

Family Forum Minutes

Tuesday 29th April 2025 – CDNT Office Arklow Primary Care Centre

Who was present: Jennifer Sheridan Children’s Network Team Manager CDNT7(CDNM), John McCusker Family Forum Facilitator, Frances Fitzell, Children’s Services Manager, Family Members from 7 service users.

Family Representative: Tara Casserly

Chair: John McCusker

Minutes: Lisa Wilson, Administration



What happened: Agenda



Introduction

John welcomed everyone and thanked them for attending the meeting. He introduced the CDNT Managers present and family representative.

Family Forum Facilitator Update

John envisaged that the Family Forum format will change, this was CDNT lead but will become more parent/family lead. Tara Casserly has agreed to become the family representative for CDNT7.

John acknowledged that there were issues around communication, staff recruitment and retention especially for those on the waiting lists. Issues are at regional and higher level. How can we improve and how can we make people accountable. Issues discussed nationally are having an impact locally.

John asked for all to have a positive approach, let every voice be heard as this is a safe meeting.

CDNM update

Jennifer gave an update on service delivery.

Main positives

Occupational Therapist position was accepted and started in Jan 2025. This position was vacant for 3 yrs and has impacted on service delivery.

Cygnets training course for parents starting tomorrow 30 Apr. 17 families have registered their interest for 5-10yrs group. Please email us if you are interested in future Cygnets group 11-18yrs.

Sleep workshop also took place during April.

Team planning day next week so we can plan for groups, assessments, staffing for the next 6 months.

A member of the team will be attending a specialised sleep clinic course in Scotland which will be a great resource to have.

Transition to Primary and Secondary groups took place and the SENO also attended which was very helpful to families.

Consultant Paediatrician has been appointed for CDNT Wicklow services. Dr O'Mahony current Paediatrician only sees children with Physical disabilities. New consultant will be working part time between CHI Tallaght and CDNT will be working with other disabilities ie. Sleep, behaviours and food. She will be mainly based in Bray so families will need to travel to appointments.

Challenges

The team are going through a period of catch up now as we almost have our complement of staff.

The CDNT are very assessment based leading to a lot of our time doing assessments.

Rising population in Arklow rising to a lot of new referrals and increased wait lists.

Caseload: Currently there are a total of 365 families known to the team. We have 238 active children on our caseload and 127 children on our waitlist.

Waitlist: We are currently opening referrals made in June 2022 from the waitlist. Children on our waiting list are also included for assessment in the case of AON, School transition, no school place.

IFSP: 86% of children who are 'active' have an Individual Family Support Plan in place.

Appointments: January to March 2025 we offered 457 appointments, these are mainly groups sessions. 219 children either individual or group appointments. 33 appointments were not attended.

New recruits: We have been successful in recruiting Senior Occupational Therapist has accepted the position and has commenced in January 2025. We will continue to recruit for Senior Speech & Language Therapist and Senior Social worker. Interviews for Senior Physio to take place early May 2025.

Groups/Interventions offered Jan – Mar 2025: Jennifer went through some of the intervention programs that took place:-

Parent Support sessions

Screening appointments for waitlisted families

Early Years MDT Group

Transition to Primary School

	<p>Transition to Secondary Sleep Workshop</p> <p>Assessments: Assessments currently ongoing with the team:-</p> <p>Assessment of Need</p> <p>Psychology/Diagnostic assessments:- Currently working on children who do not have a school place, school transition, inappropriate school placement.</p>
What is helpful for us ?	Please share any reports you might have done privately. Also update us with any changes in your address, phone number or email.

Table 2

Q& A Section	
<i>Family members present were given the opportunity to write down questions they had and these were directed to management for answering</i>	
Question	Response
<p>Question 1: Is there a plan for children who aging out of service/ transitioning to Adult services ?</p>	<p>Yes we will be reviewing their needs from approx. 5th year but you can call the office to flag your child to the team. There is a day opportunities officer whose role is to support families and children and advise them of what services are available to them when they reach 18 years of age, please see below for details. The CDNT/HSE run a Future planning group for 17+ annually, we will be in contact once a date agreed.</p> <p>Phone: 01 2744188 (<i>Monday-Friday 9am to 5pm</i>)</p> <p>Email: disabilitydayservices.cho6@hse.ie</p> <p>Post: Disability Day Services HSE Community Healthcare East, Block B, Civic Centre, Main Street, Bray, Co Wicklow, A98 X329</p>
<p>Question 2: How do we refer our child or know if they have been referred ?</p>	<p>Central Referrals forum Bray deal with all referrals and send them to us. Your Public Health Nurse, GP or a parent can refer a child.</p> <p>You can also call the Arklow office on 0402 91028 and we can check this for you.</p>

	<p>Parents report they are getting a lot of mixed messages from GP as they unsure where to refer a child. Also receiving a lot of push back from services like CAMHS, CDNT.</p> <p>Family Forum group will be looking into making a video to go to the GP's to give information on how to refer children to CDNT's., hoping this will be ready by June.</p>
<p>Question 3: Domicillary Care Allowance forms difficulties ?</p>	<p>Parents report they are having difficulties with getting the DCA forms completed as some GP's are not familiar with the child. Social workers and resource centres can help carers. There will also be a video for parents on benefits and entitlements.</p>
<p>Question 4: When to apply for Autism class or when is too late ?</p>	<p>Children are currently waitlisted if they need an ASD assessment for school and this is based on date of referral so the sooner you know please contact the team to let them know.</p> <p>The team will be running groups for transition to Secondary and Primary school. For secondary school the group starts for children in 5th class which will consist of young persons group in April and then a parent and child group in July.</p> <p>The NCSE now have autism advisers in some schools so they can assist with any issues you are having.</p> <p>John will circulate a link to FAQ/Guide for school placements.</p>
<p>Question 5: Will my child be allocated a Keyworker ?</p>	<p>We are currently working on this as we previously did not have enough staff to allocated to the children. For the moment we are allocating priority cases and looking at IFSP's and then go back to the caseload for Keyworkers.</p>
<p>Question 6: How does the service work? With other agencies in Primary Care and CAMHS.</p>	<p>Jennifer advised parents that there is a good working relationship with clinicians in CDNT and the primary care service. Clinicians meet informally and formally with their colleagues in primary care and there is good information sharing to ensure that children get the appropriate service.</p> <p>Parents report that some families are with both Primary Care and CDNT and that they are having difficulties being seen by CAMHS. Work ongoing for the proposed Disability Roadmap initiative which is a National group with other agencies.es can be improved, how to build relationships and simplify engagement with other services. The Head of HSE looking into this also combining CDNT/Primary Care and Mental Health. Work is ongoing to build relationships with the CAMHS service.</p> <p>Parents complemented the CDNT team for their support to parents/children in comparison to other services. CDNT staff have been so helpful considering lack of resources.</p>
<p>Question 8: Parents gave some positive feedback on the CDNT:-</p>	<p>Parents gave the following positive feedback: Staff are committed</p>

	<p>More openness and transparency – this has changed over the last year or so.</p> <p>A lot more communication from the CDNT – emails, phonecalls. Parents would like more reminders as life is busy and they sometimes forget.</p> <p>Jennifer explained to parents that there is a new text system up and running. CDNTIMS new database system for our service users will make a big difference as can be used for communicating to families, reporting and figures along with all service user information..</p>
Conclusion by Jennifer Sheridan	<p>Jennifer thanked everybody for their attendance they asked parents to please stay involved and spread the word.</p> <p>There will be further updates from the chair and family rep regarding work that is being done at a national level.</p> <p>The newsletter and minutes will be sent in the next two weeks, as always parents are welcome to make suggestions for these.</p> <p>The dates are to be agreed for further family forums in June 2025.</p>

Table 3

Feedback	
<i>Family were asked to provide written feedback on the meeting</i>	
I liked	I did not like
Found the Family Forum very helpful and interesting	