

Minutes of East Limerick Children Services Family Network Meeting

Thursday, 3rd October 2024, 11am to 1 pm

In attendance: forty family members in attendance, Family Rep Audrey Byrne; Baerbel Schlueter, Service Manager, Brian O’Flanagan and John McCusker, Independent Facilitator

Apologies: Nicola Haran Breen, Interim Children Disability Network Manager

Agenda:

Baerbel outlined draft agenda for the morning.

Update from CDNT Manager: The Children Services Manager (Baerbel) gave a brief update on service delivery as of October 2024. Please see the attached presentation for your attention.

Update from Regional Family Rep: Our Family Representative Audrey gave an update on her attendance at the Regional Family Network Forum.

Audrey is of the opinion that while progress is slow, processes are now embedded and work is coming to fruition, for example: website improvements, Newsletter for local teams and information to parents’ handbook being adapted for local use.

On challenges and frustrations Audrey stated: there is a need for a structured approach on how the regional forum’s work – to include a strategic plan, work plan with clear identified actions with end date identified. Currently, there is no clarity from senior management, topics go around in circles with no outcomes. This has resulted in some regional reps leaving the group as they are frustrated with the lack of progress. There is a real need for some positive outcomes.

Audrey appealed for the local family forums members to encourage other parents to come to the meetings – ‘We are stronger together’

Family members spoke about their experience in their engagement with the CDNT manager and clinical team.

Overall, families are happy with where the teams are at: Comments and feedback included below:

1. the staff have the best interests of children at heart,
2. Parents have noticed an improvement in engagement and communication since commencement of the family Network Meetings.
3. Families are feeling supported, and they feel that the system is now open and transparent.

4. The CDN team manager and the team are making definite efforts to engage proactively with families through face-to-face meetings, group sessions and one-to-one meetings.

What is not working and what could be improved: Questions and Queries from Parents.

Parents felt that under the circumstances, the service is doing well as they recognize that management and staff are doing their best and a lot of the issues of concern are around systemic failures and are out of control by CDNT. However, communication is still poor, in some instances emails are not answered, or it can take a few weeks for a return phone call.

Questions and queries raised in the forum:

1. SENO, and educational services:
 - a. What is the protocol to engage with SENO and school services? Parents spoke about how difficult it is to contact and deal with SENO –
 - i. Parents do not know who the SENO reps are,
 - ii. The majority of parents present, find the SENO reps to be unhelpful, they hide behind data protection and will not give straight answers, If data protection is the issue, Parents have no difficulty in giving permission to SENO and other agencies to use their information if requested to do so.
 - iii. In some instances, they find the SENO staff rude.
 - b. Is there an identified pathway to the transition for children from fifth class to primary school?
 - i. What role does the CDNT team do to help the transition?
 - ii. Is there an interdepartmental working group in place to discuss specific needs of children with SENO and special schools?
 - c. What interaction does the CDNT team have with NEPS?
 - d. Can parents be included in mechanisms or meetings for interdepartmental working with SENO, CDNT and primary and secondary schools? – Is there an interdepartmental working group in place?
 - e. Three suggestions from parents on how to engage with the education services. (a) cover maternity leave, (b) provide training to teachers who work with children with autism and (c) Employ OT and other staff to work directly in schools.

In response to the queries above, The CDNT manager indicated that the role of the CDNT is to focus on health and the service has no jurisdiction or remit over education services, however if a child is trying to enter the system, they will consult with the school to offer additional help and support. The team will also share the Individual Family Support Plan to inform the education service of the support that CDNT can offer. Baerbel advised that each parent should proactively link in with the SENO, and primary or secondary school regarding the education of their child, where appropriate the CDNT will support.

2. Who is responsible for making a referral to the CAMHS service?

3. What therapies are in place for children who are experiencing anxiety and loneliness?
4. If a child application for CAMHS is not granted, - even though that the CDNT, GP and the school have written letters of support. Is there a mechanism in place to appeal this decision?

The manager outlined that the process for referral to CAMHS is through family GP and that the CDNM and team can not refer directly. Baerbel outlined that there are ongoing meetings in place for children who attend both services. There are also local engagement meetings where discussion about pathways and collaborative working are addressed. The aim here is to identify gaps in the service and to develop better pathways for clinicians to work together. Parents felt there were no transparent pathways with one parent saying that the system is “crazy” and another saying that it is “so bureaucratic”.

Other suggestions from parents included. (a) Parents are willing to volunteer – please ask us! (b) create a platform of information and video presented by parents who have experience around challenges parents are dealing with to help parents who are entering the service. (c) update on recruitment – What is the status on employing Physiotherapist and Occupational Therapy staff?

Next Steps:

1. Agenda items for the Regional Family forum: Audrey, Nicola, John and Baerbel are to meet to agree items that can be brought to the regional family forum.
2. Two parents have volunteered to facilitate a coffee morning once a month in the East Limerick Children Services centre – John will give the two names to Baerbel. The rationale is that the service will provide a room with tea and coffee on a set date and time each month. The two family members will facilitate this session.
3. Baerbel to explore the possibility of bringing in students to work with staff on a voluntary basis so that they can get experience.
4. Baerbel and Brian to explore the possibility of using colour coded banner for specific emails to parents.
5. To use text messages to cut down on generic emails that are sent to parents.

The meeting agenda for the 2025 meeting schedule is to follow.