



<b>Family Forum Minutes</b> <b>Thursday 20<sup>th</sup> June 2024. Wicklow Primary Healthcare Centre</b>	
<b>Who was present: Participants</b> 	
<p>John McCusker Family Forum Facilitator, Elaine Byrne, Children's Disability Network Manager CDNT 6, (CDNM), Frances Fitzell Children's Services Manager, Ashling Doyle Administration, Sue Martin Administration, family members from 7 service user families.</p> <p><b>Family Representative: There is currently a vacancy for the Family Rep for CDNT6</b>  <b>Chair:</b> John McCusker <b>Co-Chair:</b> Elaine Byrne  <b>Minutes:</b> Sue Martin &amp; Ashling Doyle</p>	
<b>What happened: Agenda</b> 	
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.            Frances introduced herself as Children Services Manager with Enable Ireland Wicklow and Dublin            One parent connecting remotely introduced herself also.</p> <p>Housekeeping for the building and ground rules for the session reviewed by Elaine.            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>John outlined the vision for the family forum and focus on how we can work together towards improving and streamlining services from parents' perspective.</p> <p>All views are welcome and there is expertise within the forums and this expertise can be harnessed and it is hoped that we can get volunteers from parents to</p> <ul style="list-style-type: none"> <li>(a) help us with issues around recruitment and retention</li> <li>(b) IT and communication supports</li> <li>(c) to capture the story from parents who are in the system for a number of years - to use video and online platforms to capture the lived experience from parents.</li> <li>(d) The family forum is part of the governance structure for progressing disability services.</li> </ul> <p>Children's Disability Network Team (CDNT) 6 family forum has not met since October of 2023. Our aim is to recommence family forum meetings and to ensure that a robust communication pathway is in place to engage and inform parents throughout CDNT.</p>

	<p><b>Update on Family Representatives (reps) and the Regional Family Forum:</b> Two family reps are elected from CDNT6 with an opportunity to elect two alternate delegates to support. 14 reps have been elected form across the CHO 6 health area. This regional group will meet 2 to 3 times each year and will share discussion form the local forum. Currently we do not have reps from CDNT6.</p> <p>The next regional family forum is scheduled for September 2024.</p> <p>John advised that in July and August, he will be working with the regional group to have a work plan and actions for local family forums to work on in the next year. As part of this process 4 sub-groups are to be established: (a) Communication, (b) Recruitment and Retention, (c) Education and (d) To examine policies, procedures and the governance procedures.</p> <p>John is also to follow up on the possibility of conducting a once off survey with parents that will ask 6 to 10 questions about service delivery. – It is to be established if this survey will cover all of CHO 6 or will 2 to 3 CDNT teams be identified to take part.</p>
CDNM update	<p>Elaine delivered information on caseload numbers as of June 2024.</p> <p><b>Caseload:</b> We have 356 active children on our caseload and 167 children on our waitlist. We are activating children from March 2021 on the waitlist. Some of our active service users also have to wait for 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 &lt;12month old referrals, and honour any transfers into the team that are active on other teams. 15 service users have been activated between January-May 2024 in these categories.</p> <p><b>Individual Family Support Plan:</b> 322 active children have an Individual Family Support Plan (IFSP) in place.</p> <p><b>Discharges:</b> We have discharged 22 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><b>School placements for special class/school:</b> We have completed reports for children starting school in September 2024 who required a special school/ class placement. We are now looking at and planning our 2025 children.</p> <p><b>Team Update:</b> We lost a number of staff between Dec23-Jan 2024. We lost 2 senior Occupational Therapist (OT), a senior Speech &amp; Language Therapist (SLT) and an Assistant Psychologist (AP).</p> <p><b>New Recruits:</b> We have been successful since May-June month in recruiting a senior OT, an AP and a part time SLT. We also had a senior SLT return to the team from a career break. We will continue to recruit, we are hoping to have a new Physiotherapist starting with us in July. Our Psychologist will return to the team in September from career break.</p>

	<p><b>Appointments:</b> – We had 130 children seen in March, some of these children might have attended numerous appointments over the month. 139 service users got 1 to 1 in April and 115 in May.</p> <p><b>Groups:</b> Elaine went through some of the Intervention programs that took place from January to May.</p> <p><b>Early bird</b> – Our Early Bird group has some of families from our waitlist attend.</p> <p><b>Managing Emotions</b> <b>Transition to Primary School</b> <b>Hanen more than word</b> – This was run by a private provider <b>Attention and Gross motor listening</b> – This is a physio based group run by our Early year’s advisor &amp; Physiotherapist. <b>Steps to Independence</b> <b>Lamh</b> – Dearbhla from North Wicklow CDNT5 kindly offered to support Wicklow and Arklow with these sessions <b>Parent Support Sessions</b> – This is a very popular group which runs at the beginning and end of the year once a month for 3 months, with a different theme at each session, some of the themes at the group this time included, ‘Community Participation and a Sense of Belonging’, Living with Additional Needs: Others Experiences” And “Promoting Positive Mental Health in the Family”. The next Parent Support Sessions will take place in September October &amp; November.</p> <p><b>Upcoming Intervention Programs:</b> <b>Busy Fingers</b> – fine motor skills group running three different age cohorts. 4-7 years, 7-10 years and 10-12 years.</p> <p><b>Transition to Secondary School:</b> This will run in August, and will include waitlist children. Colaiste Chill Mhantain have agreed to host us for this. This helps to prepare children with practicalities around starting secondary such as reading time tables, using lockers; as well as some social and emotional supports.</p> <p>In September we continue with our 1 to 1 sessions. Generally there are less continuous intervention programs during September as parents have feedback previously that this is a difficult time to commit to programs due to return to school demands.</p>
<p><b>What is helpful for us?</b></p>	<p>Please share any reports you might have had done privately, also updating us with any changes in your address, phone number or email address.</p>

Table 2

<p style="text-align: center;"><b>Q &amp; A Section</b></p> <p style="text-align: center;"><i>Family members present were given the opportunity to write down questions they had and these were directed to management for answering</i></p>	
Question	Response
<p><b>Question 1. CDNT is currently opening children with a referral date of March 2021, what advice would you give to newly referred families who have a long wait ahead?</b></p> <p><b>Follow up questions:</b></p>	<p>We acknowledge this is a difficult situation for families.</p> <p>We have commenced waitlist initiatives. For example our 0-6 year old Early Screening and Advice clinic is up and running for waitlist families since March 2023 and has now met</p>

<p><b>What happens to her if I am not able to go private? It is difficult to find what you need on the web.</b></p>	<p>with over 50 families. We are working on plans to expand this to the 6-18 waitlist families.</p> <p>We identified at family forum that families would like direction on available resources in the community while waiting, and that we will work on an information resource for families to bring to next family forum to be reviewed. We discussed it can be important to search by need e.g. sensory, communication; rather than by discipline/ type of therapy.</p> <p>In the meantime, we would encourage families to email in to the central email with a brief description of the area of need they would like more information on, and we will endeavour to provide information on what is available in the community.</p>
<p><b>Question 2. It can feel like you have no information – what are CDNT doing to improve communication?</b></p>	<p>We acknowledge communications need to be supported going forward e.g. at the family forum on the day discussed website, and newsletter ideas; where calendars of upcoming events could be put.</p> <p>Our Social media is getting better, and we would encourage families to link with Enable Ireland's Website, YouTube and Instagram pages for updates and launching of new video resources.</p>
<p><b>Question 3. We have been in CDNT services for a few years now and we had to go private, it would have helped if we had information from the very beginning. It took me a year and a half to realise we need to go private, If I had known that CDNT did not have time for us, we would have gone private much earlier.</b></p>	<p>We can estimate and indicate the waitlist is currently 3.5years. It can be harder to estimate access within the team for specific services as this goes up and down with staffing. For example when we are down in SLT, we can only do priority 1 work which is Feeding, Eating, Drinking, Swallowing difficulties( FEDs) and Alternative Augmentative Communication (AAC). This means the waiting time for other needs e.g. speech sounds; goes up.</p> <p>We are often asked about private providers, and we cannot stand over recommending particular ones, as we do not know private provider qualifications, Garda clearance, experience etc. We do recommend however that families check if their private provider is CORU registered for social work, occupational therapy, physiotherapy and speech and language; or registered with a professional body e.g. Psychological Society of Ireland (PSI) for psychology.</p>
<p><b>Question 4. How long is it taking to get through the waitlist?</b></p>	<p>Currently it is around 3.5 years. This moves depending on staffing, and new referrals for</p>

	<p>babies under 12mths, children in care, and transfers in all of which must be activated immediately.</p> <p>Opening from the waitlist is a balancing act. If we open people too early then they will be waiting on the active side for supports within the team.</p>
<p><b>Question 5.</b> I was waiting on diagnosis for my daughter, she was not speaking, when I got the report from the assessment it knocked me for six, I contacted the Public Health Nurse, she said she would help her, and she organised my daughter to see SLT in PCCC and asked if she was linked in with Enable Ireland and then she could not see my daughter. Can you explain this?</p>	<p>– This is a national issue.</p> <p>These are two levels of service within the community health services. Primary care who generally work on their own i.e. one discipline only, and work with children with non-complex needs.</p> <p>The CDNT is for those with more complex and multiple needs. A child cannot be receiving services from both PCCC and CDNT. This can be very confusing for parents, as children's needs can change over time, or as we find out more about them. Therefore, clinicians can recommend moving up or down the levels of service. Please be aware however that both services have agreed that original dates of referral will be considered.</p> <p>All new referrals are screened by a central referral forum for the region of CHO6, and we do make all efforts to ensure children are waiting on the right waitlist based on their needs.</p>
<p><b>Question 6.</b> Why don't the CDNT team &amp; the HSE Primary Care work together?</p>	<p>One of the recent local initiatives in Wicklow was for Primary Care and CDNT clinicians in South Wicklow to meet, and encourage communication and discussion.</p> <p>We have made progress with clarity around backdating referrals when children are moving between services.</p>
<p><b>Question 7.</b> Pay Parity –what can we do as parents?</p>	<p>This is an important issue affecting our recruitment and retention in CDNT's nationally. Enable Ireland staff are in general paid less than equivalent public sector health employees and are not included in any public sector pay agreements. We are encouraging parents to support raising queries to politicians and those going for election in relation to pay parity.</p>
<p><b>Question 8.</b> Is there funding in Enable Ireland that can be used for Private Therapy?</p>	<p>Where we have pay savings from vacant posts we do try to use this to contract some private therapy to meet urgent needs.</p>

	<p>For example in 2024 so far 19 children have had full private diagnostic assessment completed from CDNT6 through our contracted private providers. We contracted an external Speech and Language therapist to complete Hanen More than Words intervention programs, and a private OT to complete some assistive technology assessments. These pieces of intervention would not have been completed otherwise.</p> <p>However contracting private providers comes with its own difficulty as they can usually only complete set pieces of work that have a clear start and finish, and that will fit the remit of contracted work.</p>
<p><b>Question 9. How is Hanen delivered?</b></p>	<p>There are 8 parent sessions, and 3 face to face sessions individual with the parent and child.</p>
<p><b>Question 10. I saw a webinar two years ago it was about entitlements for parents, it was very good. Where can this be found?</b></p>	<p>That is now on Enable Ireland YouTube website. Some resources go up on website with free public access; others need to be sent a link by email to access.</p> <p>Online- Click on links for each recorded video:  <a href="#">Benefits &amp; Entitlements Part 1</a>  <a href="#">Benefits and Entitlements Part 2</a>  <a href="#">Benefits and Entitlements Part 3</a></p>
<p><b>Question 11. My child is 2.5 years old and I am waiting on an assessment but I don't want to have it too soon. I cannot leave him in any childcare setting. I have no diagnosis so he cannot go into ASD class. Where do I go? Without a diagnosis I get no support</b></p>	<p>Please note that all children are entitled to preschool education access, and supports are available through the Access and Inclusion model (AIMs). A diagnosis is not needed to apply for AIMs supports. The website is <a href="#">The Access and Inclusion Model Homepage - Access and Inclusion Model (aim.gov.ie)</a></p> <p>Parents sometimes discuss with us the balance between getting an assessment 'done in time' and allowing time for their child to develop. For some school support options e.g. ASD class placement, special school access; a diagnostic assessment is still required by the Department of Education; and generally, we recommend that this is completed/ applied for approx 1.5 years before you intend to commence primary schooling.</p> <p>However Department of Education do not require a diagnostic report for access to learning support or special needs assistants; schools now receive an overall school</p>

	<p>allocation rather than individual allocation to a child. However where a report is available they can be used to help inform the schools allocation decision.</p>
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Table 3

Feedback	
<i>Families were asked to provide written feedback on the meeting</i>	
I liked	I did not like
<p>It was great to meet everyone and see what the family forum is about. Interesting to hear how everything is going within the CDNT re waiting lists, staffing etc.</p> <p>Meeting face to face, clarity and questions.</p> <p>It was clear and straight to the point. That the system is clear that it will be multiple years until assessment.</p> <p>I liked meeting with the other parents and I also learned many things. Thanks so much for calling us in here.</p> <p>I like meeting other people in the same boat as myself. I really enjoyed the session.</p> <p>The straightforward language without feeling patronised.</p> <p>Being listened to.</p>	