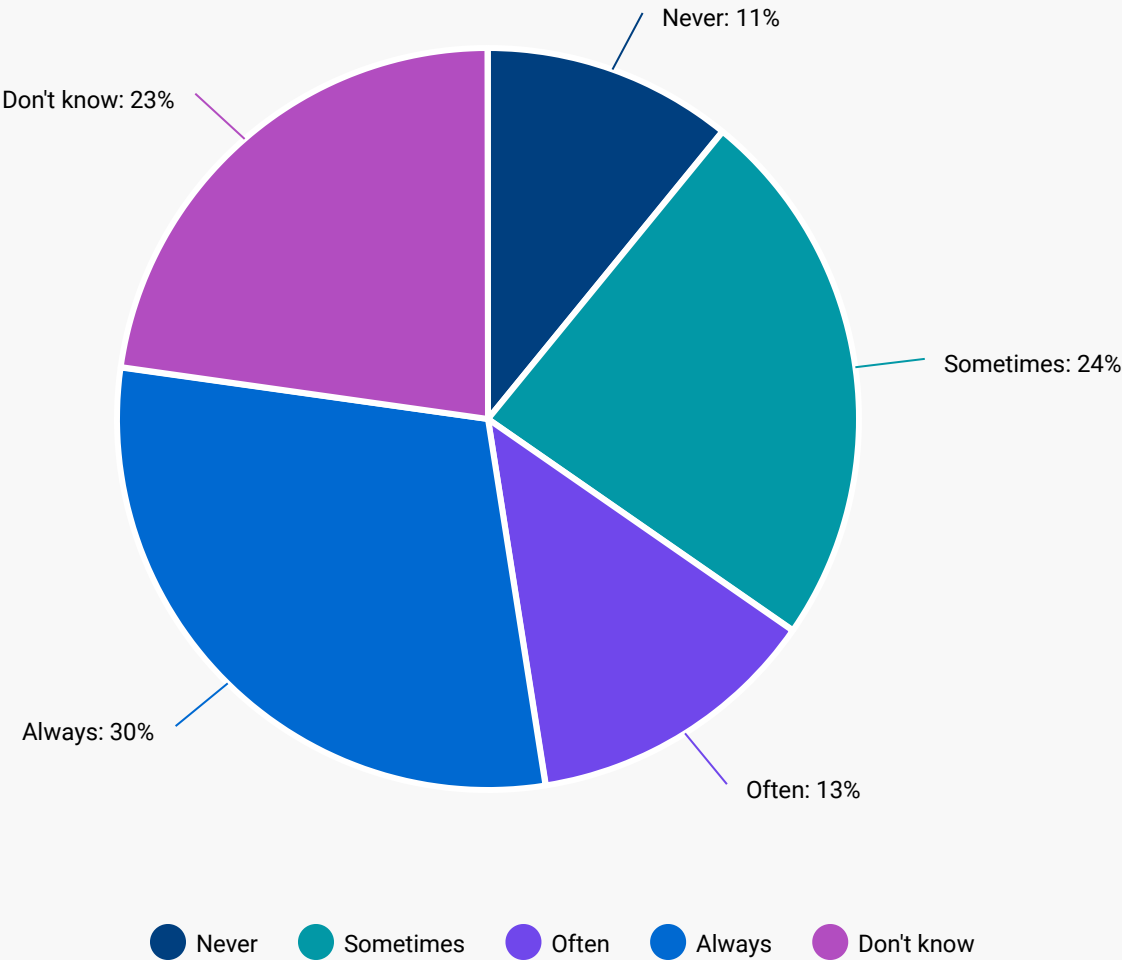
The survey findings indicate that almost half of Family Representatives (49%) were clear or very clear about which issues were going to be escalated to the Governance Group.

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



However, while almost a third (30%), of respondents report that communication between the Governance Group and the FRGs about which issues are actioned is always clear, this leaves a significant portion who experience less consistency. a concerning 24% noted that communication is only sometimes clear. Even more troubling, 11% of respondents stated that there is never any clear communication regarding the outcomes of the issues raised.

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



This lack of consistent feedback is reflected in the focus groups where qualitative comments capture 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.”

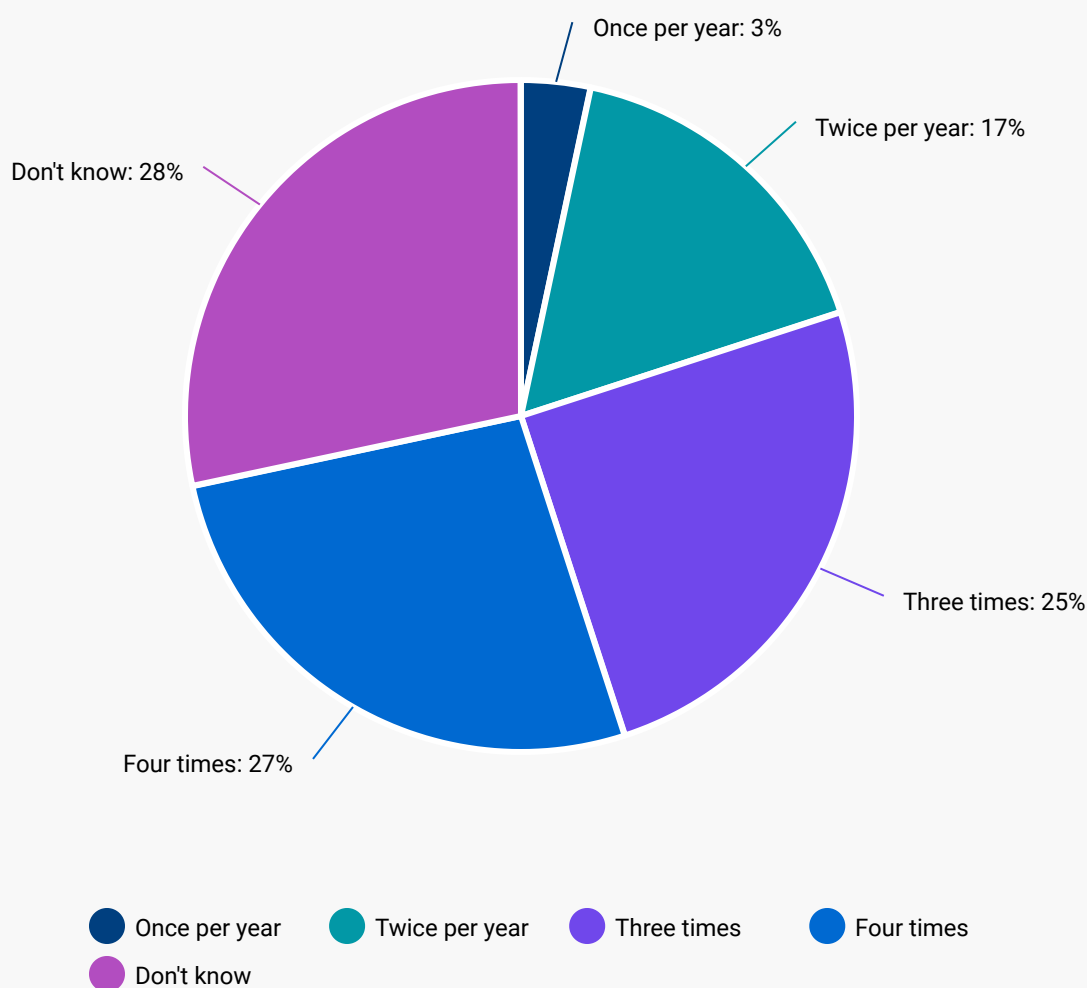
“It feels very much like any issues we have raised have been dismissed and not taken seriously, like a pat on the head to be there, but nothing more. Not once did I feel validated in my role, nor that we were seen as having value, beyond lip service and it was business as usual behind the scenes that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

One CDNМ suggested the need for a more structured approach, advocating for a “written format by which FRG can put issues to the Governance Group and time slots at GG meetings to present their issue and discuss it. “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”.

Family Representatives on the OMG

A significant portion of respondents were uncertain about the frequency of contact between the FRG and the OMG. Forty percent 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



Family Representatives on the OMG

This uncertainty is reflected in qualitative feedback from Family Representatives. Many 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.

However, experiences were inconsistent. Some representatives felt their concerns were not being heard, underscoring challenges in ensuring consistent engagement across different areas. When CDNMs were asked how often the OMG creates action plans based on FRG feedback, nearly a third indicated this happens only sometimes, and a quarter noted that issues raised are often beyond the OMG's capacity to address. Despite these challenges, some CDNMs reported that increased engagement with FRGs improved relationships and trust.

Responses varied significantly among CDNMs. While some felt their roles were not fully recognised and lacked follow-up on issues, others appreciated the perspectives Family Representatives brought to the OMG. Regarding clarity on which issues are escalated from the FRG to the OMG, only 39% of Family Representatives felt clear or very clear about the process, while 30% did not know, highlighting significant gaps in communication and transparency.

There is also a deep-seated frustration with repetitive discussions without real progress, leading to feelings of exhaustion and futility. Many Family Representatives have resigned because of the frustrations of the role. Representatives expressed the need for a more genuine partnership approach, recommending more regular meetings, open and honest dialogue, accountability, partnership values, and training to engage effectively. This indicates a desire not only for better communication and action but also for the tools and support necessary to participate meaningfully in the process.

Governance: Ways forward arising from the data

Increased Clarity on Role, Purpose, and Function: Provide comprehensive information about the role, purpose, function, and remit of the Governance Groups. This should include clear examples of what can realistically be achieved within specific timeframes, helping to manage expectations and foster more constructive engagement.

Clearer Role Definitions and Comprehensive Induction Processes: Establish well-defined roles for all Governance Group members, including Family Representatives. A robust induction process will help ensure that representatives understand the Governance Group's remit and the constraints within which it operates. This will contribute to aligning expectations with the group's capacity to deliver change.

Better Terms of Reference and Information Circulation Guidelines: Develop clearer terms of reference for Governance Groups regarding the circulation of information and documents, ensuring that parents, as volunteers, are given sufficient time to review materials. Guidelines should also be put in place around the cancellation of meetings, minimising last-minute changes and respecting the time commitments of Family Representatives.

Discussion: Ways forward

Despite the endorsement of family engagement, collaborative working, and co-design into national guidance on family forums, translating these commitments into tangible service improvement remains a significant challenge. The findings identify areas that have potential to enhance family engagement in service development and improvement and embed family engagement into governance structures.

Ways Forward

The study offers evidence-based ways forward directly drawn from the findings. The findings highlight the importance of refining the purpose, structure, and operations of Family Forums, while defining the nature of Family Representation, and providing support structures around the role. By moving towards a more integrated, goal-oriented, and child-centred approach, these forums can serve as a foundation for meaningful family engagement and tangible service improvements.

At the most fundamental level, there needs to be clearer articulation and dissemination of the purpose of Family Forums, including defining and communicating the remit of CDNMs and CDNTs to set clear parameters around the forums. Clearly defining the roles and remit of CDNMs, CDNTs, and Family Representatives is a crucial step identified in the findings. This clarity could help manage expectations, prevent the misallocation of accountability, and ensure that each stakeholder understands their specific contributions to service improvement.

One of the critical findings of this study is the perceived lack of tangible service improvements resulting from Family Forums and FRGs. To address this gap, it is essential to transition from tokenistic engagement to genuine co-design practices. Setting nationally standardised, measurable service improvement objectives is a constructive way forward identified in the findings. Establishing specific, trackable goals for forums and regularly communicating progress to stakeholders can highlight both short-term and long-term developments.

Across regions, many successful initiatives and lessons have emerged within local Family Forums. However, without a structured mechanism to share these insights, the benefits remain confined to individual areas. A coordinated approach—perhaps through regular, quarterly dissemination of best practices—could bridge this gap, enabling forums nationwide to learn from each other's experiences. This sharing process will promote incremental improvement and assist forums to adopt innovative solutions, while creating consistency across regions.

The development of Family Forums efforts depends on clear, consistent communication regarding roles and responsibilities. Families, service providers, and CDNTs each play distinct parts in the system, yet misunderstandings about what falls within each role's remit can create tensions. Defining roles and establishing boundaries would foster better collaboration, helping each stakeholder understand how they contribute to the larger mission of improving service outcomes for children. Nationally standardising induction, training and support for Family Representatives would address a significant gap identified in the findings. Support could include implementing induction programs, more information on governance processes, defining roles, and offering ongoing support to address emotional well-being.

Governance Groups and OMGs should critically review their decision-making capacity to ensure that Family Representatives have a meaningful role in shaping decisions. To maintain trust and transparency, the Governance Group and OMG should implement robust feedback loops that inform all stakeholders about decisions made, including the rationale behind those decisions and how family input contributed.

After decisions are made, concise summaries could be circulated to Family Representatives and other stakeholders. These summaries should clearly outline what was decided, why the decision was made, and how input from Family Forums and Family Representatives shaped the outcome. Publishing regular reports on the Governance Group's and OMGs impact and key decisions coming from the family forums would further strengthen transparency. These reports could highlight areas where family input was pivotal and provide insights into how decisions have translated into practical improvements.

Moreover, a regular review of decision-making processes and feedback effectiveness could help identify areas for improvement. As the Governance Group and OMG learns from ongoing feedback, it can refine these processes, ultimately creating a responsive governance structure that reflects a commitment to family input into service improvement.

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