



Family Forum Minutes Thursday 05th December 2024. Wicklow Primary Healthcare Centre	
Who was present: Participants 	
<p>John McCusker Family Forum Facilitator, Elaine Byrne, Children's Disability Network Manager CDNT 6, (CDNM), Frances Fitzell Children's Services Manager, Sue Martin Administration, family members from 8 service user families.</p> <p>Family Representative: There is currently a vacancy for the Family Rep for CDNT6 Chair: John McCusker Co-Chair: Elaine Byrne</p> <p>Minutes: Sue Martin</p>	
What happened: Agenda 	
Introduction	<p>Elaine welcomed everyone and thanked them for attending the meeting. She introduced herself and her role as interim Children's Disability Network Manager.</p> <p>John introduced himself, and his role as an independent facilitator employed by the HSE. He asked for all to have a positive approach, let every voice be heard as this is a safe meeting.</p> <p>Families introduced themselves.</p> <p>Frances introduced herself as Children Services Manager with Enable Ireland Wicklow and Dublin.</p> <p>Frankie introduced herself as Director of Services with Enable Ireland Wicklow and Dublin</p> <p>Housekeeping for the building and ground rules for the session reviewed by Elaine.</p> <p>Elaine informed the parents that questions were welcomed, and would be recorded as part of the minutes (see appendix)</p>
Family Forum Facilitator update	<p>Update from John about how Family Forums work:</p> <p>John spoke about the vision and the role of parents within the family forum. He outlined to the group, the structure of the Family Forum; explaining that there are seven teams in the Dublin and Wicklow area, six managed by Enable Ireland and one team is managed by the HSE.</p> <p>Each team nominate two Family Representatives who then participate in a Regional Forum of fourteen. Their role is to collect ideas, questions and suggestions for beneficial actions for the CDNT service from parents locally at the three family forums each</p>

	<p>year. For the safety and wellbeing of Families and Reps, governance documents that outline the role of family reps specify that communication between Reps and Families should only take place at the Family Forums. Thus, it is important that parents are encouraged to attend Forums to share their ideas and suggestions with their local Family Reps. Currently, there is no Local Family Rep in the Mid-Wicklow service. it is extremely important that a new rep is elected as soon as possible.</p> <p>From the group of fourteen local representatives, two Governance Representatives have been elected to be part of strategic decision making at the Governance group meetings of senior managers from the HSE and Enable Ireland. The Regional Representative's role is important as they are the voice of parents in communicating/advocating for all families, and monitoring, engaging and holding the service to account.</p> <p>Two parents volunteered at the end of the meeting to become Family Reps, they are, Andrew McGrath and Barbusa Svegova.</p>
CDNM update	<p>Elaine delivered information on caseload numbers as of December 2024.</p> <p>Caseload: We have 361 active children on our caseload and 153 children on our waitlist (This is down 15 on last year). We are activating children from January 2022 on the waitlist. Some of our active service users also have to wait for some services, as we do not always have the capacity or staff resources to meet active need.</p> <p>Elaine also explained to the families that we activate all <12month old referrals and honour any transfers into the team that are active on other teams. 24 service users have been activated between July - December 2024 in these categories.</p> <p>Individual Family Support Plan: 338 active children have an Individual Family Support Plan (IFSP) in place.</p> <p>Discharges: We have discharged 68 children since January these would be children that either have aged out of service or have been referred to a more appropriate service based on need. Children may also be discharged if they do not require our services at this time, but they are aware that they can return to us if they need to.</p> <p>Team Update: We are losing 2 Basic Grade Occupational Therapist (OT) in January. 1 Senior Social Workers is on Maternity leave and our CDNM is on Maternity leave.</p> <p>New Recruits: We have been successful in recruiting a 0.5 Positive Behaviour post, an additional 0.5 Occupational Therapy Assistant post, 1 Basic Grade Physiotherapist and 1 Speech and language Therapist since previous family forum in June.</p>

	<p>Our CDNM Olive, is returning in January 2025 and we have 1 Senior OT returning to the team at this time.</p> <p>We will continue to recruit for 2 x Basic Grade OT's, 1 x Basic Grade SLT, 1 x Basic Grade Psychologist and 1 x 0.5 Social worker Maternity leave.</p> <p>Appointments: We had 181 children seen in August, some of these children might have attended numerous appointments over the month. 134 service users got 1 to 1 in September and 119 in October.</p> <p>Groups: Elaine went through some of the Intervention programs that took place from June to December.</p> <ul style="list-style-type: none"> • Planning for Adulthood – we are deciding if we are going to run this every year or every 2 years. • Parents Plus Early Years – this is for Service Users up to 6 years of age. This was offered to some Waitlist Families. • Transitioning to Secondary School: This is run in August and is open to everyone on the Waitlist. • AAC Workshop - This is for Service Users who are using Augmentative and Assisted communication devices. • Baby Massage: Offered to all under 18 months • Parent Sensory and Individual follow up – We are struggling with the up take on this course. We are hoping to run a teen sensory group next year, that will be for young people to attend themselves • Managing Emotions 10 - 12-Year-olds – This is open to Active Service Users. It moves to Decider Intervention support when the child gets older (secondary school age). This is will be offered in 2025, and we are working to identify our host school for this. • Hanen more than words – This is for young people who are working with Language development. This is a private provider initiative.
Q & A	See additional notes below (Table 2)
Topic of interest:	<p>The families attending the Family Forum were asked to help review an invitation to a sensory Processing group to suggest improvements that the CDNT could implement for better engagement with families regarding non-attendance for appointments. They also reviewed the CDNT Newsletter suggesting changes.</p> <p>Review by families on Invitation</p> <p>Suggestions from parents regarding our invitation –</p> <ul style="list-style-type: none"> • An explanation of Sensory / What is sensory processing maybe sharing a link. • A short notice to say - what age group it is for, can the child come too or are only parents to attend. • An idea of who else will be there. • An idea of what you will be doing.

- What specific problems is it going to solve.
- One to one follow up is a selling point – but it in a bold font.
- A link for a video of the of a session, so people can click and see what it will be like.
- Clear time and date are on the top, maybe put that on the bottom.
- Use the format of the service update, like a poster.
- Focusing on practical skills, what are we going to learn. parents can read theory online.
- Do some people who are active think they know what 'sensory processing' is already
- Timing – one week after another is difficult to make if you need to get a babysitter each time.
- Face to face is preferred to online
- Use MS forms for the response, teams is easy and user friendly.

Other comments From CDNT –

- When we were not getting the uptake we, are trying different formats.
- Times are alternated between days and evenings, trying to capture all parents.
- You need to have at least a week in between sessions.
- We appreciate when families reply to invites, even to indicate they do not wish to attend.
- Elaine will bring this back to the wider team and show them the changes.

Barbara, Ellen, Emma have volunteered to review the new format of the invite – to be completed in early 2025; prior to next Parent Sensory program

Review by families on Newsletter

The newsletter is for sharing resources, signposting what we are coming across and any information from the team.

- Overall, the newsletter is good – YouTube should be on the newsletter as is immediate link to try and find resources.
- Smaller boxes, more little headlines and big headlines, stating the categories.
- If you combined the update with the newsletter, as information as well. CDNT - We usually pair the service update with family forum which will be 3 times a year.
- IT is good to bring up October as grief awareness week so people know what is going on nationally.
- Links should be at the end, so people don't click away.

- Would it be possible to put calendar on for the next 3 months, not too specific but just know what is coming up with a brief description of what the event is.
- It would be helpful to differentiate who it is available for – invite only? Or everyone on the waitlist. Sometimes it will be Children that we know it is an identified need. If you need to discuss this further as to why you are not getting the invite you can contact someone.
- Managing emotions between - 10-12 it is good to know that it is restricted to that age group.
- A query came back from another Family Forum – would a 14-year-old who is at a younger developmental level be able to attend a 10- 12 year old Group.
Answer: Some programs have licenses so we can only take Children of a certain age; however where appropriate there are times that children are placed by their development level, not just their age. This is usually decided through discussion with parent, and clinician facilitating the intervention.

Elaine thanked families at the family forum for their feedback which will be used to make changes to parent invites and newsletter going forward.

Parents thanked for their contributions in 2024. The schedule of local Family Forum meetings is to be agreed in early 2025.

Table 2

Q & A Section	
Family members present were given the opportunity to write down questions they had and these were directed to management for answering	
Question	Response
<p>What are the challenges around recruitment and retention.</p>	<p>Elaine and Francis discussed the recruitment challenges faced across the service, noting that some positions remain unfilled even with regular advertising efforts. The process of filling these roles has been difficult. Enable Ireland in partnership with the HSE is exploring innovative solutions, (a) such as collaborating with the Foras Union to create a generic therapy assistant position. (b) actively engaging and advocating with national, regional and international communities and universities to attract clinical staff for the disability service, (c) Enable Ireland have local autonomy and all vacancies have a recruitment plan in place, (d) Enable Ireland now has access to HSE panels, (e) the HSE has provided bursary grants to support psychology students working within the organisation.</p> <p>The main challenge (a) is the delay in accessing work visas and CORU registration, (b) a limited pool of clinicians available. (c) no provision in budget to pay for backfill for maternity leave.</p>
<p>What does an Occupational Health Therapist (OT) Assistant do?</p>	<p>An OT assistant is there to help the occupational therapist. To assist in the administration (organise and send out appointments, clean mats and equipment et cetera. They can also assist alongside an OT in clinical intervention provision e.g. second person within an intervention group, follow up on OT programs etc. This allows the OT to focus in on their role as a clinician and spend more time with children.</p>