

HSE High Level Action Plan to address Genio Recommendations ***as approved by the Service Improvement Programme Board***

June 23rd, 2025

Introduction

National HSE Disability Services standardised governance of Children's Disability Network Team (CDNT) Services in 2021 with the development and launch of the *National Policy on CHO Governance of CDNT Services*¹ ([here](#)) for implementation. This policy defines the new structures of:

- **Family Forum** – 1 per CDNT nationally, 91 of which are currently in place.
- **Family Representatives Group (FRG)** – 1 per CHO including 2 family reps elected by families of each Family Forum. 8 of 9 are currently in place.
- **Operational Management Group (OMG)** – comprising all CDNMs of that CHO
- **CHO CDNT Governance Group** – Head of Service Disabilities led on behalf of the Chief Officer and including amongst others, 2 FRG elected family reps and 1 OMG rep.

To support the Policy's implementation, National Disabilities in partnership with CHOs, parent voices and Inclusion Ireland developed the *Guide to Setting up and Sustaining Family Forums for CDNMs and Independent Facilitators 2022* ([here](#)), and hosted a number of workshops over 8 months on setting up the Family Forums. Family Forum events have enhanced communication with families, and their awareness of service challenges e.g. vacancies, recruitment activities. However, stakeholders report significant challenges in sustaining and achieving outcomes from Family Forums. In July 2024, HSE National Disabilities commissioned Genio to complete an **independent review of the functionality and sustainability of Family Forums and Family Representative Groups**. See Genio Final Report [here](#) for details here on their research approach, findings and recommendations arising.

Roadmap Working Group 4, Communication and Engagement proposed a high level HSE Action Plan to address Genio's recommendations arising from the review to the Roadmap's Service Improvement Programme (SIP) Board in May. The SIP Board requested the draft be circulated to FRGs for input and FRGs feedback received was taken on board by the Working Group to inform the final Action Plan submitted to the SIP Board. This plan was approved today and subgroup 1 to drive Actions 1, 2 and 3 forward will commence tomorrow in light of the new, shortened delivery target dates.

The Action Plan will be delivered in a structured, timed Improvement Programme laid out as follows:

- Short-term Actions - 1 to 6 months
- Medium-term Actions - 7 to 9 months

¹ Note: the National Policy on CHO Governance of CDNT Services will be reviewed to realign the structures within to the new Health Regions and relevant roles, pending finalisation of the latter.

HSE Action Plan to address Genio Recommendations

Actions for delivery in the short-term: next 1 - 6 months

- 1. In June 2025: we will issue a Communication on the Genio Review and HSE's Action Plan to address its recommendations** to all key stakeholders on the findings of Genio's independent review and recommendations, and the HSE's plan to address those recommendations with its partner Lead Agencies. This should include an outline of the plan to restate the Family Forums as the platforms for families to contribute their ideas and proposals for service improvements, developments and innovation, to define, strengthen and communicate the role and purpose of elected Family Reps on the Family Forum, working with the OMG and participating on the Governance Group, and training to develop and solidify codesign practice at all levels.

- 2. By October 2025, we will review the *Guidance on Setting Up and Sustaining Family Forums 2022* including**
 - CDNM role in setting up, participating in and reviewing the Family Forum event, and raising issues and service improvement ideas prioritised by the Family Forum to the OMG, and where appropriate via the OMG, to the CDNT Governance Group.
 - What is within the CDNM role to address in regard to CDNT services.
 - Escalation process, pathway and feedback loop for items beyond the CDNM's control e.g. respite, CDNT staff colocation to enable child and family centred services, CDNT staffing levels and recruitment.
 - A nationally standardised invitation letter to families for each Family Forum event.
 - Review of the Independent Facilitator (IF) role, building on 2 years' collective experience, and including their responsibility of upholding psychological safety for all participants, ensuring respectful engagement and maintaining Family Forum focus on service improvement. Consider also alternative options of Family Forums and FRGs facilitation e.g. self-facilitation and requirements for transition to this.
 - Transitioning from 'townhall events' to outcomes focused Thematic Forums, informed by families' preferences identified in the Family Forums, harnessing 1 area's success on this approach to date.
 - CDNT staff rotating on attendance at the Family Forum to support CDNMs and delivery of the Family Forum's TOR, process and outcomes e.g. SW support for families, Admin providing timely access to personalised waitlist position
 - End of Family Forum event survey on what families found useful, suggestions for improvement and feedback in the next event on how their input was onboarded.

We will extend the guidance to include **Guidance for FRG and the CDNMs Operational Management Group** to support effective collaboration and meaningful codesign practice within the CDNT governance. It will include:

- Purpose and Terms of Reference of the FRG including its remit, its scope and how it connects to CDNT Governance
- Roles of family representatives in the Family Forum, in the FRG, collaborating with the OMG, and on the CDNT Governance Group, clearly defining what the role includes and excludes for transparency and shared expectations
- Roles and responsibilities of the OMG including
 - how it contributes to CDNT governance and service improvement
 - working collaboratively with the FRG through codesign processes
 - developing a joint FRG/OMG SMART Action Plan with measurable, service improvement goals focused on priority areas agreed for codesign and feedback loop on progress of OMG actions to the FRG
 - feedback loop from the OMG to the FRG and joint OMG/FRG feedback from the Governance Group for their respective Family Forums.
 - tracking/gathering/sharing emerging and innovative Family Forum practices and achievements across the Family Forums, OMG and the Region
- Defining the purpose and scope of the OMG/FRG codesign process and a formal mechanism for joint working including the structure, standing agenda, who leads it, who attends, and frequency
- Defining the joint role of OMG and FRG members on the CDNT Governance Group in proposing their codesigned SMART Action Plan on service improvement priorities for approval and updates on its progression, delivery and any challenges arising.

3. By November '25, we will develop **Joint Regional FRGs members, CDNMs and Independent Facilitators Training events** on

- their respective roles in regard to the Revised and Extended Guidance (No. 2 above)
- Developing and sustaining codesign culture and practice.

4. Between Sept '25 and Mar '26, we will commission and deliver **Training for CDNMs and staff participation in Family Forums** on trauma informed approaches, de-escalation techniques, active listening and role playing to enable optimal engagement and communication with families.

5. By Oct '25, we will develop a **standardised Induction Programme for newly elected family reps on FRGs** including an induction pack for issue pre induction/training and record the training to be available for subsequent elected parents. It is anticipated that in time, the training programme of service user and family representatives under the National HSE Patient Service Users Engagement structures, in development, will underpin the above CDNT induction programme.
6. By December 2025, we will develop and roll out **nationally standardised key performance indicators** to measure and monitor the progressive implementation of codesign practice and outcomes at Family Forums, at FRG/OMG and at CDNT Governance Group levels.
7. By Dec '25, we will **review and update the CDNT Governance Policy** to
 - Align to new Health Regions, and final new roles and responsibilities once finalised
 - Strengthen the role of the Governance Group in developing codesign practice.

Actions for delivery in the medium term over next 7 - 9 months

8. Between By Dec '25 and March '26, we will deliver **Joint Regional FRGs members, CDNMs and Independent Facilitators Training Programme²** in all 6 Regions (see action 3).
9. By March '26, **each Region's realigned CDNT Governance Group² will review in line with Genio recommendations:**
 - Frequency of Governance Group meetings for consistency and continuity.
 - Standing Agenda Item: themes and ideas for service improvements and developments raised by FRG members and jointly prioritised with the OMG.
 - Training of the Governance Group including the two 2 FRG elected members on
 - Role of FRG elected members on the Governance Group as outlined in the Guidance for FRGs and OMGs (Action 3 above)
 - Role of the Governance Group supporting the 2 FRG elected members, and exploring their insights and proposals jointly prioritised with the OMG, for feasibility and impact.
 - Ground rules for participation
 - Developing and sustaining codesign practices as a group.

² Target date is dependent on Regions' realignment of FRGs to new Regional structures

- Development of a process for gathering, reviewing and sharing the outputs and outcomes of all Family Forums and the FRG based on *FRG/OMG's Annual Joint Work Plan* to all key stakeholders at Regional level.

10. By Quarter 1 '26, to scale effective Family Forum and FRG practices nationally, we will

- Develop a standardised approach to gather and share nationally the innovative practices emerging in Family Forums and Family Representative Group/Operational Management Groups to spread exemplars of collaborative working and outcome focused achievements, gathered Regionally by the OMGs.
- **Develop a National Database of innovative codesign practice and service innovations generated as a result** and share across all Health Regions Governance Groups, OMGs and FRGs.
- **Share innovative design practices via a quarterly Innovation Bulletin.**

See *Appendix 1 for HSE Action Plan Table Summary.*

Conclusion

This high level HSE Action Plan has been approved by the SIP Board for implementation over the next 9 months to address Genio recommendations arising from their independent review of the functionality and sustainability of the FFs and FRGs. A more detailed project plan to support its delivery will be developed by WG4 Communication and Engagement to drive its implementation over the next 9 months and an update will be provided each month during this period to the SIP Board in its monthly meeting on the status of its implementation.

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National Service Improvement Lead

Roadmap for Service Improvement 2023-2026, Disability Services for Children and Young People.

June 23rd 2025



Roadmap for Service Improvement 2023-2026
Disability Services for Children's & Young People



Appendix 1 : Action Plan Table Summary

Short-term Actions for delivery over next 1 - 6 months from SIP Board approval				
No.	Action	Lead	Target	Cost
1	Communication on the Genio Review and HSE's Action Plan to address its recommendations	National Service Improvement Lead	June '25	Nil
2	Review and update the <i>Guidance on Setting up and Sustaining Family Forums 2022</i> and Extend to include <i>Guidance on Role of FRGs and OMGs</i> as detailed above.	National Service Improvement Lead	Oct '25	Subgroup members time
3	Develop Joint Regional Training of FRGs members, CDNMs and Independent Facilitators on (i) their respective roles in line with above Guidance (ii) developing and sustaining codesign practice	National Service Improvement Lead	Nov '25	Subgroup members time
4	Commission and deliver training for CDNMs and staff participating in Family Forums on trauma informed approaches, de-escalation techniques, active listening and role playing	REOs nominees /Lead Agencies CEOs	Sept '25 to March '26	TBC once training has been developed, sourced and costed
5	Standardised Induction Programme for newly elected FRG members	National Service Improvement Lead	October '25	Subgroup members time

6	Define and implement nationally standardised key performance indicators for Family Forums, FRG/OMG and CDNT Governance Group levels on codesign practice and outcomes	National Service Improvement Lead and REOs nominees	Dec 2025	Subgroup members time
7	Review CDNT Governance Policy to align to Health Region structures and roles once finalised and strengthen Governance Group role in developing codesign practice	National Service Improvement Lead with REOs nominees	Dec 2025	Time of staff involved
Medium Term for delivery over next 7- 9 months				
8	Deliver Joint Regional Training of FRGs members, CDNMs and Independent Facilitators on their respective roles and developing codesign practice (see Action 3 above). <u>This is pending realignment of FRGs to Regions.</u>	REOs' nominees	Dec '25 - Mar '26 REOs to confirm	Facilitator costs unless NPSUE Training available by then
9	CDNT Governance Groups will <ul style="list-style-type: none"> - review their meeting frequency and standing agenda items, - complete training on members roles and codesign practice - agree a process for gathering and sharing outcomes from its Family Forums and FRG/OMG Annual Joint Work Plan <u>This is pending realignment of FRGs to Regions.</u>	REOs nominees/Chairs of CDNT Governance Groups	March 2026 REOs to confirm	Time of staff involved
10	Standardise approach to gather and share nationally innovative codesign practices in Family Forums and FRGs/OMGs, collaborative working exemplars and outcome focused achievements, supported by a National Database.	National Service Improvement Lead/ REOs' nominees	Jan - March '26 For REOs agreement	