Children's Disability Network Team

Family Engagement

27th August 2024

Engagement with families currently waiting to access or accessing services through their Children's Disability Network Team in Mid West Community Healthcare.

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Introduction

The Regional Family Representative Group was established in the Mid-West Community Healthcare network in early 2023. This group is made up of representatives from the Children's Disability Network Team's (CDNT) Family Networks. Feedback from this group was that there was need for greater communication with families.

In quarter two of 2023 a scoping discussion took place with family representatives sitting on the Regional Family Representatives Group (FRG) for the Children's Disability Network Teams (CDNT). The aim of the discussion was to further identify the communication and information needs of families currently waiting for or accessing services through the Children's Disability Network Teams across Mid-West Community Healthcare. Within the Mid-West there are eight CDNT's with services being provided by the HSE, Avista, Brothers of Charity, Enable Ireland and St Gabriel's Foundation. Following discussion with family representatives in quarter three of 2023, the need to capture family's views in relation to communication and information needs was agreed. The project was led by Michael Cronin, Patient & Service User Engagement Lead for HSE Mid-West Community Healthcare and seven Children's Disability Network Managers (CDNM), Olive Barry, Ann Somers, Grainne O Leary, Aideen Shinners, Lizette Marais, Nicola McMahon and Baerbel Schlueter.

In quarter three of 2023 family representatives from the Regional Family Representative Group (FRG), through engagement with a number of the CDNM's and Patient Engagement Lead identified the need for a standardised newsletter across the seven CDNT's in the Mid-West. The family representatives identified the need for the newsletter to be available in hardcopy but also on service websites. Concurrently a working group was established to co-produce an "Entrance to Service Pack". The goal of the pack was to inform families of the service CDNT's provide. It was decided that wider engagement with families could further inform the development of this pack. In addition, a working group was established to develop a resource platform for families who are waiting on CDNT services. The goal of the platform was have readily accessible information and resources available for families while they are waiting on CDNT services.

Due to the high numbers of children and families accessing or waiting access to services across the CDNT's, it was decided that the Smart Survey tool would be used to gather feedback. The aim of the survey was to engage with families to understand their information needs and communication preferences while waiting for services and when receiving services. This feedback would then inform the development of the "Entrance to Service Pack", and newsletter. The survey consisted of sixteen questions divided into three areas outlined below.

Area 1: The information needs of families who are waiting to access services through their CDNT. Families currently waiting services were provided the opportunity to provide feedback. Families who had been waiting for services in the past were also consulted to understand what may have supported their information and communication needs while waiting.

Area 2: The development of an “Entrance to Service Pack”, to be provided to all families.

Area 3: The development of a regular newsletter for all families waiting for or currently accessing services.

Methodology

The Smart Survey tool was used to disseminate the survey to **7002 families of which 5917 are currently receiving services and 1359 on the waiting list.** A number of methods to disseminate the surveys were used including links/QR codes which could be issued by text, email or included with correspondence issued via post by the services. This allowed families to access the survey using smart phones etc.

The survey was broken into three key areas.

Area one: The first four survey questions sought to understand the information/communication needs of families awaiting services or who had awaited services in the past. To capture this information a combination of multiple choice questions and open ended questions were used. Question one provides eight options which were informed through discussion with a number of families currently accessing services through a focus group facilitated by Patient Engagement Lead and CDNM Olive Barry of Black Berry Park, engagement with a number of the family representatives and input from the seven CDNM’s across the Mid West.

Area two: Questions five to ten of the survey provided families with the opportunity to identify areas and topics which they felt important to include in an, “Entrance to Service Pack”, received by all families prior to their first appointment.

Area three: Questions eleven to sixteen of the survey used both multiple choice and open ended questions to enquire information information/communication needs in the development of a regular newsletter for families to keep them informed of supports and service updates while accessing or waiting for services.

On completion of the survey, a qualitative analysis and coding of all comments was completed by the Patient & Service User Engagement Lead and a number of the CDNM’s. This identified the main themes across areas one to three.**1159** survey responses were returned representing **16.6%** of all families currently accessing or awaiting CDNT services across the Mid-West.

Main Findings

Area 1: Information/communication needs whilst waiting for services

Question one of the survey sought to understand topics and issues families would like information on while waiting for CDNT services. Families were provided with eight options and the opportunity to provide further feedback. Families could choose multiple options. (*Fig.1)* below indicates the overall results of 1159

As can be seen in Figure 1, the top 3 options selected were:

1. “When will my child be seen” (65.5%)

2. “Children’s Disability Network Team (CDNT) services” (58.3%)

3. “Applying for educational supports” (53.8%)

Figure 1, indicates that 65.5% of respondents wanted to know ‘When will my child be seen’. 58.3% of families would like or would have liked more information regarding what a CDNT is and the services they provide. 53.8% stated that they would like information regarding applying for educational supports and 48.3% indicated further information regarding specific diagnosis would be or would have been useful. 46.2% required further information regarding community supports and 40.8% information regarding applying for allowances and benefits. Information on Housing support and Family centred practice were selected by lower proportions of respondents (*Fig.1)*

Eighty eight (8.3%) selected the “other” option and identified additional information needs. 57% of these related to the Service delivery theme. One individual stated, **“How the whole system actually works, should be first point of call”.** Another individual stated, **“Some sort of 'introduction to disability' workshop that helps parents understand their child's diagnosis, what to expect from it, what supports are available, what the (realistic) timeline for access is, and what families can do in the meantime”.**

41% of the eighty eight individuals indicated that there was a lack of information regarding the community services available to families who are waiting to access the CDNT. One person stated, **“More information on inclusive recreational services”,** with another individual stating, **“Everything, as much as possible”**.

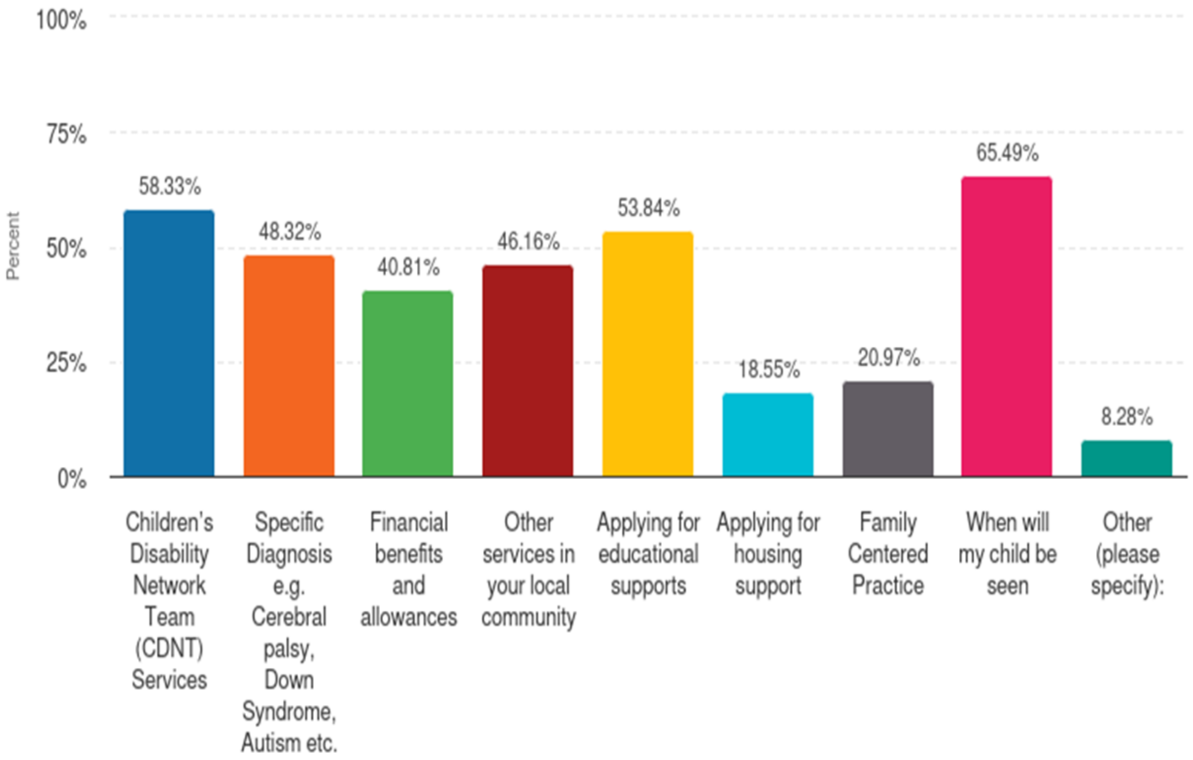

Fig.1: Waiting List Information Needs.

Question two asked families currently waiting or who have previously been on a waiting list for services to identify “What topics would you currently like/would have liked advice on or strategies to try, while waiting for services? Eleven options were provided based on feedback through a focus group with families accessing services, engagement with a number of the family representatives and input from the seven CDNMs. The areas included toileting, sleeping, eating, school, and emotional/sensory regulation. The questions also provided an option for families to indicate other areas of interest. Families could choose multiple options.

All 1159 respondents answered this question with 82 families providing further information through the “Other” option available. Fig (2) indicates the findings.

As can be seen in Figure 2, the top 3 options selected were:

1. “Emotional Regulation” (67.33%)
2. “Sensory Regulation” (58.10%)
3. “Communication” (55.78%)

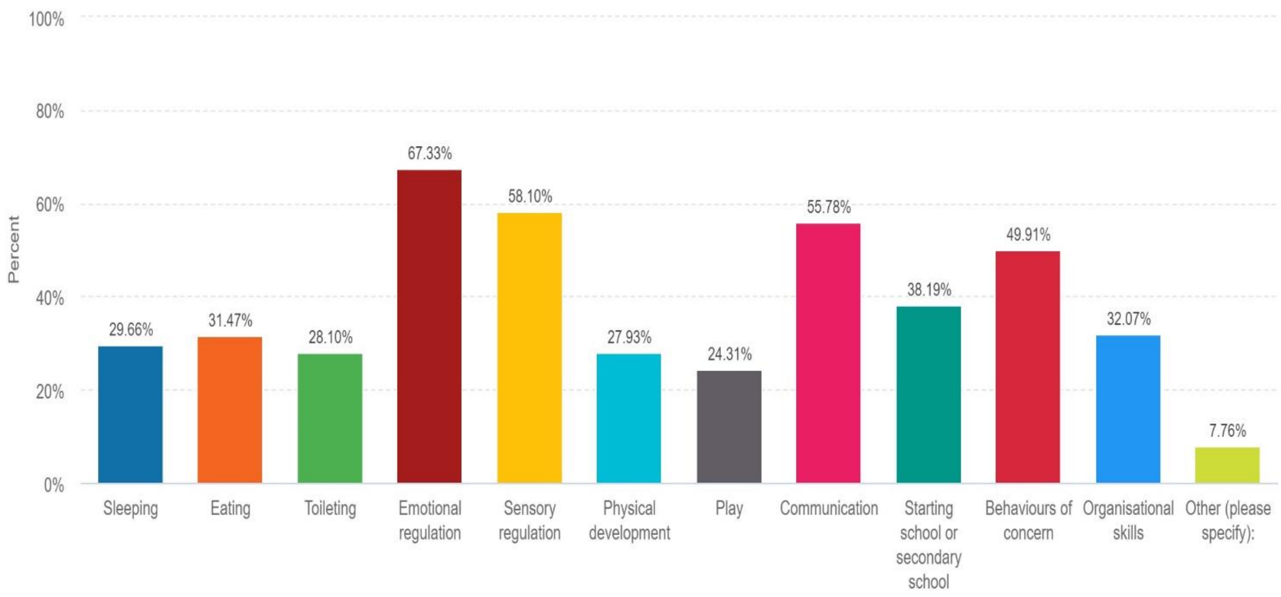

Fig 2: Waiting List Strategy Support

The 2 other principle areas that respondents identified as areas they feel further support would be important were mental health services available to support the child and or wider family (23%) and to activities the child could access (17%) such as community groups, activity groups social clubs and summer camps.

One family stated, “**Support with social anxiety**”, with another stating, “**Support dealing with anxiety so my daughter can attend school**”**.**

The remaining 60% of comments could be categorised under the options provided in Question 2

Question three was an open-ended question to allow participants n to identify other areas they felt they needed more information on while waiting to access services stating, “Please include any other subjects/topics which you feel should be included for families waiting to access services”. In total 430 families provided additional comments. The main theme to emerge was service delivery with 43% of all comments related to how the service was delivered. Of the 186 comments related to service delivery, 35% related to the waiting list and 53% related to increased communication and further information on community support available. One family stated, “**Realistic information of the services we will experience, and the timelines associated**”. Another family stated, “**Regular updates on where you are on the waiting lists, regular contact so you know you're not forgotten, any**

information on any local support services for both parents, as well as the child. Another family stated, "**People should be fully informed on the process when applying for a service and an estimated wait time. People should be assigned a waitlist number or date for each service**

Question four sought to understand the preferred method or methods of delivering information to families regarding the needs identified in questions one to three. Question four asked "Which of the following would currently suit you/would have suited you best to access this information or advice while waiting for services? Rate in order of preference, 1 being you're most preferred and 4 being your least preferred".

Participants were provided with four options a printed booklet, newsletter, website and "other", option and were asked to rate each based on their preference with one indicating their most preferred method of communication and four indicating their least preferred option. The smart survey tool provided the results based on a weighted calculation. Participants were also provided the space to detail "other" communication options if they felt the other three options did not meet their communication needs.

The printed booklet ranked first with a weighted score of 3323, followed by a newsletter with 3293, a website with 3229 and, "other" methods scoring 1755. Very few votes separated the top three options chosen. 246 families indicated alternative options for sharing information or reinforced the need for one of the above options. The following comments highlight a number of additional views provided.

links to programmes and websites could be added to help parents access these form websites.

Updates on a website

Gathering those for introduction morning so that parents could meet and greet and chat amongst each other.So not yo feel so alone and worried.

Email information is handy to keep organised

Website with diagnosis specific info … info on strategies that are universal.

Even a dedicated person within the team to get back to family

Communication with designated liaison person to stay updated on where my son is in the system. We feel invisible now

Information has to be digital, use of AI should be explored for services in this area, being able to book session online

In person

Text

Grouped Zoom mtg with parents . Eg. All those whose child has toileting issues in one group. Qs can be asked and answered. Hand outs can be sent to parents who attend. It will cover alot of issues on a topic with alot if parents

I feel that any new clients being referred to the services should receive a welcome pack to include information on what will be covered during participation with the service, I was completely blind when referred and have met with the service once since diagnosis, I do not know who to call when I need assistance or need to make an appointment

An app

All of them

Area 2: Entrance to Service Pack

Questions five through ten of the survey sought to gather feedback from families regarding the development and delivery of an ‘Entrance to Service Pack’ for families. Questions five to nine provided yes, no or don’t know options with question ten providing an opportunity for families to detail any other areas they felt would be important to consider as part of the development of the pack.

Question five asked “Is it important we include information regarding who can access the services provided by a Children’s Disability Network Team, including questions such as “Why has my child been referred to a CDNT?, Does my Child need a diagnosis to avail of supports from a CDNT?”.

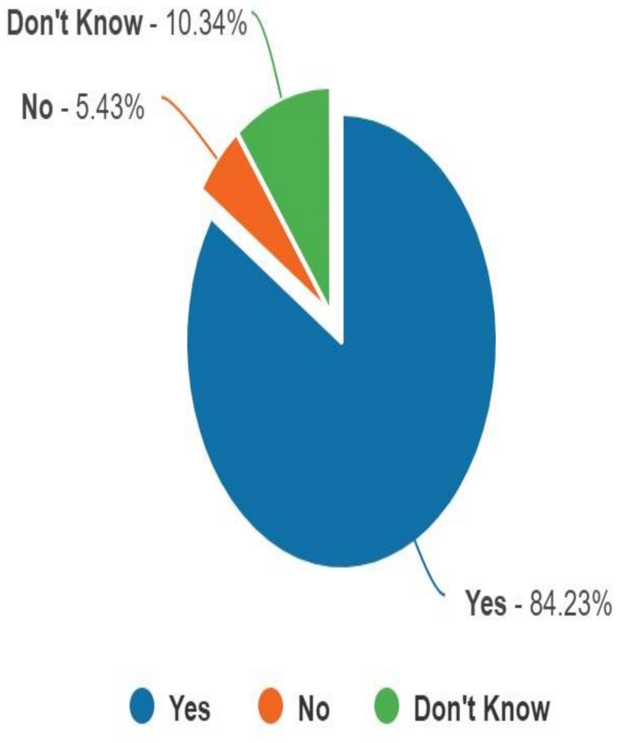

Fig 3: Is it important to share information on who can access a CDNT, why has my child been referred, does my child need a diagnosis first.

Question six asked “Is it important we explain the professionals which makes up a Children’s Disability Network Team and their role within the team?”

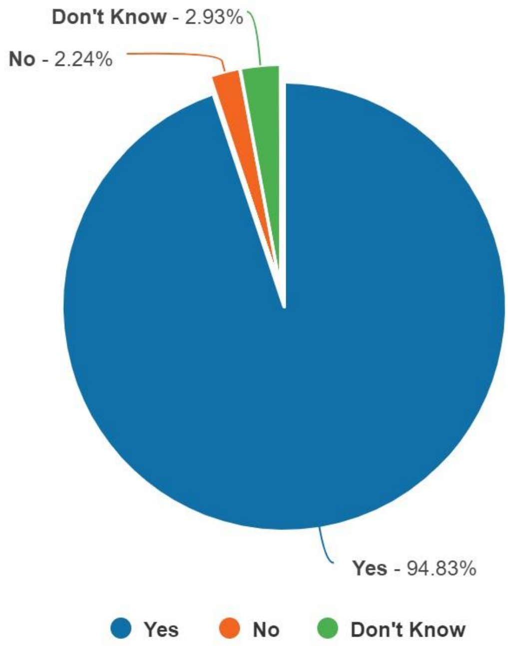

Fig 4: Is it important to explain staff in the CDNT

Question seven asked “Is it important we include what to expect when you are referred to your CDNT, including the initial family meeting and the initial individual family support plan meeting?”

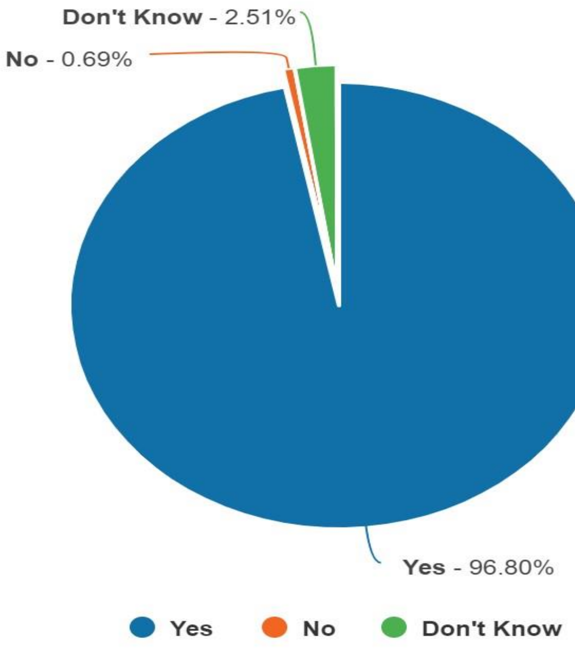

Fig 5: Is it important to include what to expect when referred

Question eight asked “Children’s Disability Network Teams work from a family centred practice approach, is it important we explain the meaning of this and what to expect?”

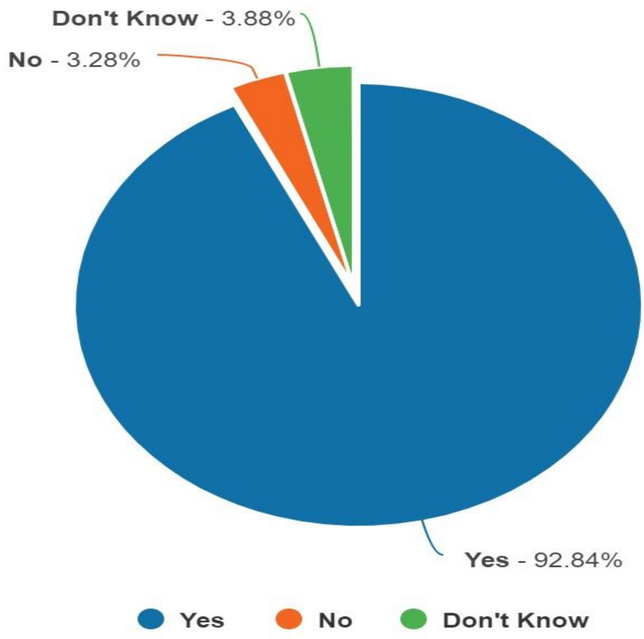

Fig 6: Is it important to explain Family centred practice

Question nine asked, *“*Is it important we include the role of the Family Network Meeting?”

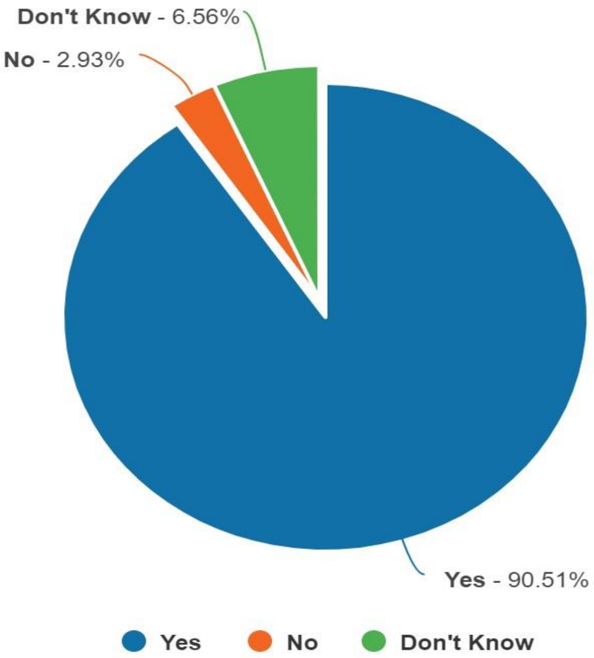

Fig 7: Is it important to explain the role of the Family Network Meeting

The final question, provided an option for families to indicate any additional information they would like considered for inclusion. In total 280 families completed question 10. The main theme from the responses was that of service delivery with 46% of all responses relating to service delivery. One family stated, “**Table format illustrating journey and pathway included**”. With another family stating, “**Everything should be done in layman's terms! It's so stressful going through it and everything is abbreviated which is frustrating also, everything should be broken so simply to remove the stress”.**

20% stated they wanted increased information on the range of community services available to support the needs of their child, this included mental health support and also family support for parents and siblings who require additional support. A further 16% stated that waiting times should be highlighted in the Entrance to service pack.

Area 3: Newsletter

The final six questions, eleven to sixteen, sought to understand the information needs of families regarding the development of a regular newsletter to keep families informed and up to date. Questions eleven through to fifteen gave families yes/no/don't know options. The final question, question sixteen was open-ended providing families to make other suggestions for newsletter content

Question 11 asked "Would you like the dates of your next Family Forum/Network meeting included in the Newsletter?" (Figure 8)

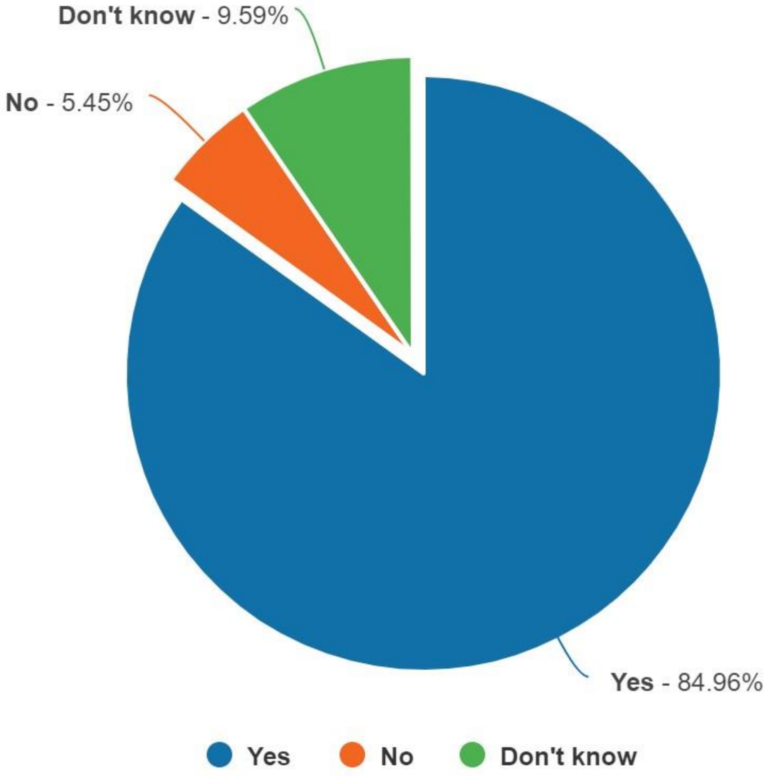

Fig 8: Is it important we share the dates of the next Family Network Meeting

Question 12 asked “Would you like updates from your last Family Network meeting included in the newsletter?” (Figure 9)

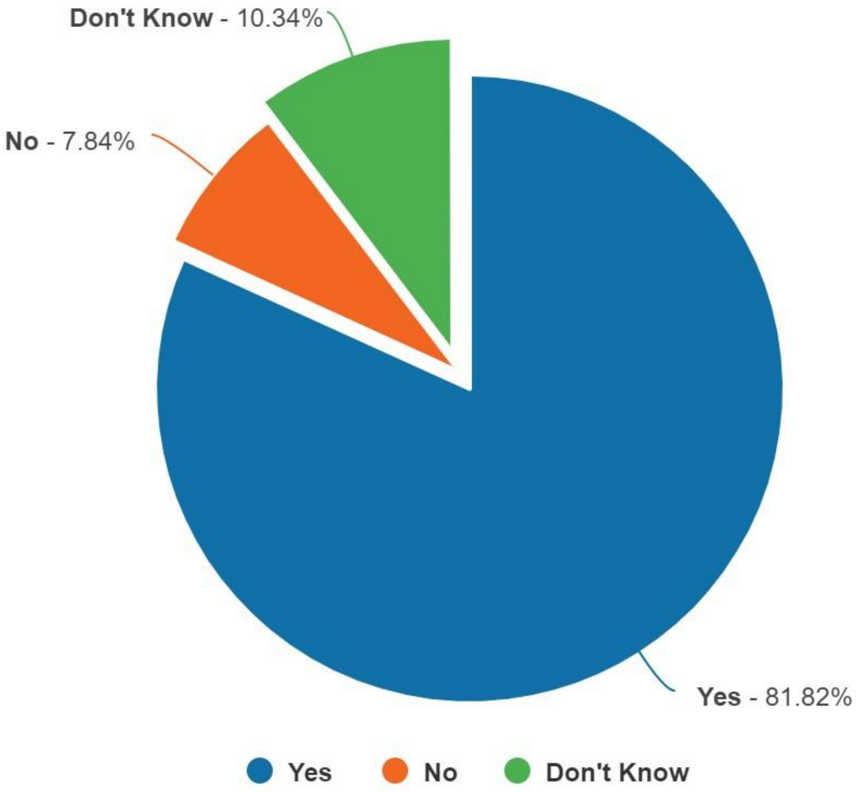

Fig 9: Should we include updates form the last Family Network Meetings

Question 13 asked, “Would you like useful suggestions/helpful tips from our team to

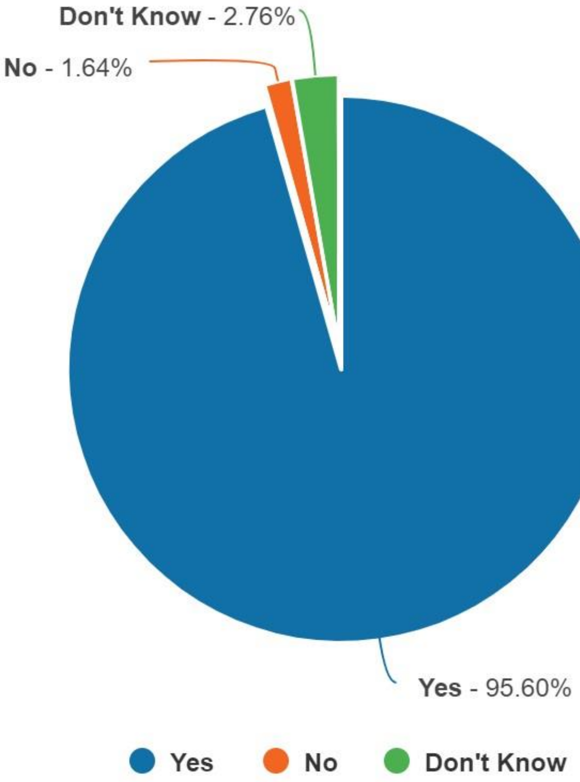

Fig 10: Is it important we share useful suggestions/tips from the team

Question 14 asked, “Would you like information on upcoming events, such as information seminars or family training?”

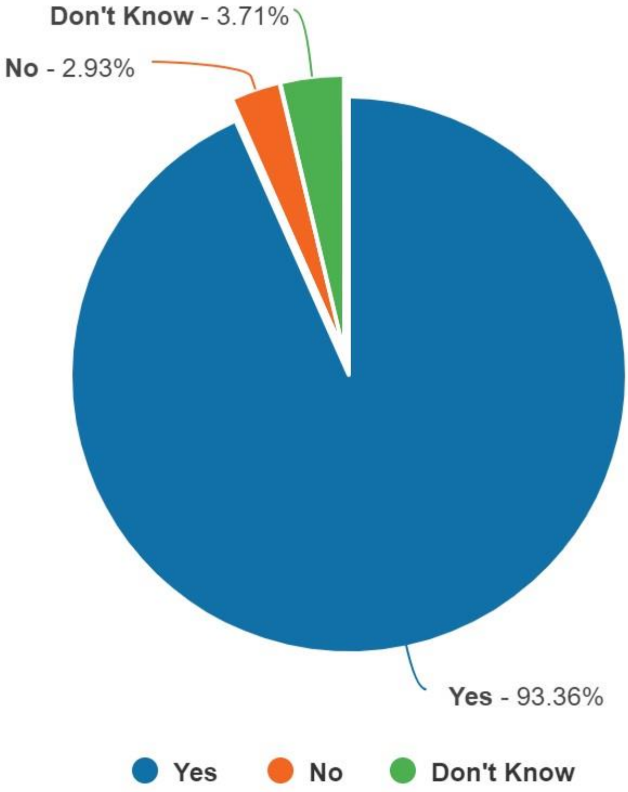

Fig 11: Is it important we share information on upcoming events

Question 15 asked, “Would you like to see information included regarding activities/clubs your child may like to get involved in in your area?”

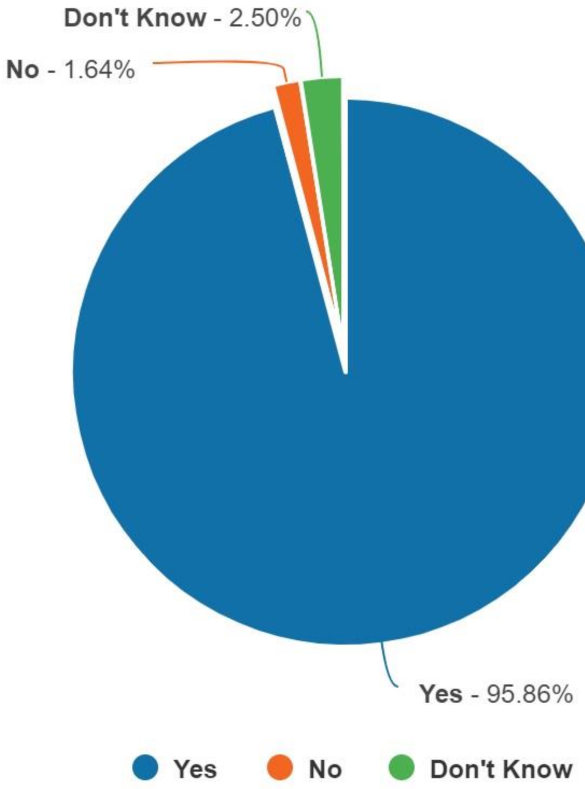

Fig 12: Is it important we include information about activities/clubs for your child

The final question of the survey, question sixteen, asked participants to comment on any other information they would like to be considered for inclusion in a regular newsletter. In total 185 families responded. Two main themes emerged: 42% of comments related to further information on how the service is delivered and 41% sought further information on community services available.

In relation to service delivery families sought information and updates on supports from the CDNT through the newsletter with one family stating, “**Parental training courses and seminars, delivered by staff. The newsletter to include dates and times”.** Another family stated, “**Planning for the future- most parents worry about their child's future in terms of financial support, estate planning, trusts as the children are and may continue to be vulnerable especially if they have complex need, more information about the assisted decision making act”.** With a final comment in relation to supports stating, **“Advice on how to cope with your child attending parties/ being in social situations when they have speech difficulties, advice on how to manage playdates if your child has speech difficulties, advice on how to look after ourselves as parents. Is there a free counselling service that parents can avail of? List of activities/ sports available locally that**

are tailored for kids with additional needs. Is there free play therapy for kids with additional needs".

Of the 41% of comments associated with community services, the main theme which emerged was increased information sharing regarding clubs/activities available in the wider community which children can avail of. One family stated, "**Any info on holiday clubs would be amazing as for working mums the holidays are so tricky".** Another family stated, "**Make families aware of any inclusive camps which operate offer holiday seasons and sports clubs etc."**

Next Steps

- The information gathered via the smart survey from 1159 families will directly inform the development of an Entrance to Service Pack which can be used across all eight CDNT's and address the main information needs highlighted by families in this survey. A working group was convened and the final draft is currently with the CDNM and family representatives for final review.
- The CDNM's, Patient Engagement Lead and representatives from the Regional Family Representative Group will meet in early October 2024 to discuss the development and co-production of a standardised newsletter to meet the needs of service users and their families informed by the responses families provided to this survey
- A working group was convened and has developed an information platform on the Mid-West CDNT's website, for families who are waiting on services based on the feedback in the survey. Readers can scan the QR below to view

- Question four of the report asked families to identify their preferred method(s) of communication. The use of a booklet, newsletter and website ranked almost equal to one another highlighting the need for all three methods to be utilised. An Entrance to Service Pack is near completion at the time of writing this report and further engagement will take place in early October 2024 regarding the production of a standard newsletter. A website was identified by respondents to this survey as an important method of communication with families and a means of offering support. While the CDNT have a website for a number of years, this website is out-dated and in need of updating. CHO7 have developed a CDNT website which could be used as a prototype for the HSE Mid-West CDNTs. Readers can scan the QR code below to view.

Conclusion

In conclusion, this report sought comprehensive feedback from families currently accessing or awaiting services through their CDNT. The survey gathered feedback on three key areas and sought to develop the effectiveness of communication between CDNTs and the children and families they support.

Area One identified information those waiting or who had waited for services need. Waiting list information ranked high along with the services the CDNT offers, including the make-up of the CDNT team in Fig. 1 (Page X) represents the key areas and indicates a need for continued information across a number of areas and that current information should be reviewed and updated to include the needs this survey identified.

Area Two of the survey related to the Entrance to Service Pack and sought to identify key areas to include. Priority areas identified for inclusion in the pack included, what a CDNT is, what professionals make up the team, what a family centred approach is , the role of the Family Network meetings .,community services available to support a family ,and waiting list information.

Area Three of the survey looked at the development of a newsletter. Figures 8-12 (Pages X to Y) highlight the views of participants with regard to specific topics to include in a newsletter. This report finds that families want further information on service delivery, such as courses available, relevant legislation for future planning, and community services available to support children and families.

This report summarises the vast levels of feedback received across the Mid-West from families waiting for or accessing CDNT services provided in the Mid-West. The findings indicate a need for a co-production model to be used when creating information content for children and their families accessing or waiting to access services through their CDNT, including the co-design of newsletters, websites and booklets.