EXPERIENCES OF CAMHS: A FAMILY PERSPECTIVE

JUNE 2024

Families for Reform of CAMHS

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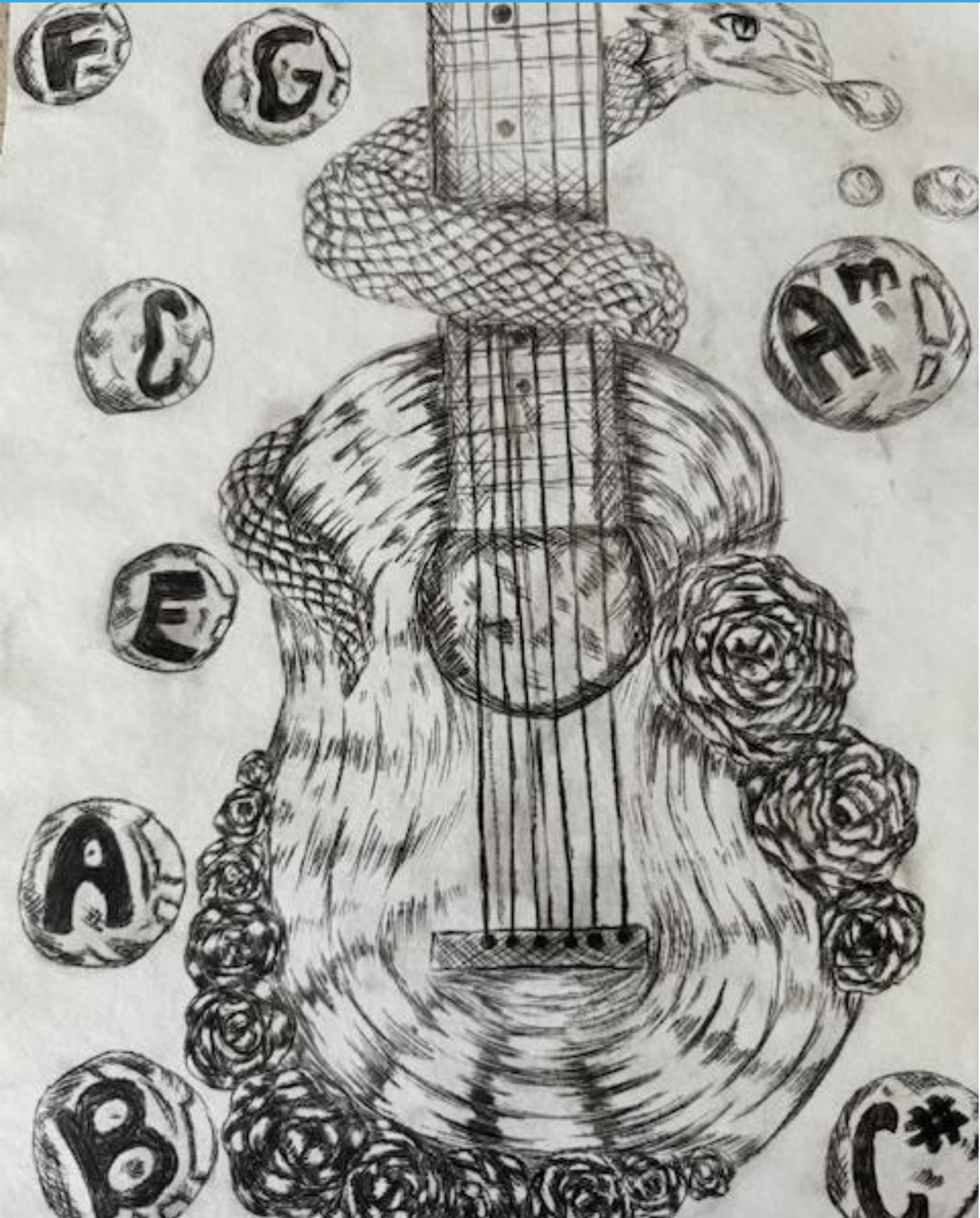
Glossary

ADHD	Attention deficit hyperactivity disorder
AMHS	Adult mental health services
AON	Assessment of Need
ARFID	Avoidant restrictive food intake disorder
CAMHS	Child and adolescent mental health services
CAMHS-ID	CAMHS service for children with intellectual disabilities
CBT-E	Enhanced cognitive behaviour therapy
CDNT	Child disability network teams
CHO	Community healthcare organisation
DBT	Dialectical behaviour therapy
EBSR	Emotional based school refusal
FASD	Fetal alcohol spectrum disorders
FBT	Family based treatment (FBT).
OCD	Obsessive compulsive disorder
ODD	Oppositional defiance disorder
OSFED	Other specified feeding or eating disorder
OT	Occupational therapy
PTSD	Post traumatic stress disorder
SLT	Speech and language therapy

1. Introduction



1. Introduction

This report sets out the quantitative and qualitative findings from the April 2024 national survey held by *Families for Reform of CAMHS* on the experiences of families with CAMHS.

In total 736 responses were received to the survey representing the experiences of 736 children in Ireland.

The survey was held over a 3 week period from 6 April – 28 April and the findings paint a stark picture of the reality of trying to access mental health supports for a child in Ireland and the impact it has on the family.

The results of our survey provide an insight into the difficulties at *every* stage of the process for families; from trying to get through the referral process, to lengthy time periods spent on the waiting list, to the difficulty accessing therapeutic supports once in the service, and finally to children being discharged before families feel they are ready to be.

While stats and figures are hugely important for our campaigning work, what should not be forgotten is that behind each number is one of our children.

Each of our children are so much more than their experience of trying to access mental health support. But not being able to get that support can have devastating consequences.

We would like to thank our children and young people who submitted their artwork which is included throughout this report. And to acknowledge the beautiful painting provided by Grace Feeney which has been used for the report's cover. We hope that this art, along with the words and stories from families, will act as a reminder of the wonderful children behind the numbers who don't deserve to be forgotten.

2. Background

2. Background

Families for Reform of CAMHS is a family representative, advocacy and support group for families who are trying to access the *Child and Adolescent Mental Health Services* (CAMHS), currently with CAMHS or who are no longer with CAMHS.

The group was set up in May 2023 and 12 months later is now made up of over 1,200 members. Our children are found in communities, groups and families across Ireland. Nobody knows if or when mental health challenges will occur, but we all hope that support will be available if we or our loved ones need it.

In 2023, reports from the Mental Health Commission[1] and the United Nations Committee on the Rights of the Child[2] highlighted serious concerns about the insufficient and inadequate mental health services for children. The reports portrayed an overwhelmed and poorly governed system with inadequate staffing and resources. The Inspector of Mental Health Services at the time, Dr Susan Finnerty, publicly stated that she could not *"provide an assurance to all parents or guardians in all parts of Ireland that their children have access to a safe effective, and evidence-based mental health service."*

The concerns set out in last year's reports are not new but were also raised in the Mental Health Commission's 2017 report[3] and the UN Committee's 2016 report[4].

Not only are families being let down but also dedicated staff within CAMHS who are trying their best to help children despite the system rather than with the support of it. The Government and the HSE have acknowledged service deficits and yet we have seen no real reform. And children continue to suffer as a result.

As a group, we have spoken in Leinster House numerous times[5] to highlight the challenges and realities faced by families. We have contributed to radio shows, podcasts and articles[6] to spread awareness of the battle that families have to undertake to try and access help for their child.

We are now looking for action.

Families for Reform of CAMHS is calling on the Government and the HSE to address the significant failings of the service urgently and as a matter of priority.

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[1] Independent Review of the provision of Child and Adolescent Mental Health Services (CAMHS) in the State by the Inspector of Mental Health Services

[2] February 2023 Observations of the United Nations Committee on the Rights of the Child

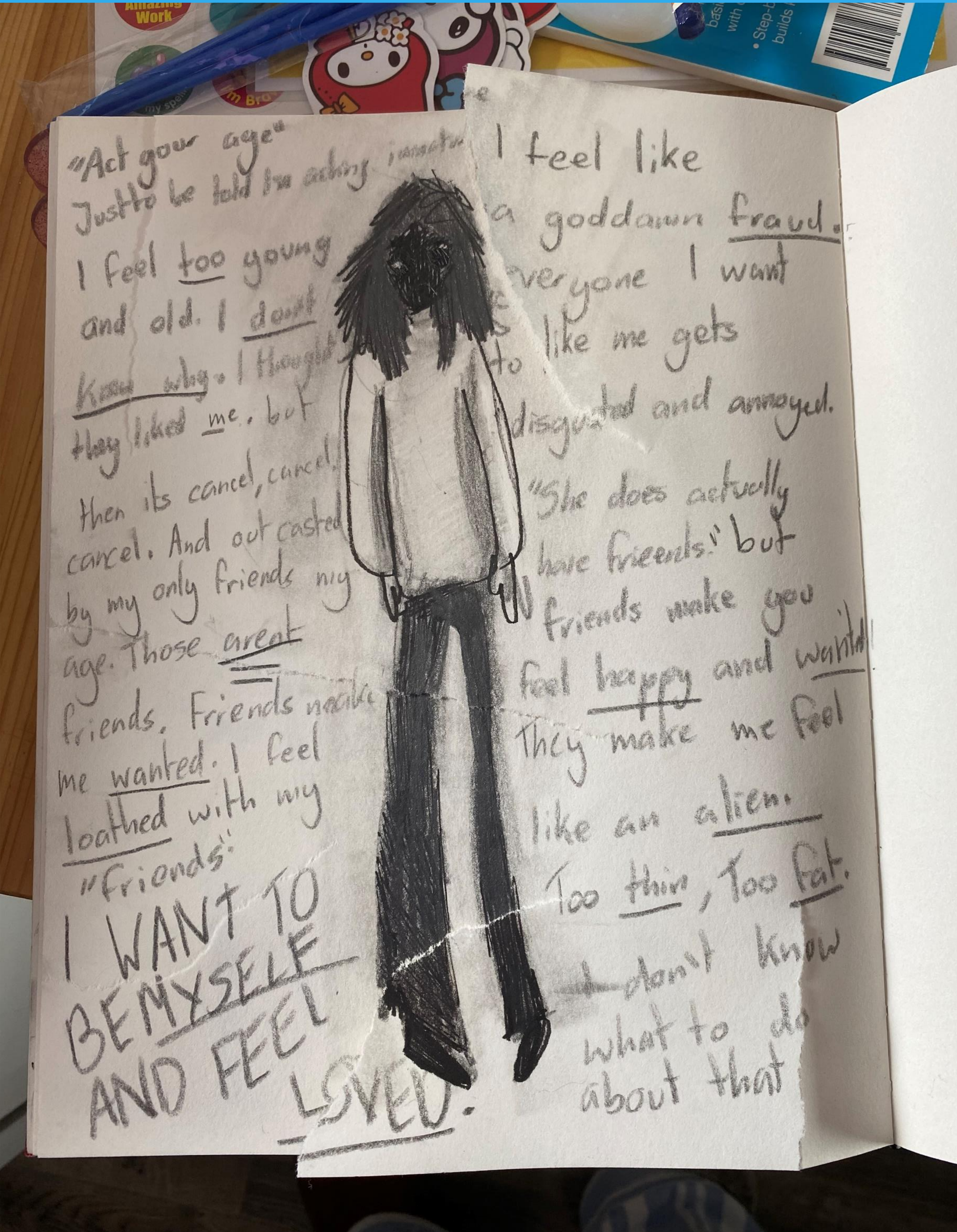
[3] Mental Health Commission annual report 2017: including report of the Inspector of Mental Health Services

[4] Concluding observations on the combined 3rd and 4th periodic reports of Ireland: Committee on the Rights of the Child

[5] For more detail see: https://www.families-for-reform-of-camhs.com/news

[6] For more detail see: https://www.families-for-reform-of-camhs.com/in-the-media

3. Purpose and methodology



"Act your age"
Just to be told I'm acting immature
I feel too young and old. I don't know why. I thought they liked me, but then its cancel, cancel, cancel. And out casted by my only friends my age. Those arent friends. Friends make me wanted. I feel loathed with my "friends".

I WANT TO BE MYSELF AND FEEL LOVED.

I feel like a goddamn fraud. everyone I want to like me gets disgusted and annoyed.

"She does actually have friends!" but friends make you feel happy and wanted. They make me feel like an alien.

Too thin, Too fat. I don't know what to do about that

3. Purpose and methodology

Purpose

The purpose and aim of our survey was to better identify patterns and collective experiences of families with CAMHS across the country.

The results from the survey, as captured in this report, will be used to:

(i) promote greater awareness of the reality facing families trying to access mental health supports for their children; and
(ii) inform our future campaigns and engagement with policy makers and politicians.

Methodology

The survey was initially open for members of *Families for Reform of CAMHS* for a two week period from 6th – 20th April before being made available for a further week to families beyond our group. It was promoted on social media and shared with groups working in the mental health or disability areas.

In total 736 responses were received representing the experiences of 736 children in Ireland[7].

Of the 736 responses received, 445 were from members of *Families for Reform of CAMHS* and 291 responses were received from non-members.

The survey asked 80 quantitative questions and 4 qualitative questions. However, over half of the quantitative questions also contained optional comment boxes for any additional information, experiences or thoughts that the respondents wished to share and a vast amount of qualitative data was collected.

The survey was divided into the different stages involved in engaging with CAMHS, namely:

- the referral process;
- time spent on the waiting list;
- Experience and supports while with CAMHS; and
- Experience of leaving CAMHS.

Respondents only replied to the sections relevant to their experience and throughout this report it is indicated how many respondents replied to each section.

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[7] Respondents were asked to submit one response for each of their children that they had who they were seeking support from CAMHS for/ who was with CAMHS/ who was no longer with CAMHS. Only one response per child was to be submitted even if there were multiple members from the same family in our group.

It is to be noted that there were also a number of sections in the survey which were open to all respondents and these included:

- general respondent information
- supports sought outside of CAMHS
- impact on family; and
- impact on school attendance.

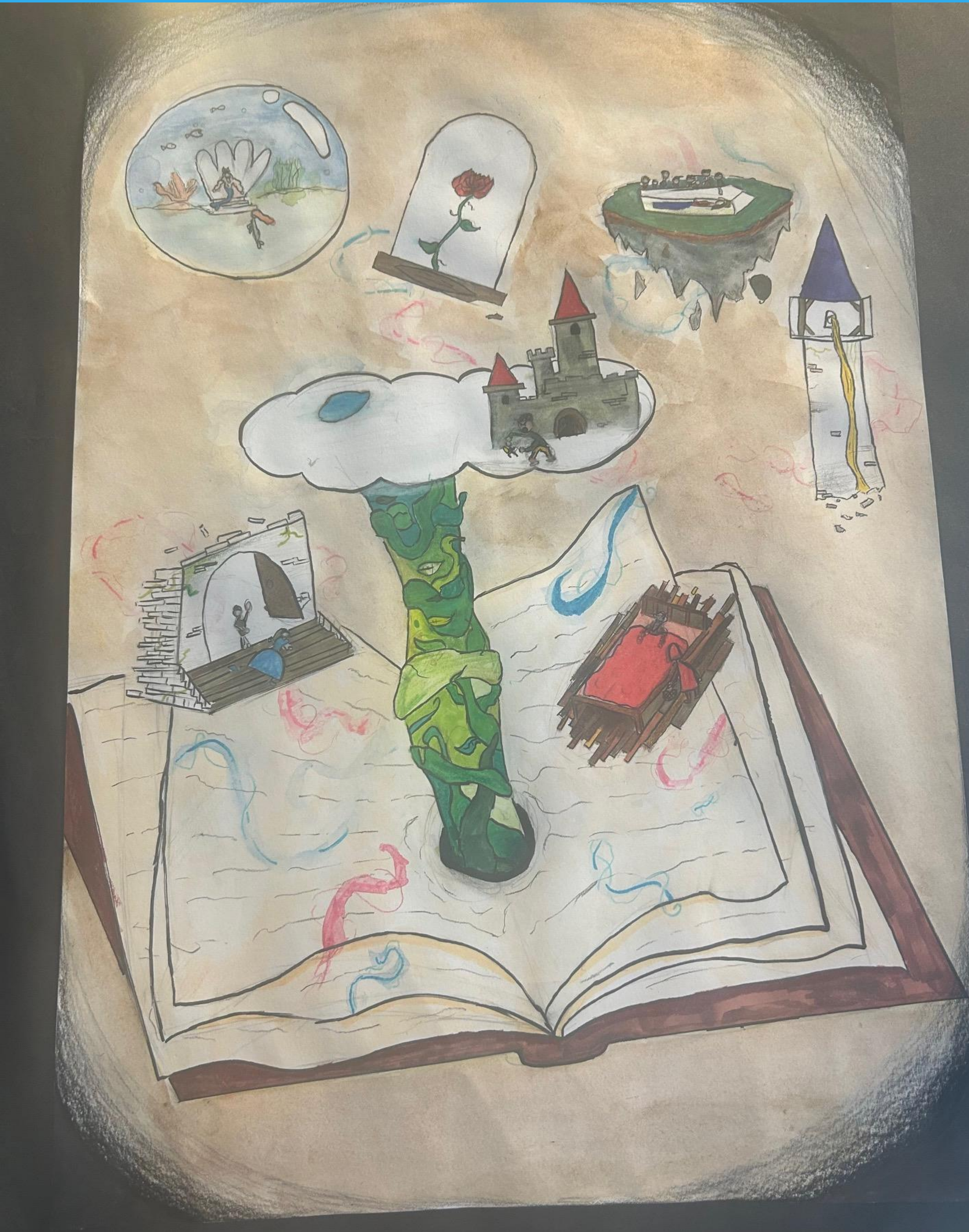
In addition, the experiences of certain groups of children were sought, including:

- autistic children;
- children with an intellectual disability;
- children with ADHD;
- children with an eating disorder; and
- children who had experienced suicidal ideation or suicidal intent.

Figure 1: Number of respondents per section of report

Section of Report	Number of respondents who answered
Referral process	Total respondents: 736 • 159 currently in referral process • 577 who have had a referral accepted
Waiting list	Total respondents: 577 • 99 currently on the waiting list (33 having been with CAMHS before and who are seeking support again) • 478 who are through the waiting list and are either now currently with CAMHS (315) or have finished with CAMHS (163)
Experiences with CAMHS* *This section includes the experiences of certain groups with CAMHS	Total respondents: 511 • 33 used to be with CAMHS and are seeking support again • 315 currently with CAMHS • 163 no longer with CAMHS
Leaving CAMHS	Total respondents: 196 • 33 used to be with CAMHS and are seeking support again • 163 no longer with CAMHS

4. Executive Summary



4. Executive Summary

Experiences of CAMHS: A Family Perspective sets out the detailed quantitative and qualitative findings from the April 2024 national survey held by *Families for Reform of CAMHS* on the experiences of families with CAMHS.

In total 736 responses were received to the survey representing the experiences of 736 children and young people across Ireland[8].

The results of the survey provide an insight into the difficulties at *every* stage of the process for families; from trying to get through the referral process, to lengthy time periods spent on the waiting list, to the difficulty accessing therapeutic supports once in the service, and finally to children being discharged or aging-out before families feel they are ready to leave the service.

In a system where a lack of resources and capacity result in the door to mental health supports being only a fraction ajar - and usually just to those who first have to reach the most critical of situations - families whose children's mental health is deteriorating have the door closed in their faces again and again.

92% of all 736 respondents said that they felt their child's mental health deteriorated during the referral process to CAMHS alone and 43% took additional steps to try and get their child's referral to CAMHS accepted. Steps included getting a private diagnosis; seeking political support from a local politician; going to A&E; not mentioning an existing diagnosis; or going public with their experience.

The fight for services had to continue in the time period subsequently spent on the waiting list where 69% of respondents sought private support; 39% of respondents had to bring their child to A&E; 15% of respondents sought political support; and 5% went public with their experience.

Many respondents referenced just how crucial accessing private support was for their child when they couldn't access support from CAMHS. Some respondents mentioned sleepless nights caused by the worry of how to pay for private care and the financial strain this placed on families. This was especially so given that many parents had to take unpaid leave or leave employment to care for their child.

Other families could not afford to go private[9] and did not have the option of getting a private diagnosis which might better their chance of having a referral accepted to

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[8] Respondents were asked to submit one response for each of their children that they had who they were seeking support from CAMHS for/ who was with CAMHS/ who was no longer with CAMHS. Only one response per child was to be submitted.

[9] Currents rates for accessing a private psychiatrist are often a minimum of €700 for the assessment; €150 for reviews; and €100 for form filling/reports. Parents also referenced paying 70/80 euro per week or per fortnight for counselling. And similar prices or more to access private OTs.

CAMHS or to pay to get therapeutic support/access medication while they waited or fought for help from CAMHS.

And some families could not find a private child psychiatrist who was taking on new clients or had their child turned away from private practitioners as their needs were deemed “too complex” especially if the child had an intellectual disability.

Children were and are left in a vulnerable position with nowhere to turn.

Once in the door of CAMHS, the top support identified by respondents was individual staff members. Respondents acknowledged the huge strain staff were under, the heavy work load they carried and how staff were stuck fighting fires. The positive impact that an individual staff member could make when families felt they were being listened to, believed and validated made a huge difference. Some staff members went out of their way to ensure a child received some form of intervention or wasn’t discharged prematurely.

Unfortunately, there was little consistency across the board in terms of families’ experiences with CAMHS teams and there was wide recognition that many CAMHS teams simply didn’t have the time or the capacity to offer appropriate care to their child.

Almost 70% of children had been offered medication whereas much smaller percentages had been offered other forms of intervention[10]. 29% of those respondents whose children were on medication did not feel they had adequate support with and monitoring of the medication. And some families spoke of being discharged after refusing medication as there were no other interventions available.

Availability of interventions (therapeutic support, OT, speech and language therapy etc.) varied widely from one CAMHS service to the next. And those families who managed to access interventions generally felt relief and wished their experience was that of other families and children around the country.

Varying approaches were seen across different CAMHS teams, one example is where a child could not attend an appointment (ordinarily due to anxiety), 28% of children were told they would be discharged if they could not attend whereas 25% of children were told to wait until the child could attend, 8% were offered a home visit and 8% were offered an online appointment. Huge gratitude was expressed by families when more supportive approaches were offered and high levels of frustration and distress were expressed by those who felt dismissed and unsupported.

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[10] 19% had been offered 1-5 therapy session, 22% had been offered more than 5 therapy sessions, 20% had been offered OT, 5% had been offered music/art/play therapy, 13% had been offered speech and language therapy, 25% had been offered a parenting course. 14% had been offered no intervention.

Experiences of certain cohorts of children were sought specifically, including experiences of autistic children, children with an intellectual disability, children with ADHD, children with an eating disorder and children who have experienced suicidal ideation or intent. While the detail is set out in the relevant sections of this document, some of the more unsettling figures included:

- 70% of respondents felt that their child being autistic negatively impacted access to CAMHS and/or the mental health supports offered to their child.
- 77% of children with an intellectual disability had no access to a CAMHS-ID service and only 14% were receiving any interim support.
- 73% of respondents who have a child with ADHD did not feel their child was getting adequate support for their ADHD.
- 86% of respondents who have a child with an eating disorder did not feel their child was getting adequate support for their eating disorder.
- 74% of respondents who had a child who experienced suicidal ideation/intent did not feel their child had received adequate support for suicidal ideation/intent.

Many respondents felt that there was a severe lack of accountability or anywhere to turn to when services were not being provided or when there was an issue with the approach/support (or lack of support) being provided.

23% of respondents had submitted a complaint, however only 30% of respondents were happy with how that complaint was handled. Over half of respondents had considered submitting a complaint, however, 33% said they were worried about the potential impact on their child's care and 20% of respondents were unclear how to actually raise a complaint.

In terms of leaving CAMHS, 69% of respondents were not in agreement about their child being ready to be discharged. The difficult and lengthy experience of trying to access the service plus the real potential of being discharged before they felt ready, led to a large sense of distrust in the system amongst respondents. Families who were currently with CAMHS often expressed a worry about being discharged and this was amplified by the fact that if the child needed help again in the future they knew how difficult it would be to get back in the door.

For respondents who had children “age-out” of CAMHS at the age of eighteen, 63% did not feel their child was ready to leave CAMHS. Respondents mentioned the disruption and impact that being discharged at eighteen had, especially as it often took place during the child’s Leaving Cert year. Half of children who aged-out of CAMHS went onto adult service and half did not. In some cases families were happy for their child to be discharged to the GP who would manage medication going forward. However, for a sizeable proportion of respondents they just hadn’t been able to access adult services and have been told there was “no transfer pathway”, “they do not deal with ADHD patients”, or they were on the waiting list for adult services.

We would like to thank all the families who took the time to feed into the statistics gathered in this document. We hope that Government will take note of the findings of this Report and resolve to finally take meaningful action to tackle a broken system that is failing children nationwide.

5. Detailed survey results

Section 1: General Respondent information

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Section 1: General Respondent information

This section was open to all respondents and was responded to by 736 respondents.

1.1 Location

The experiences of children captured in this survey are children who are located right across Ireland, however the majority are based in Leinster (59%), followed by Munster (27%).

Figure 2: Location of respondents

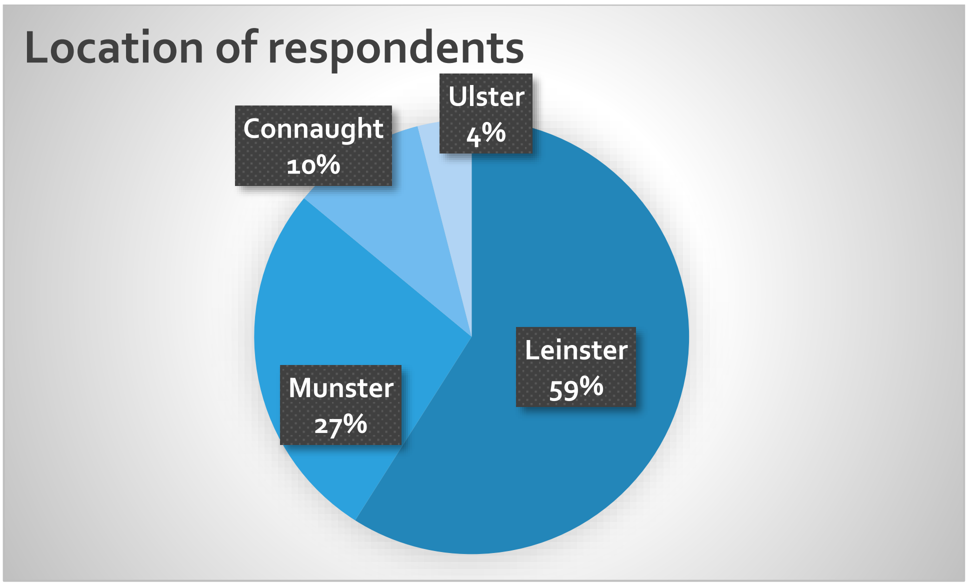


Figure 3: Table with numbers and percentages re. location

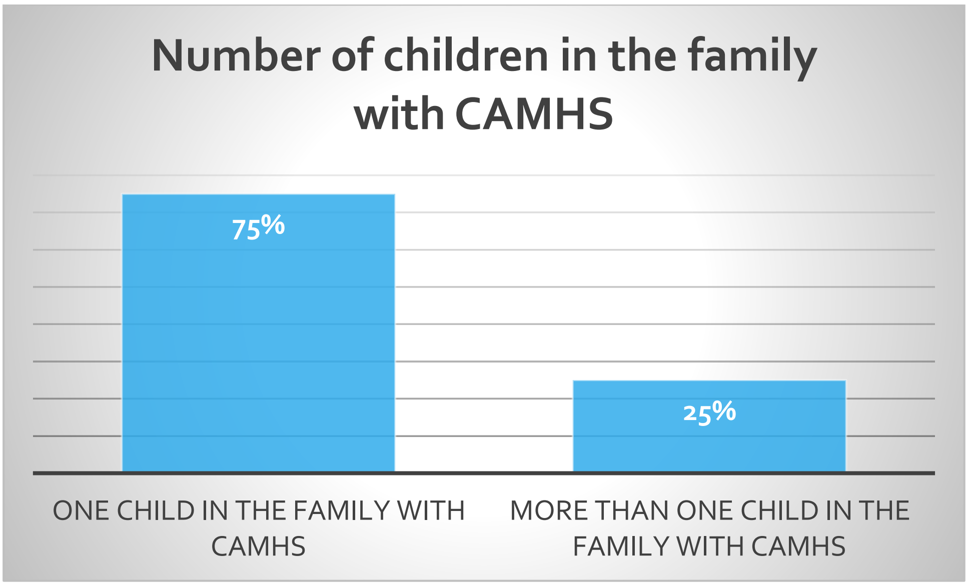
Province	No. of respondents	Percentage
Leinster	435	59%
Munster	200	27%
Connaught	75	10%
Ulster	26	4%

1.2 Number of children in the family with CAMHS

Three-quarters of respondents (549 respondents) indicated that the child/young person whose experience they were capturing was the only child in the family with CAMHS (or trying to access/no longer with CAMHS).

Whereas one-quarter of respondents (187 respondents) indicated that they had more than one child/young person within the family who is with CAMHS (or trying to access/no longer with CAMHS).

Figure 4: Percentage of respondents with one or more children in the family with CAMHS



1.3 Age at first referral to CAMHS

There was a wide range of ages for when children were first referred to CAMHS, however, approximately half of the children of respondents (52% or 384 children) were first referred to CAMHS between the ages of 5-9 years old and half (48% or 352 children) were first referred between the ages of 10-16 years old.

Figure 5: Age at first referral

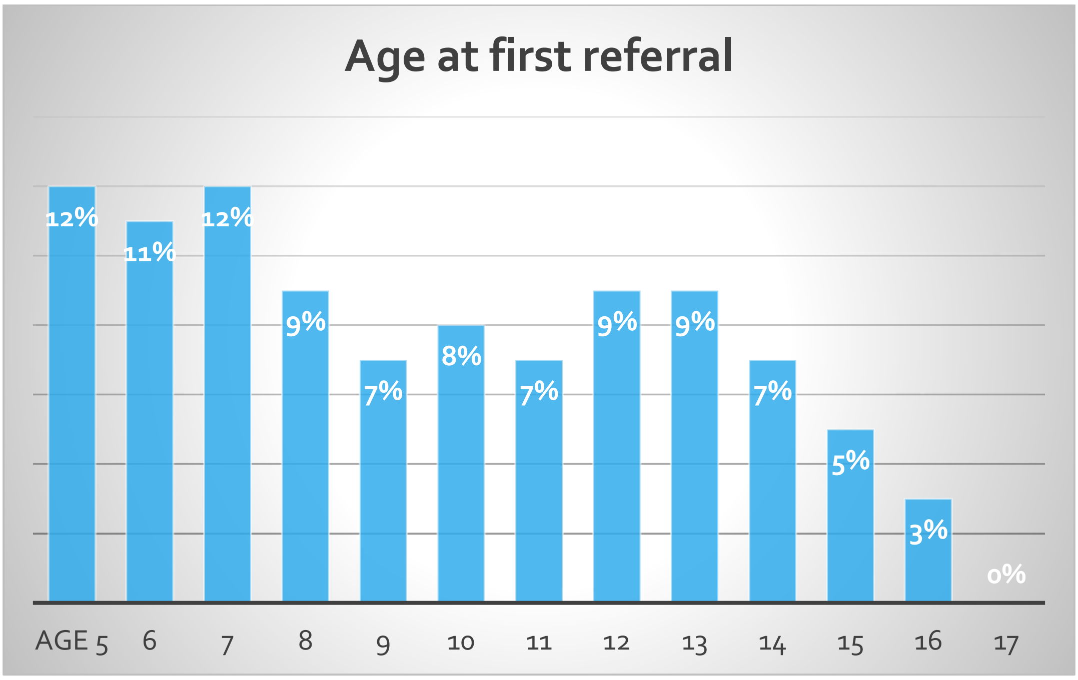


Figure 6: Breakdown of top reasons support sought by age group

For children between the ages of 5-9 years old (384 respondents - 52%), the top five reasons that support was sought at referral were:

i. ADHD (74%)
ii. anxiety (59%)
iii. suicidal ideation/intent (20%)
iv. depression (20%)
v. self-harm (17%)

For children between the ages of 10 – 17 years old (352 respondents – 48%), the top five reasons that support was sought at referral were:

i. anxiety (69%)
ii. suicidal ideation/intent (44%)
iii. depression (40%)
iv. ADHD (39%)
v. self-harm (39%)

1.4 Neurodivergence

Respondents were asked to indicate whether the child/young person whose experience they were capturing in the survey is autistic and/or has ADHD. This could be diagnosed, suspected or awaiting assessment. Respondents could choose all that applied.

Figure 7: Neurodivergence figures

64% of the experiences captured in the survey relate to the experiences of autistic children (439 children)

59% of the experiences captured in the survey relate to the experiences of children with ADHD (405 children)

11% of respondents (75 respondents) selected ‘other’ and some of the other issues mentioned included dyspraxia/developmental coordination disorder (DCD), sensory processing disorder, dyslexia, dysgraphia, dyscalculia and Tourette’s Syndrome.

1.5 Intellectual Disability

Respondents were asked to indicate whether the child/young person whose experience they were capturing in the survey has an intellectual disability.

Figure 8: Intellectual disability figures

11% of the experiences captured in the survey relate to the experiences of children with an intellectual disability (76 children)

1.6 Reason why support is/was sought from CAMHS

Support is/was sought from CAMHS for a variety of reasons captured in the table below with Anxiety and ADHD being the most common reasons for support being sought.

Respondents were asked to select all that applied and they could relate to suspected or diagnosed issues.

[please see section 1.3 for a breakdown of reason support was sought by age categories].

Figure 9: Reasons why support sought

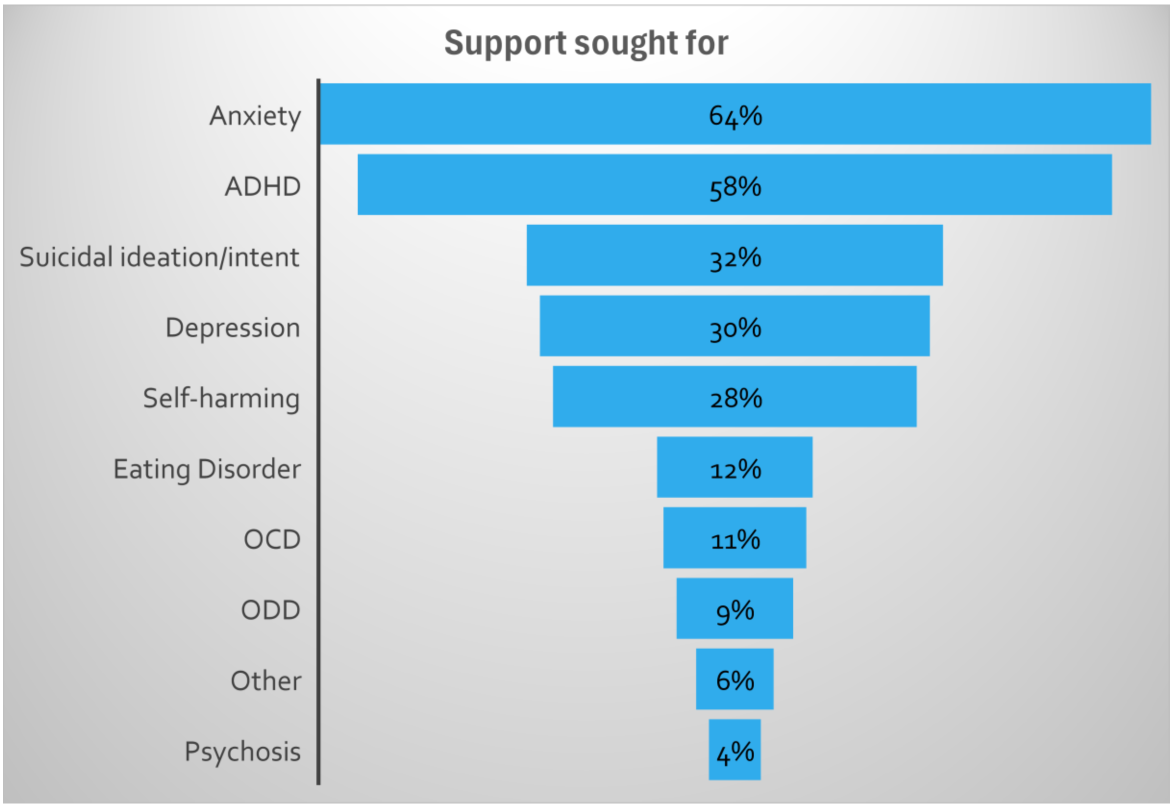


Figure 10: Table with numbers and percentages re. support sought

Support sought for	No. of respondents	Percentage
Anxiety	464	64%
ADHD	420	58%
Suicidal ideation/intent	230	32%
Depression	215	30%
Self-harming	202	28%
Eating Disorder	87	12%
OCD	82	11%
ODD	68	9%
Other	42	6%
Psychosis	25	4%

6% of members also chose ‘other’ and the main reasons specified included aggression/anger, emotional based school refusal (EBSR), panic attacks, fetal alcohol spectrum disorders (FASD), phobias, PTSD, hallucinations, and paranoia.

1.7 Current status with CAMHS

Respondents were asked to indicate whether the child/young person whose experience they were capturing in the survey are currently trying to access CAMHS, with CAMHS or finished up with CAMHS.

Figure 11: Current status with CAMHS

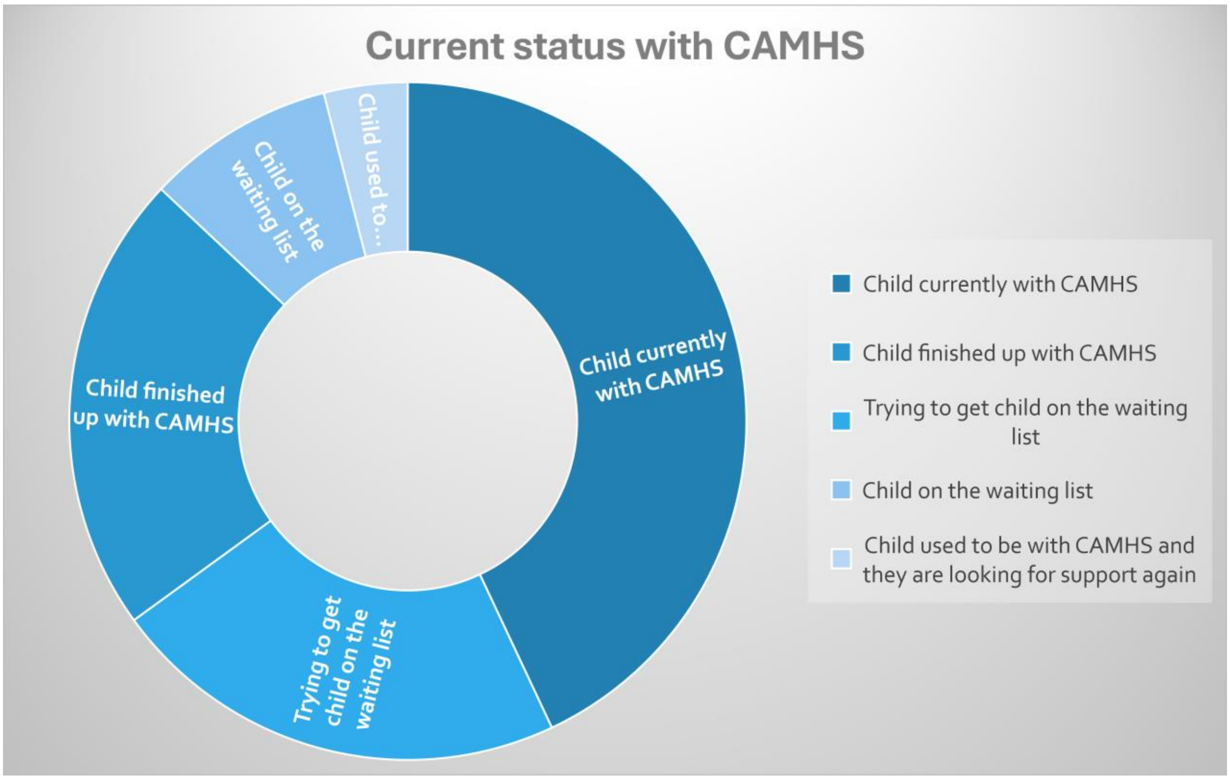


Figure 12: Table with numbers and percentages re. current status with CAMHS

Current status with CAMHS	**No. of respondents**	**Percentage**
Child currently with CAMHS	315	43%
Child finished up with CAMHS	163	22%
Trying to get child on the waiting list	159	22%
Child currently on the waiting list	66	9%
Child used to be with CAMHS and they are looking for support again	33	4%

The following section details the experiences of children with:

- the referral process;
- time spent on the waiting list;
- Experience and supports while with CAMHS; and
- Experience of leaving CAMHS.

Section 2: Journey through CAMHS

Step 1: Referral Process

Section 2: Journey through CAMHS

Step 1: Referral process

Section 2 provides information and insight into the experiences of families in making a referral to CAMHS. The referral process is the first step you take to seek support from CAMHS when your child is experiencing moderate to severe mental health issues. A referral is made by a *referral agent* and the relevant CAMHS team reviews the referral and comes to a decision as to whether CAMHS is the right service for that child.

While public attention and media frequently centres on the 4,000 plus children currently on the waitlist for CAMHS, those numbers do not capture the difficulty many children face accessing the waiting list in the first place nor the children still caught in the referral process.

This section was open to all 736 respondents, however experiences were sought separately from:

i. those currently in the referral process who have not yet had a referral for their child accepted [responded to by 159 respondents]; and
ii. those who have had a referral accepted and made it onto the waiting list or beyond [responded to by 577 respondents].

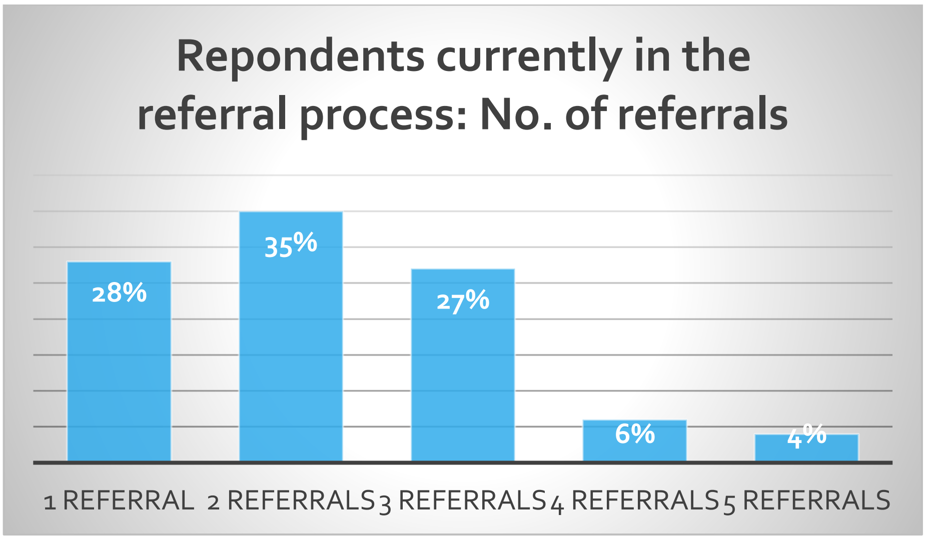
The results from both groups are examined side by side below for comparison purposes.

2.1.1 Number of referrals

Children currently in the referral process

72% of the 159 respondents whose child is still currently in the referral process for CAMHS have already made more than one referral to CAMHS. And over a third of those respondents have made more than 2 referrals.

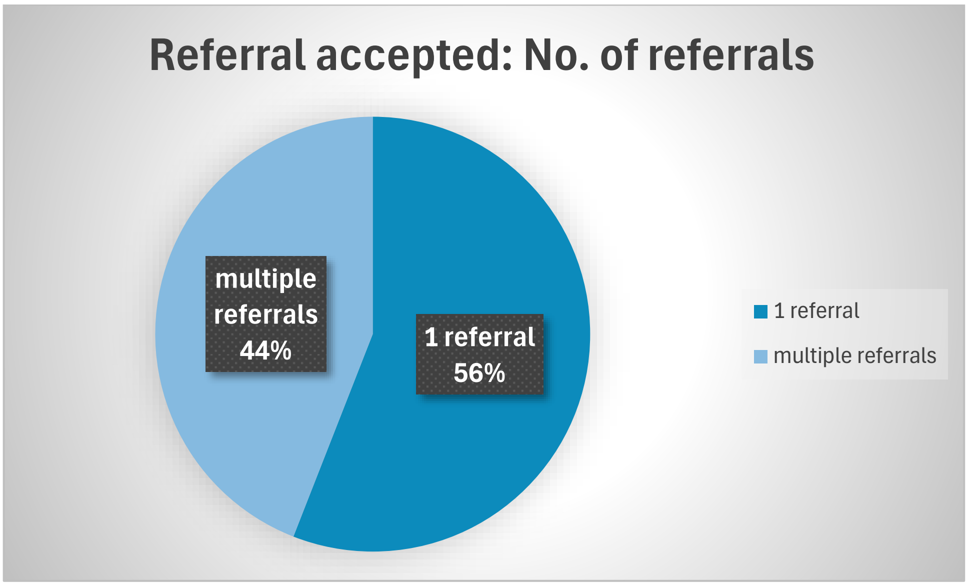
Figure 13: Currently in referral process: number of referrals



Children whose referral has been accepted

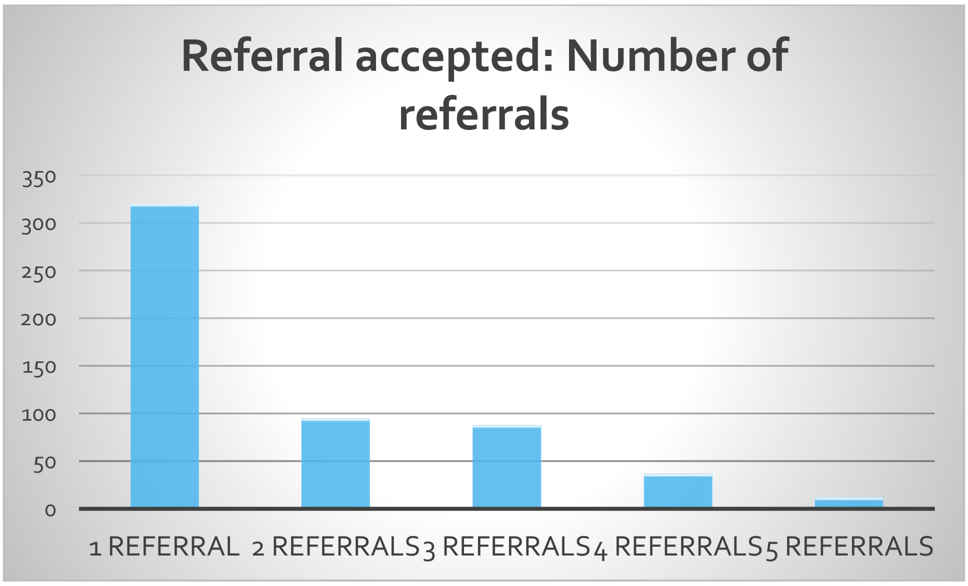
Of the 577 children whose referral has been accepted by CAMHS, 56% required only one referral before being accepted onto the waiting list, whereas 44% required multiple referrals.

Figure 14: Referral accepted: number of referrals



Of the 252 children who required multiple referrals, 40% required 2 referrals, 37% required 3 referrals; 16% required 4 referrals and 5% required 5 referrals.

Figure 15: Referral accepted: Multiple referrals



- *They said he was not actively in crisis as he had not made a suicide attempt, again he was 8yrs old*
- *CAMHS said they needed an AON. Had AON and was recommended CAMHS. CAMHS refused and said to go to primary care.*
- *After multiple letter of appeal to put my daughter on waitlist (Autism & ADHD), Psychiatrist phoned me to explain that due to dual diagnoses we would need to work on her Autism first over next 3 years and if her symptoms haven't changed CAMHS might consider putting on her on the wait list then!!*
- *We were also told they have no-one who can see him due to his intellectual disability. There is no CAMHS ID in my county. So because of my child's ID diagnosis and where we live, basically his mental health is not being treated. This is a violation of his human rights and discrimination as far as I'm concerned.*
- *They told me he has no indicators of ADHD however they never met him.*
- *Because he is Autistic, was told self-harm thoughts are normal and most likely won't act on them.*
- *Child does not meet criteria for CAMHS.*
- *Didn't recognise ADHD diagnosis from Lucena when we moved to another county. Need to do parenting courses, autism services with primary care and other hurdles before being accepted.*
- *They said he would have to be checked for autism first and if he does have ADHD it's mild...I don't know how they could know that when he was never seen by them.*
- *A letter to say although my 7 year old autistic son had suicidal ideation he hadn't a plan in place so referral refused!*
- *Didn't qualify for services as he wasn't self-harming.*
- *Don't deal with autism/not harming himself enough/needs to be a significant threat to life before he would get intervention.*
- *Did not deem the preliminary AON sufficient. Advised I had to go through AON again for full multidisciplinary.*
- *Asd related anxiety and best treated by CDNT*
- *No psychiatrist in my local CAMHS to deal with ADHD had to pay €550 private to get medication for my son*
- *Didn't meet the criteria, needs to have had primary care services first*
- *Stated she didn't have ADHD but had social communication disorder and said she needs AON. This was done without talking to parents or speaking to daughter*

- *I actually lost count [of number of referrals]. I had to get his school and a TD involved. I also had to get a private educational assessment and pay for Conners 3 form to be completed privately*
- *Autism, try CDNT. CDNT would reply with "ADHD, try CAMHS" This went on for years until he was terrified he'd finally kill himself*
- *36 referrals*
- *Child's mental health difficulties were initially not deemed to be "moderate to severe". Of course 2 years later, without any sort of intervention her needs were then deemed serious enough to be accepted into CAMHS but by then she had missed over a year of school.*
- *We had 3 referrals from the GP for severe depression with suicidal ideation rejected by CAMHS. Our daughter eventually got into CAMHS following an in-patient admission.*
- *Originally went for anxiety they insisted he was autistic discharged us 2 years later after countless expenses and appointments went back with anxiety.*
- *Had to seek treatment abroad.*
- *GP made 2 [referrals] and hospital made 2 was only accepted to waitlist after an admission to hospital. CAMHS said themselves they don't look at GP referrals so had no idea of those.*
- *Overdose. Second referral from hospital A&E. First referral from GP rejected.*
- *Many [referrals] lost count, as they refused, then it got lost a few times too*
- *First referral refused but we weren't informed and waited over a year thinking he was on a waiting list.*
- *18 referrals and Department of Education NEPs writing to them twice!*
- *I did AON and then hired a solicitor*
- *In the end they took her case because we ended up in A&E in a complete crisis*
- *Only accepted after we got a private psychologist diagnosis.*
- *My 2nd child was refused despite both myself and his older sibling having ADHD. Both children also have a chromosomal deletion that has a high rate of dual diagnosis. I couldn't fight another fight to get him seen and assessed.*
- *They asked me to stop calling it would take as long as it would take.*
- *They said their service wasn't for him! He already had a private diagnosis from a very well-known and respected child psychiatrist. I had to use several TDs to help get him on the list!*

2.1.2 Length of time in the referral process

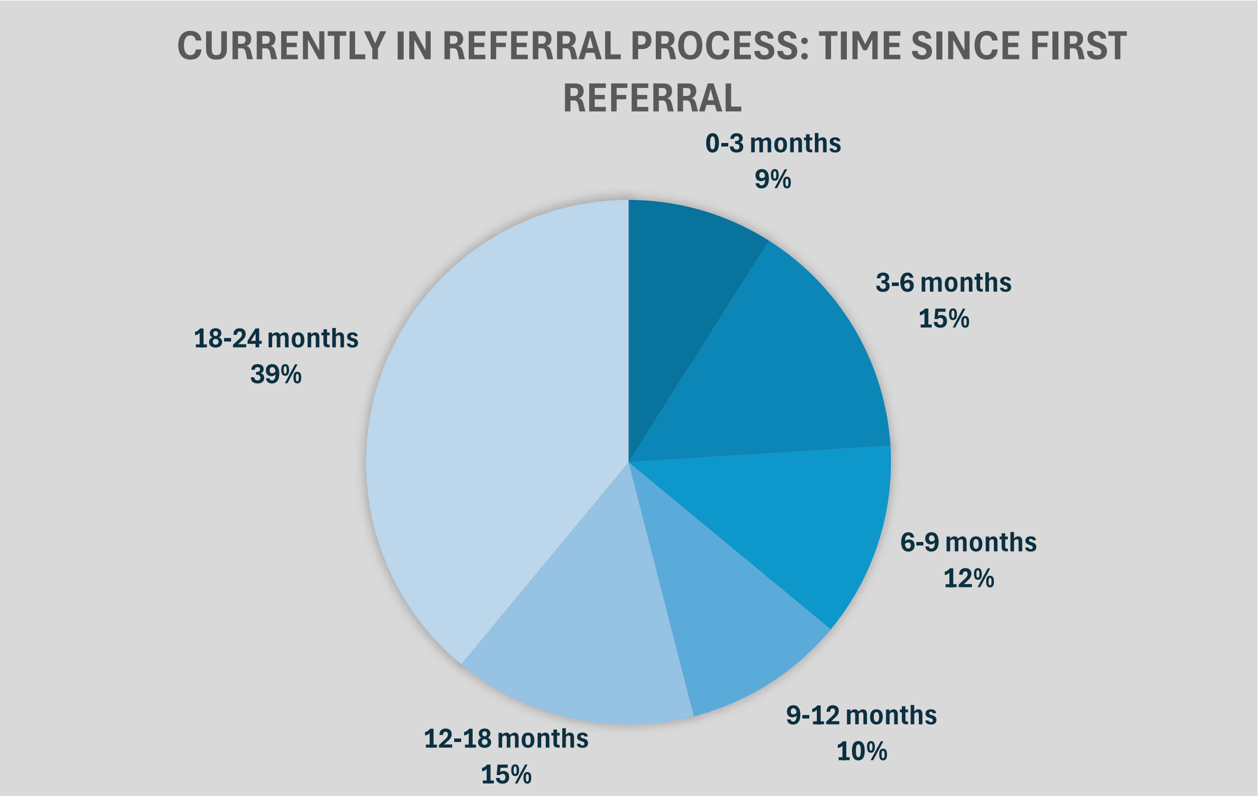
Children currently in the referral process

Just under a half of respondents (46%) currently in the referral process had made their first referral in the past 12 months.

Whereas over half of respondents (54%) currently in the referral process had made their first referral to CAMHS between 12 months- 24 months ago.

However, it should be noted that the survey did *not* offer the option of choosing more than 2 years in the referral process and 17% of respondents in the optional comment box referenced much longer time periods trying to access the service, often of between 4-5 years. For the purposes of answering the question they chose 18-24 months.

Figure 16: Currently in the referral process: Time since first referral[11]



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[11] It must be noted that the survey did *not* offer the option of choosing more than 2 years in the referral process and over 20 respondents in the optional comment box referenced much longer time periods trying to access the service, often of between 4-5 years.

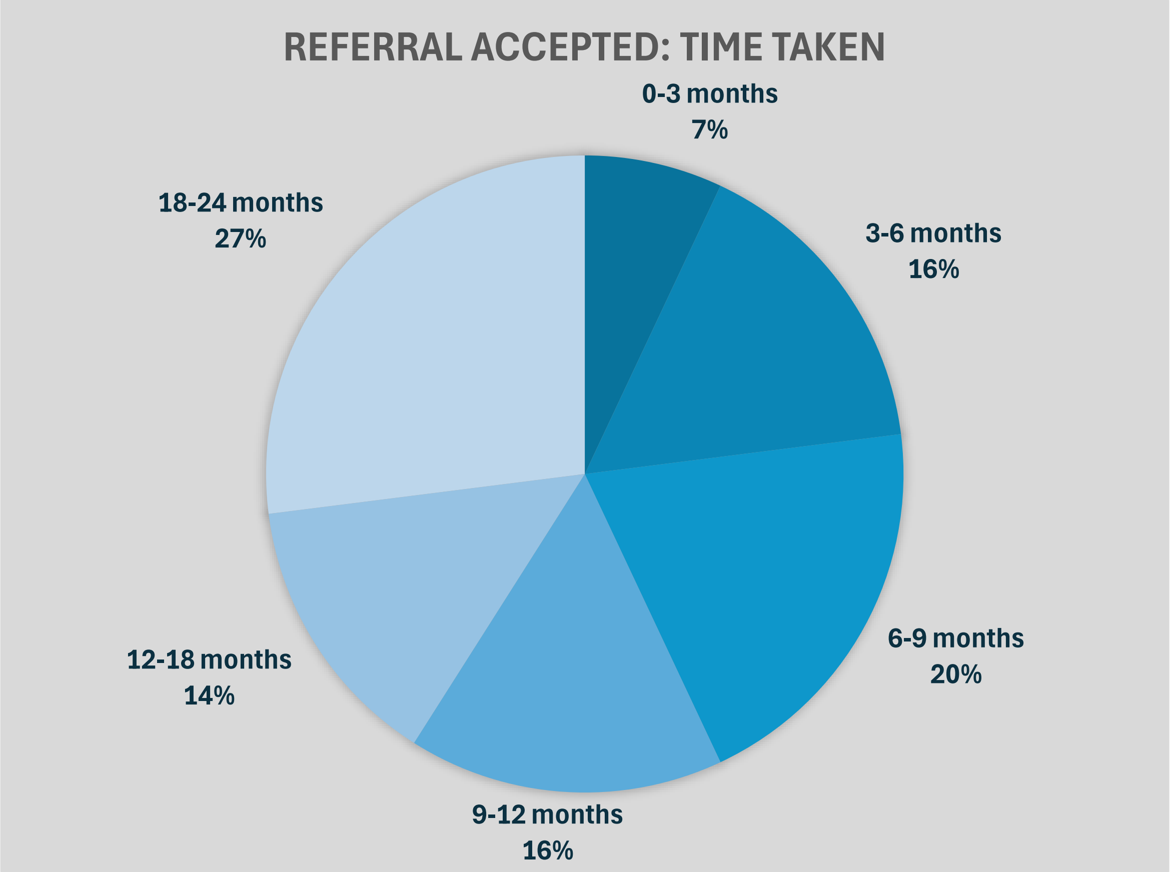
Children whose referral has been accepted

Over half of respondents (58%) whose child's referral has been accepted, had a referral accepted within the first 12 months following their first referral.

Whereas 41% of respondents indicated that it took between 12-24 months following their first referral before a referral was accepted.

However, it should be noted that the survey did *not* offer the option of choosing more than 2 years in the referral process 17% of respondents in the optional comment box referenced much longer time periods trying to have a referral accepted; approximately half of this group referenced 3-4 years and half of the group referenced between 7-10 years. For the purposes of answering the question they chose 18-24 months.

Figure 17: Referral accepted: Time since first referral[12]



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[12] It must be noted that the survey did *not* offer the option of choosing more than 2 years in the referral process and over 36 respondents in the optional comment box referenced much longer time periods trying to access the service, of between 3-10 years.

2.1.3 Communication with CAMHS on a referral

When asked whether CAMHS had ever contacted them to discuss a referral, 38% of respondents had been contacted by CAMHS to discuss a referral whereas 62% of respondents had not.

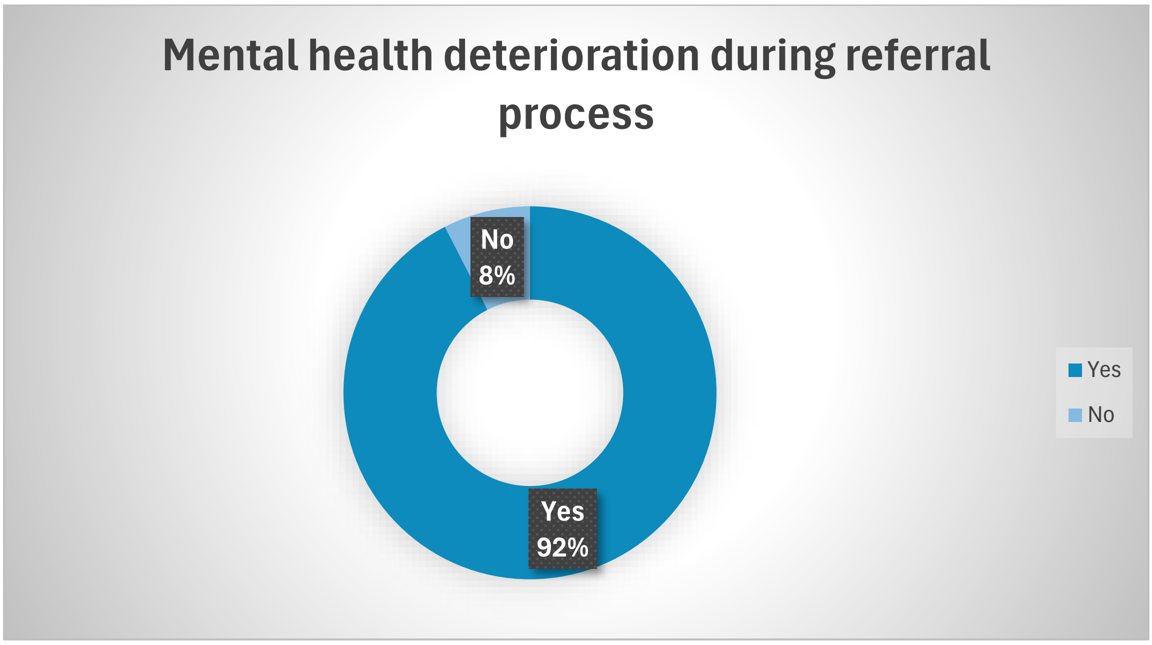
Figure 18: Communication with CAMHS regarding a referral

	Child currently in the referral process	**Child whose referral has been accepted**
CAMHS contacted them to discuss a referral	27%	38%
CAMHS did not contact them to discuss a referral	73%	62%

2.1.4 Impact on mental health

92% of respondents felt that their child's mental health deteriorated/is deteriorating during the referral process. This figure is based on responses from both those sets of respondents who are currently in the referral process and those who have had their child's referral accepted.

Figure 19: Mental health deterioration during the referral process



Average number of referrals required by different groups of children

	Average of all children in the survey	Children who are not autistic	Autistic children	Children with intellectual disabilities	Children with ADHD
Referral accepted by…	**1st referral:** 56% **2nd referral:** 75% **3rd referral:** 92% **4th referral:** 98% **5th referral:** 100%	**1st referral:** 66% **2nd referral:** 83% **3rd referral:** 92% **4th referral:** 99% **5th referral:** 100%	**1st referral:** 51% **2nd referral:** 68% **3rd referral:** 88% **4th referral:** 96% **5th referral:** 100%	**1st referral:** 46% **2nd referral:** 64% **3rd referral:** 84% **4th referral** 95% **5th referral** 100%	**1st referral:** 55% **2nd referral:** 64% **3rd referral:** 84% **4th referral** 95% **5th referral** 100%

Families' voices: Currently in the referral process: Impact of not being able to access support

- *We ended up seeing a private psychiatrist who actually works for CAMHS. So, the he doesn't meet the criteria is bullshit. He's on meds and our lives have changed!*
- *My older son used to be so happy and bubbly now he talks of suicide. He's been through so much trauma and needs mental health support! Why are autistic people, the people who often need this support most, being denied mental health supports?!*
- *We even tried to get Tusla involved as my daughter was very abusive to her brothers and we were concerned about their welfare also but we were told we did not meet the criteria for support*
- *I've had multiple visits to temple Street, CAMHs begging for help and still seem to be getting nowhere.*
- *We have been able to afford private counselling for now.*
- *I've looked for private routes that I can't afford but there is nothing. My kid is ok for now I'm broken though because there is no help coming.*
- *Yes. They made an attempt to end their life. They are only 9. Psychiatrist in A&E advised they have ADHD and some possible autistic traits. They called CAMHS psychiatrist who said they were busy and would call back later. No callback since.*
- *School placement broke down, self-harming, life controlled by debilitating OCD.*
- *To be rejected outright based on a referral letter from our GP is disheartening. She didn't meet the criteria but if her problems are left without treatment, she'll get worse and then be severe enough to be seen. It goes against everything the HSE promotes about early intervention.*

- *Both her mental health and mine are deteriorating.*

Families' voices: Referral accepted: impact of not being able to access earlier support

- *My child was talking about wanting to be dead.*
- *It was extremely bad we were on suicide watch numerous times. Ended up in A&E after a self-harming incident needing 10 stiches.*
- *Escalation in self-harm and self-isolating, panic attacks and ultimately unable to attend school by 3rd class.*
- *Severely worsened. Had to engage counselling privately.*
- *When eventually admitted to CAMHS it was to & fro to medical hospital and tube fed.*
- *Yes, he had a hospital admission with sedation due to trying to harm himself he was 6.*
- *We finally got support once my son deteriorated that he needed to be hospitalised. We never got counselling. Disability said go to CAMHS, CAMHS said go to disability, GP tried so hard to get us into Primary Care, Primary Care said no because he had school refusal...the only real support, he has a nurse who talks to him at CAMHS.*
- *She tried to take her own life*
- *We went private in the end as couldn't wait for CAMHS. We then got CAMHS at 6months and they gave meds. That's all we needed them for the meds. Private psychologist helped her over anxiety and OCD. Once she was signed out of CAMHS it was impossible to get back, did eventually. Gave meds again, wouldn't see her. Weaned her off meds again. Then she got anorexia. Shocking service had I waited for them for the anorexia my daughter would be dead.*
- *Became extremely anxious. Refused going to school. Had increasing negative thoughts leading to suicidal thoughts.*
- *Didn't see him until he actually self-harmed. And attempted suicide.*
- *Delay resulted in self-harm, anorexia, attempt on life, depression, anxiety....*
- *Suspensions in school lead to reduced self-esteem.*
- *They went from self-harming to a suicide attempt and are still very high risk.*
- *I had no choice but to present to A&E with self-harm issues. GP even agrees it was my only choice.*
- *My child's mental health deteriorated as we received no help from CAMHS as she has autism. Wrong service I was told.*
- *I didn't realise that my son had OCD so wasn't aware of how I could help.*

- *Stopped going to school. Lying in bed all day curled up. Agitated, distressed. Became suicidal.*

2.1.5 Action taken to have a referral accepted

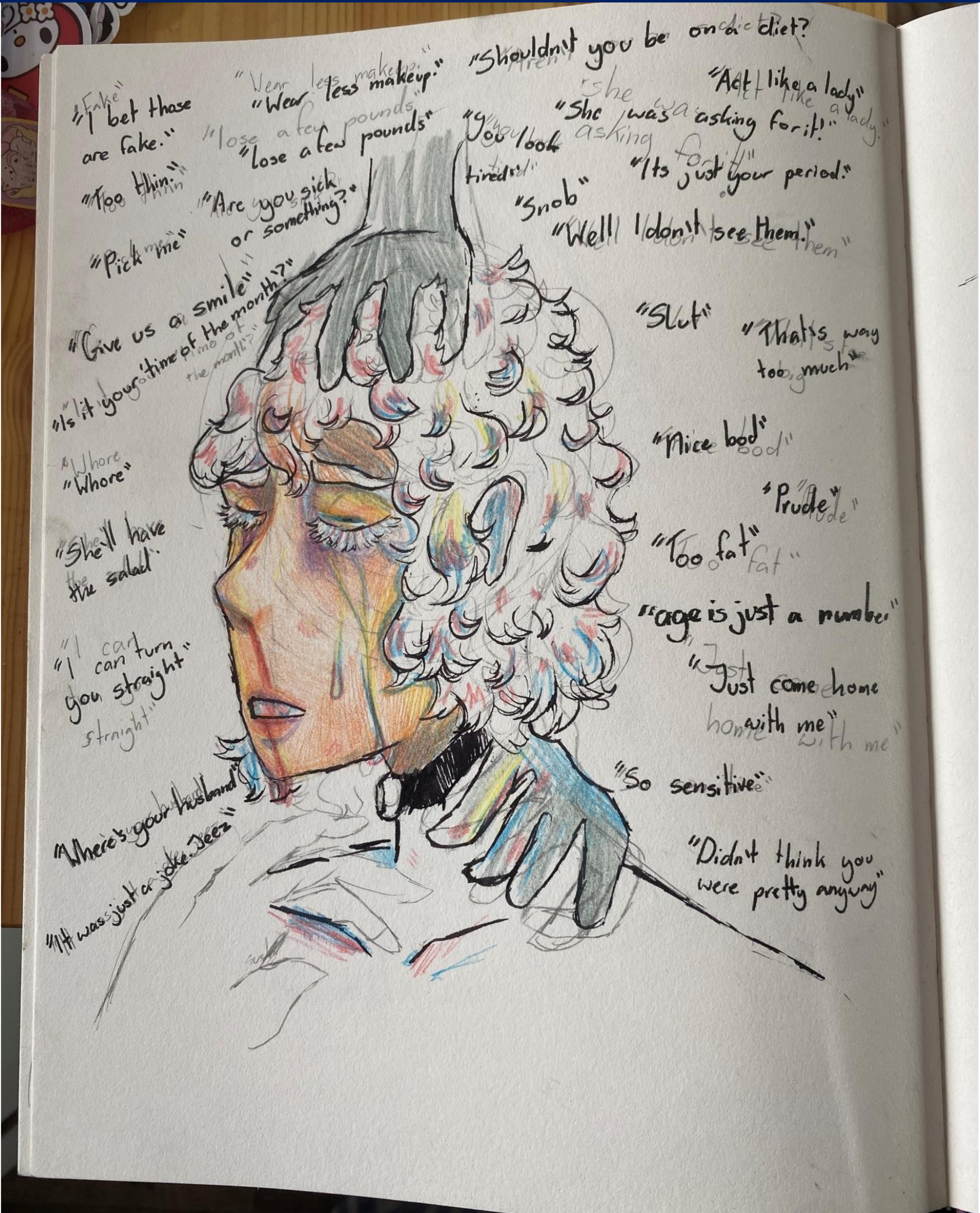
Of the 577 children captured in this survey who have had their referral accepted by CAMHS, 43% of families felt they had to take additional steps to try and ensure their referral was accepted, including:

iii. getting a private diagnosis;
iv. seeking political support from a local TD, senator or councillor;
v. going to A&E;
vi. not mentioning an existing diagnosis; or
vii. going public with their experience.

Families' voices: Steps taken to try and get referral accepted

- *Went to A&E… also went on the radio to beg for help.*
- *Got a private diagnosis of ADHD. Then got a referral for 6 months' time. In meantime had to attend A&E. Took over a month to get seen still.*
- *1. Obtain a private diagnosis 2. Use local TDs 3. Used social media.*
- *Paid for private assessments, got letters from school, wrote my own letter and got a TD involved.*
- *Doctors, Paediatricians, Psychologist, Tusla, Barnardos.*
- *Did not mention autism diagnosis second time as was advised by other professionals.*
- *Didn't mention moderate intellectual disability.*
- *I went to TD and A&E and private diagnosis to try to help my son.*
- *We went to A&E and also got a private diagnosis in which CAMHS was stated as required service but they still argued that she would be better in CDNT because of her autism*
- *I didn't realise a private diagnosis was possible. I knew so little of the system.*
- *the overall referral and intake process was very long and wasted a lot of valuable time.*
- *I also walked into the office and stayed until someone spoke to me.*

Step 2: Waiting List



Step 2: Waiting list

This section details families' experiences of being on the waiting list for CAMHS and is made up of information provided by 577 respondents[13].

Waiting list sizes vary hugely from CHO area to CHO area[14] as do wait times for urgent referrals[15]. Within the survey, experiences were sought separately from:

i. those currently on the waiting list [99 respondents]; and
ii. those who have made it through the waiting list process [478 respondents].

A third of those currently on the waiting list have been with CAMHS before and are seeking support again.

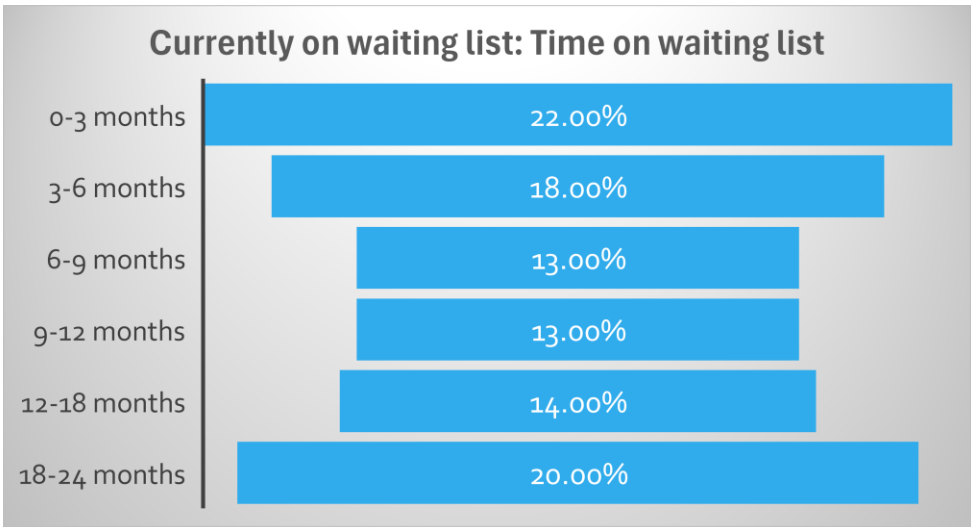
2.2.1 Time spent on the waiting list

Children who are currently on the waiting list

40% of children who are currently on the waiting list have been on it for less than 6 months; whereas 26% of children have been on the waiting list between 6-12 months and 34% of children have been on the waiting list between 12-24 months.

It should be noted, however, that the survey did *not* offer the option of choosing more than 2 years on the waiting list and a small number of respondents mentioned being on the waiting list between 3-4 years.

Figure 20: Currently on waiting list: Time on waiting list



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[13] These questions were not asked of the 159 respondents who are currently still in the referral process and who have not yet made it onto the waitlist.

[14] Waitlist (March 2023) CHO 1 – 447; CHO 2 – 311; CHO 3 – 376; CHO 4 – 1,142; CHO 5 – 340; CHO 6 – 855; CHO 7 – 364; CHO 8 – 605; and CHO 9 – 251.

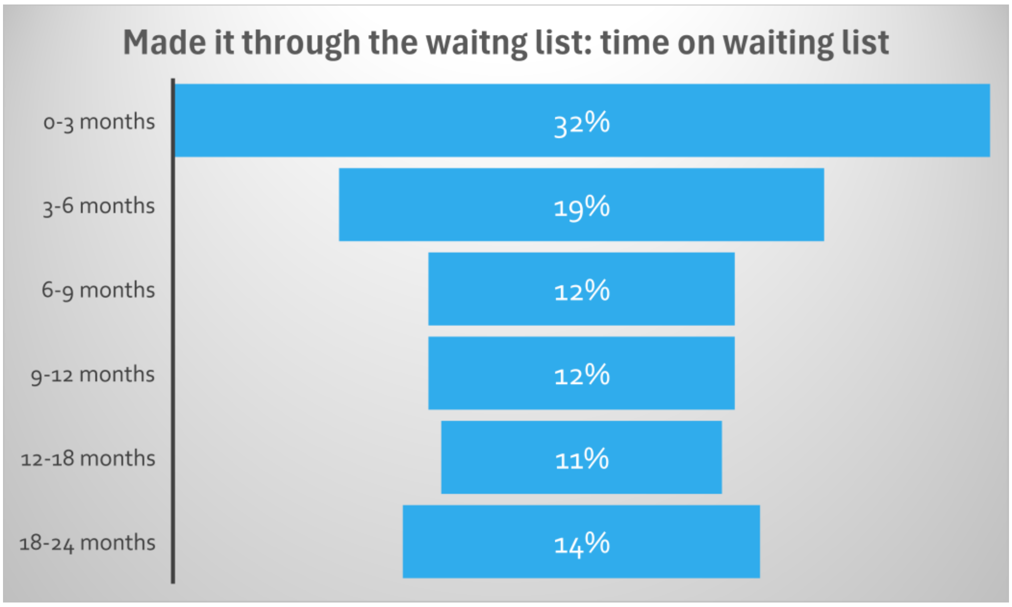
[15] According to the Mental Health Commission's individual CHO reports urgent referrals for suicidal intent varied across CHOs – CHO 1 – 35 days; CHO 2 – information not provided; CHO 3 – 4 days; CHO 4 – 60 days; CHO 5 – 10 days; CHO 6 – information not provided; CHO 7 – information not provided; CHO 8 – 11 days; and CHO 9 – 4 days.

Children who made it through the waiting list

For those children who have made it through the waiting list, half were seen within the first 6 months of being on the waiting list; whereas 24% were seen following a wait of between 6-12 months; and 25% of children after a wait of 12-24 months.

It should be noted, however, that the survey did *not* offer the option of choosing more than 2 years on the waiting list and 15 respondents mentioned being on the waitlist for longer than 2 years.

Figure 21: Finished on waiting list: Time spent on waiting list

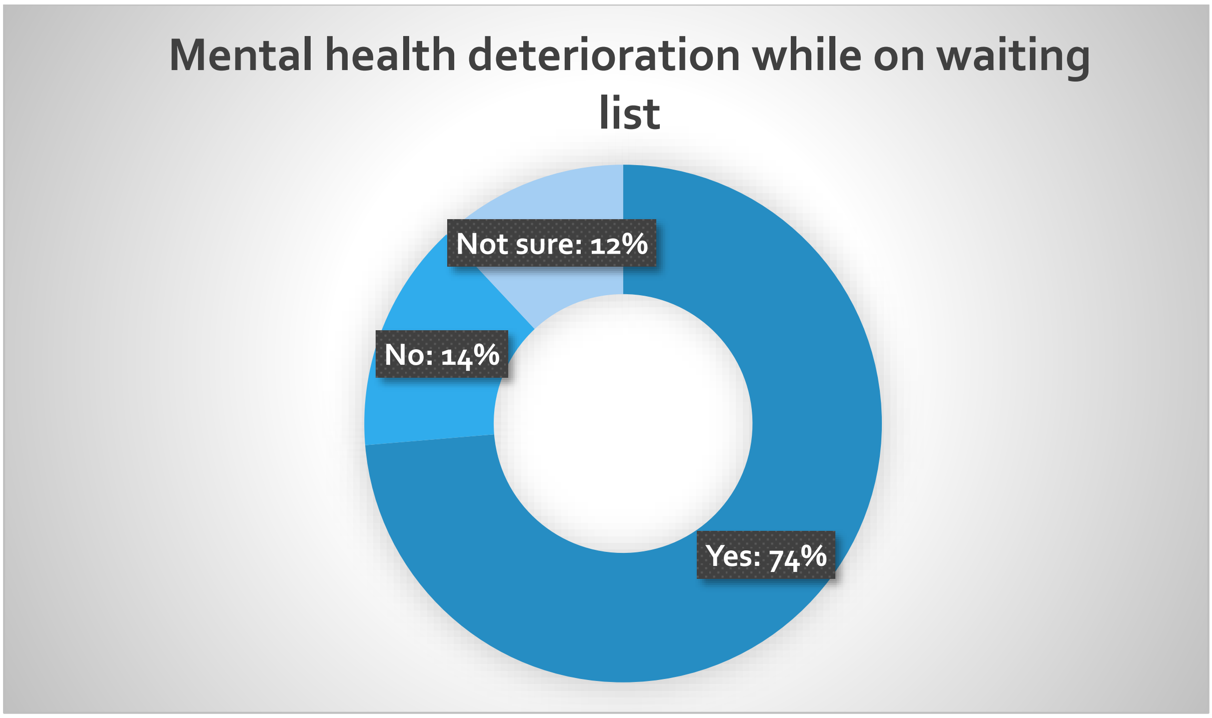


2.2.2 Impact on mental health

74% of respondents felt that their child's mental health deteriorated/is deteriorating while on the waiting list. This figure is based on responses from both those sets of respondents who are currently on the waiting list and those who have made it through the waiting list.

Respondents who thought that their child's mental health did not deteriorate/was not deteriorating while on the waiting list generally put this down to the fact that they were able to access private support in the meantime.

Figure 22: Impact on mental health while on waiting list



2.2.3 Steps taken to access support quicker

Due to the deteriorating mental health of their child, many families felt they had to take additional steps to try and get some support for their child while on the waiting list or to speed up the time spent on the waiting list.

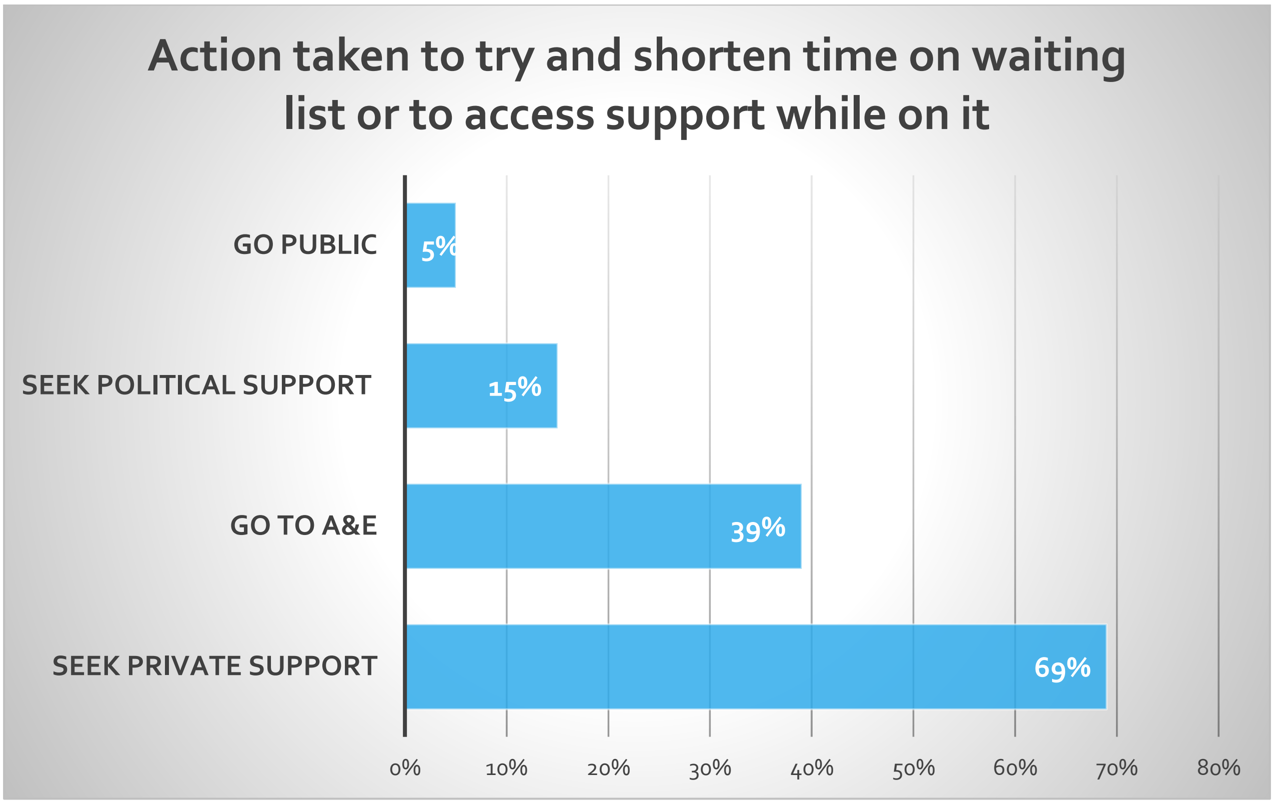
Of the 478 families who had made it through the waiting list process:

- 69% of families ended up seeking private support if:
  (i) they had enough money *or* could borrow enough money to do so;
  (ii) they could find a child psychiatrist/other private support accepting new patients; and
  (iii) their child was accepted for private support and not dismissed as too complex in need.

  The financial strain caused by paying private support was repeatedly noted as a key worry and concern of respondents, especially if it meant they could no longer afford to access private support.

- 39% of families had to take their child to A&E while their child was on the waiting list as their mental health deteriorated to a critical or emergency point.
- 15% of families sought political support to try and access support sooner.
- 5% of families felt they had to go public or to the media to try and get some help.

Figure 23: Action taken by families to try and access support while on the waiting list



Families' voices: Experiences while on the waiting list

- *Feeling he is at risk all the time. He feels forgotten and not important.*
- *He is finding it harder and harder to engage in school and has withdrawn from all extracurricular activities, which isn't fair on him as he has the desire but not the ability.*
- *They were getting much worse but after a year I found a private psychiatrist and am paying her to prescribe medication.*
- *I believe things would be different if we'd had intervention earlier. Most of us get referral as a last resort after exhausting other options.*
- *Every day is a battle and always scared, don't know how to help them.*
- *Started medication through private diagnosis*
- *He had to be hospitalised for suicidal ideation and depression*
- *Got private diagnosis and access to medications*
- *Due to ADHD/ADD school in particular became a real challenge. His anxiety levels heightened as the school environment became overwhelming for him. It was a very difficult & challenging time for him & all the family.*
- *Child disassociated, shut down completely, wouldn't leave the house, had intrusive thoughts, couldn't and still can't leave the house, can't selfcare, doesn't wash or get dressed. They will not see her and say its ASD related and to go to the disability team. Pawned off all her life. No education despite her genius iq score. I'm autistic as is my other teen so this really hurts that they say this and dismiss her. Its ruined her life and my family's life. She needs medication.*

- *became violent, avoided leaving the house, threatening to throw himself out a third story window.*
- *2 attempts to take their life.*
- *When we were referred, and he was in 3rd class he was attending school occasionally. Now he is in 5th class and has only been in school 5days for the whole of 4th class and 5th class.*
- *His confidence and situations that he was placed in because he had unmanaged ADHD will forever affect him now.*
- *She began having suicidal thoughts.*
- *Anxiety escalated as well as OCD huge fear and uncertainty about what was happening. Besides CAMHS no phone services etc either it was a horrific time!*

Step 3: Initial appointments

Step 3: Joining CAMHS: Initial Appointments

This section is based off the response of 511 respondents – those who are currently with CAMHS; those who have left CAMHS; and those who are trying to regain access to CAMHS.

2.3.1 Response during initial appointments

Difficulty accessing mental health supports unfortunately does not always end at the point when a child makes it through the CAMHS referral and waiting list processes.

- 8% of children captured in this survey were discharged at triage on the first appointment;
- 10% of children captured in this survey were discharged after 3 appointments with CAMHS;
- 13% of children captured in this survey were discharged after 6 appointments; and
- 70% of children were kept within the service for a longer period of time

Families' voices: Joining CAMHS

- *We thought getting an appointment with CAMHS was the beginning of getting help, how wrong we were.*
- *Signed off after a 20min appointment at 11 and referred again at 14.*
- *Begged for support after 3 suicide attempts but discharged with no treatment.*

Step 4: Interventions/Support

Step 4: Interventions/Support

This section is based off the response of 511 respondents – those who are currently with CAMHS; those who have left CAMHS; and those who are trying to regain access to CAMHS.

2.4.1 Top supports:

In this section, respondents were asked to list the most valuable support(s) they had received from CAMHS. This was an open-ended question and there was a wide variation of experiences and responses received.

The top three most valuable supports identified by respondents included:

i. individual staff members
ii. access to medication; and
iii. interventions or support that they had received.

It is important to note, however that some respondents (approximately 15%) found it hard to identify a support as they had not received any interventions/support to-date.

For those respondents who identified individual staff members as a top support, commentary generally centred around the difference being listened to, believed and validated, feeling empathy and care can make. Respondents acknowledged the huge strain staff were under, the heavy work load they carried and how staff were stuck fighting fires. Families spoke of individual staff members across a range of professions that went out of their way to ensure a child received some form of intervention or support. If the individual identified was a psychiatrist, many respondents expressed worry/regret about the doctor only being on their child's team for a short period of time before moving on as part of their rotation.

Unfortunately, there was little consistency across the board in terms of families' experiences with CAMHS teams and there was recognition that some CAMHS teams simply didn't have the time or the capacity to offer appropriate care to their child.

Access to medication and interventions/supports were also identified as top supports. As availability of interventions (therapeutic support, OT, speech and language therapy etc.) varies widely from one CAMHS service to the next, families who could access interventions generally expressed relief and wished their experience was that of other families and children around the country.

Families' voices: Top supports received: Individual staff members

- *Dr X, head psychiatrist, has literally kept my son alive.*
- *Social care worker was fantastic and a great support.*
- *Therapy with a wonderful mental health nurse*

- *The staff member I am dealing with is supportive by listening to my concerns and I feel cares about our daughter's welfare.*
- *Dr X is spectacular, a huge support to my daughter. Her 1st experience with CAMHS was not good but when she got Dr X it was amazing.*
- *There is a receptionist who is an angel. I kept calling her and I believe she helped me so much in this time .I felt more determined than ever to keep calling and advocating for him...*
- *My child was treated holistically she wasn't just treated as a diagnosed person.*
- *Supportive nurse who talks with my son*
- *Very supportive psychologist.*
- *There were two in particular fantastic staff that helped my son get through.*
- *Supportive play therapist*
- *Staff is lovely very supportive especially Dr X and X the child therapist.*
- *All staff have been very supportive and always at the end of the phone.*
- *Excellent advanced nurse practitioner*
- *X was a life saviour. They all helped us.*
- *Very supportive case worker who showed real concern and empathy*
- *Apart from practical help like medication, they believed us and validated us.*
- *My child's counsellor made the difference.*
- *1. Being believed and listened to 2. Staff being kind to my child 3. Being able to phone and speak with someone when I had a query or question.*
- *Excellent support from clinical nurse, give 8 one to one sessions.*
- *They were there for me as well as my child.*
- *Despite my daughter refusing to engage with CAMHS as she has no faith in them, they have not given up on her yet.*
- *She gets on really well with her therapist.*
- *A second key worker was assigned. She listened to what I wanted for my child. Was supportive when other staff members were very much dismissive. Also, she is honest and forthcoming with information.*
- *helpful doctor - he is gone now though.*
- *A very supportive therapist until she was moved somewhere else which my child found extremely frustrating and disruptive.*
- *The receptionist was very kind and understanding.*
- *OT was incredibly supportive.*

- *A supportive key worker which kept us with CAMHS as the psychiatrist tried to close our case several times.*
- *A really supportive trainee psychiatrist who bonded well with my son.*
- *One consultant eventually was quite good and genuinely interested but by then my daughter was 17 and nearly out of the system.*
- *Our case worker has been very good and someone that we trust.*
- *A genuine interest in understanding our child better and finding the best support for him.*

Families' voices: Top supports received: interventions

- *Medication - she can function when on medication.*
- *Regular psychiatrist consultation, OT, SLT, counselling with psych nurse.*
- *The DBT program and also psychiatry and meds.*
- *Psychiatrist, Regular Appointments, OT, Medication.*
- *Talk therapy and signpost to other services.*
- *Quarterly reviews with Child Psychiatrist.*
- *For one child - got good psychologist support and access to medication, for second child offered medication only.*
- *Medication SLT, OT, Psychology all very positive.*
- *Attended CAMHS hub for an intensive intervention.*
- *A diagnosis. However, when the long-standing psychiatrist retired the new psychiatrist suggested that the assessment was inconclusive, and child would need to be reassessed.*
- *On a few occasions my daughter refused to go to her appointments. The two clinical nurses and psychiatrist came to our house to meet with her, and this saved her life on one occasion. We were really grateful that they made the effort to come to us when she wasn't well enough mentally to go to them.*
- *Medication and parenting course run by CAMHS social worker specific to parenting an ADHD child.*
- *Supportive staff, medication, OT, parents' courses.*
- *Got a letter supporting home tuition.*
- *Access to peers' group.*

- *Parental classes on how to deal with challenging behaviour. Medication to help regulate concentration. Access to psychiatry*

2.4. 2 Interventions offered

Respondents were asked what interventions they had been offered by CAMHS - almost 70% of children had been offered medication whereas much smaller percentages had been offered other forms of support.

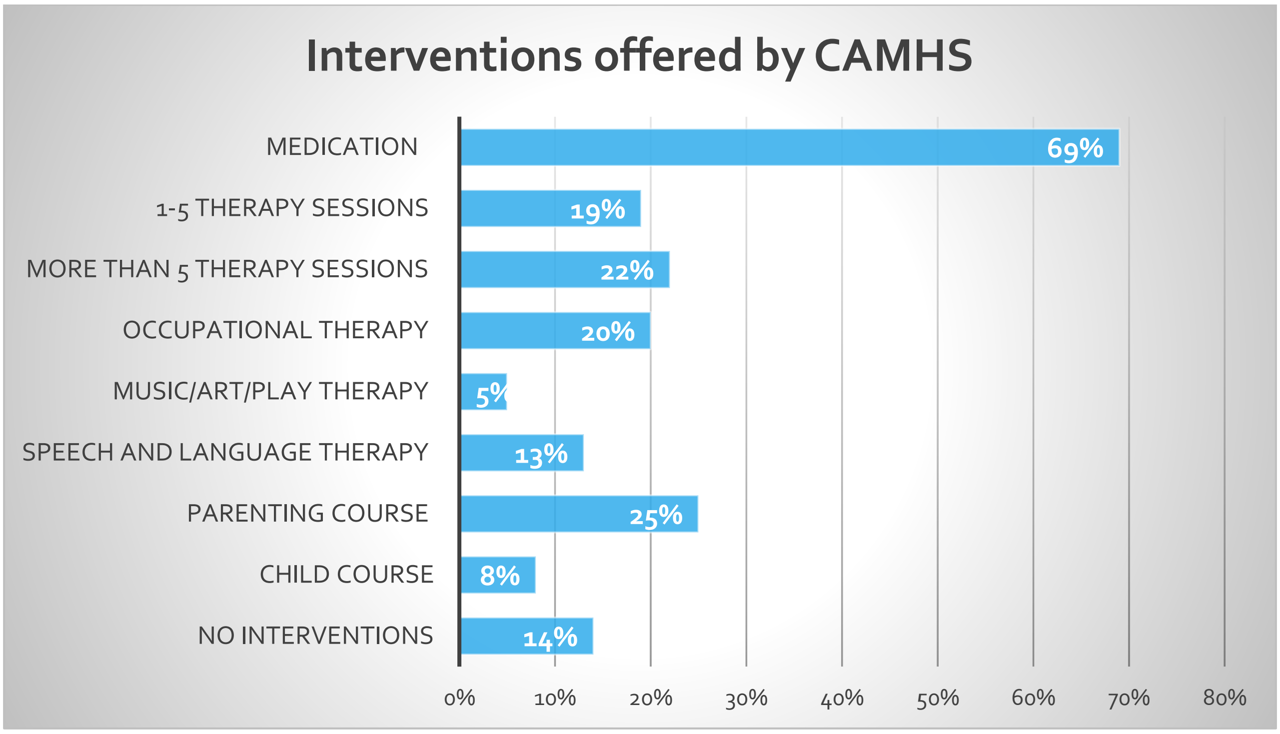
19% of children had been offered between 1-5 therapy/counselling sessions whereas 22% had been offered more than 5 sessions.

20% of children had been offered occupational therapy, 13% had been offered speech and language therapy and 5% had been offered music/art/play therapy.

25% of families had been offered a parenting course and 8% of children were offered a child course.

14% of respondents said they had not been offered any support to-date although some mentioned they were on waiting lists for particular supports.

Figure 24: Interventions offered by CAMHS



Different courses were offered by different CAMHS team. Captured below are some of the courses referenced by respondents:

For parents:

- ADHD parenting course
- Building Bridges
- Circle of security Parenting
- NVR (non-violent resistance) parenting course
- Parenting Fears and Feelings Workshop
- Parenting your anxious child
- Timid to Tiger
- Triple P parenting course
- SPACE programme

For child:

- SAS programme (Secret Agent Society)
- Deciders Course
- Transition to secondary school course
- OT sensory needs group course
- Social skills course
- Speech and language social group

Families' voices: Interventions offered

- *A 6-week 2-hour course that I'm finding it difficult to attend*
- *Behaviour therapy waiting list for a year now.*
- *We only see psychiatrist to renew prescription. No other services offered as my daughter was in private counselling.*
- *At initial assessment we were told we would see OT for sensory diet. 4 years later and still haven't gotten it.*
- *Child needs OT but no OT available. Has a 1 to 1 session every 2 weeks for the past 2 years for mental health.*
- *We have already completed ALL parenting courses that they suggested while on the waiting list.*
- *Some group for managing emotions. A teenager, with ASD, ADHD, anxiety, depression. She wouldn't agree to attend- understandably!*

- *Like stress management/decider skills- unsuitable for needs.*
- *We check in with a different doctor each time and after the appointment it is impossible to get in touch again or get any follow up.*
- *Peers group (how to make and maintain friends)and some online CBT. Parents emotional coaching.*
- *We were assigned a social worker who we never met and desperately needed at the time she had a few session with an OT and one on one therapy*
- *therapy for eating disorder only while all other issues would be ignored.*
- *Offered speech and language, now waiting over a year; offered zones of regulation now waiting over eight months; offered parenting course 18 months after I already informed them I had completed same course via ADHD Ireland.*
- *Told to source my own dietitian and they would reimburse*
- *OT was very limited and only available after being with CAMHS 2 yrs.*

2.4.3 Support with medication

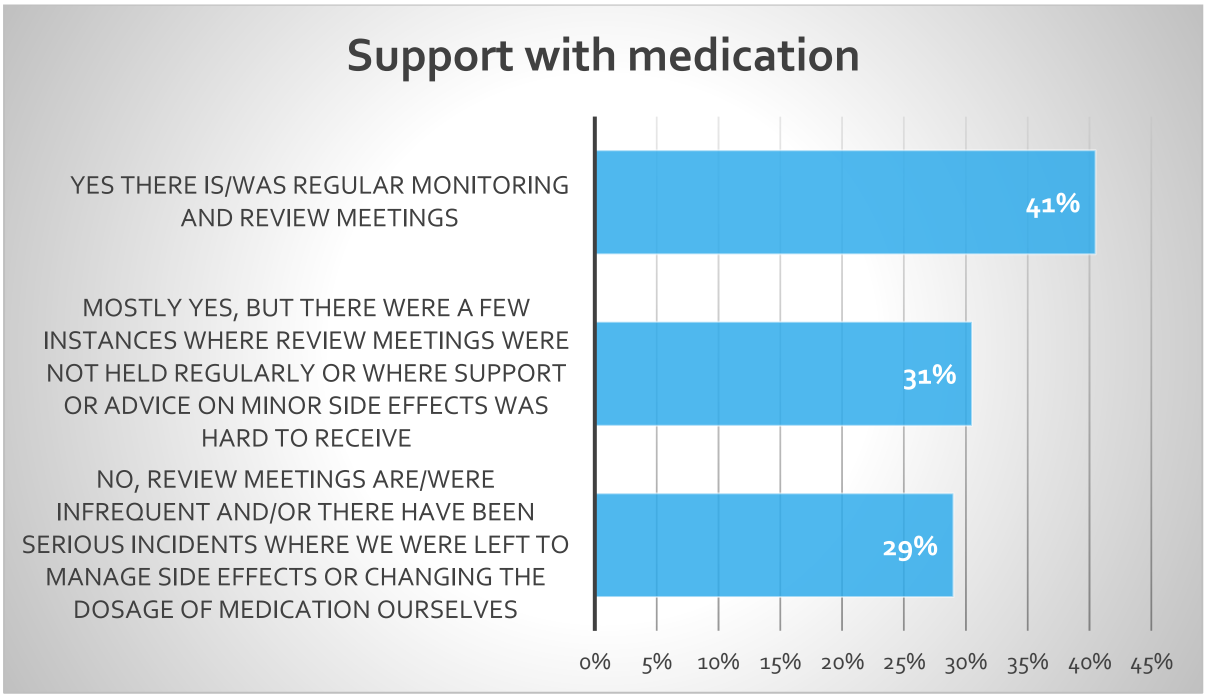
Respondents whose children were on medication were asked whether they felt adequately supported with the management of their child's medication.

72% of respondents replied yes or mostly yes, indicating there was generally regular monitoring or medication and review meetings.

29% of respondents said they did not have adequate support with medication and that either review meetings were infrequent or that there had been serious incidents where they were left to manage side effects/changing the dosage of medication themselves.

A common theme was children being discharged if families chose not to use medication.

Figure 25: Support with medication



Families' voices: Support with medication

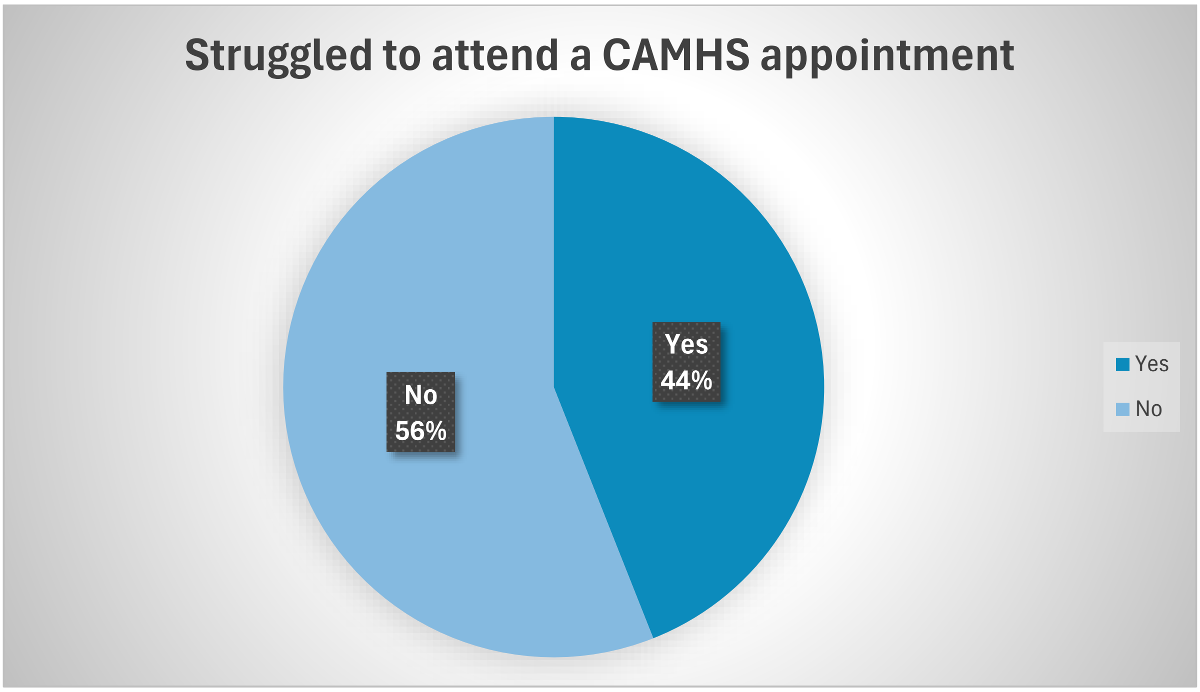
- *My son came off his medication because he said it changed his personality. He was telling them for years and they didn't listen. They just kept increasing the dose.*
- *They discharged my daughter at 18 whilst still medicated without any handover to Adult Mental Health.*
- *Very regular and comprehensive Psychiatric support.*
- *My child was prescribed anti-depressants by CAMHS, and I was told to phone every month for the prescription. As the child was only seen by CAMHS once a year, after four months I was concerned with no supervision and went to GP every two months for their check-up.*
- *The medicine was never reviewed until they took her off it. This was 1 month before she took her own life.*
- *Scripts were not available on time 4 times in a row despite at least a weeks' notice. The wrong dose was prescribed twice. Twice it was sent to the wrong chemist.*
- *Met with psychiatrist regularly.*
- *We went nearly a year without a medical review for medication, luckily there were no implications.*
- *Only reviews about once a year and only when I make a request for same.*

- *Child was physically ill from side effects. Side effects were constantly played down/ denied No other therapeutic pathways such as CBT or counselling were offered.*
- *Last doctor discharged child and then called to say he can't be discharged while on medication.*
- *My son wouldn't take the medication. Thinks they are drugs. So, he was discharged after 1 session.*
- *Constant changing in staff meant longer delays in reviewing the meds.*
- *They were stopping medication without weaning down and no consultation, no checks done after starting a medication, when was clear a medication wasn't working they just ignored it*
- *Was on Risperdal >3yrs and bloods never checked*
- *We requested other therapies but were told none are available. Medication was only option offered.*
- *As parents, we had no experience with anti-depressants or anti-anxiety meds. Our child rapidly developed an obsession with medication being the 'answer' to all her challenges, which was a big problem for us. She also developed aggressive behavioural side effects which were hugely challenging to manage. The medium- to long-term medication plan has never been clarified for us.*
- *Medication was mismanaged and highlighted in Maskey report. Then took several months of chasing CAMHS to get seen and monitor new medication. Currently seen every 3-6months but on the weekend by a locum. If an issue during the week regarding side effects, then can't get a consultant to call back.*
- *Had to go to A&E due to side effects of medication change due to no medical cover at CAMHS.*
- *Hair was falling out and CAMHS were no help so I decided myself to stop medication, then CAMHS simply decided to discharge child when we refused medication.*
- *We declined anxiety meds and were therefore discharged.*
- *Had to chase for follow up dates because they seemed quite unorganised with this, but once flagged they acted quickly.*

2.4.4 Struggling to attend appointments

Respondents were asked whether their child had ever struggled to attend an appointment. 44% of respondents said yes and 56% responded no.

Figure 26: Difficulty attending a CAMHS appointment

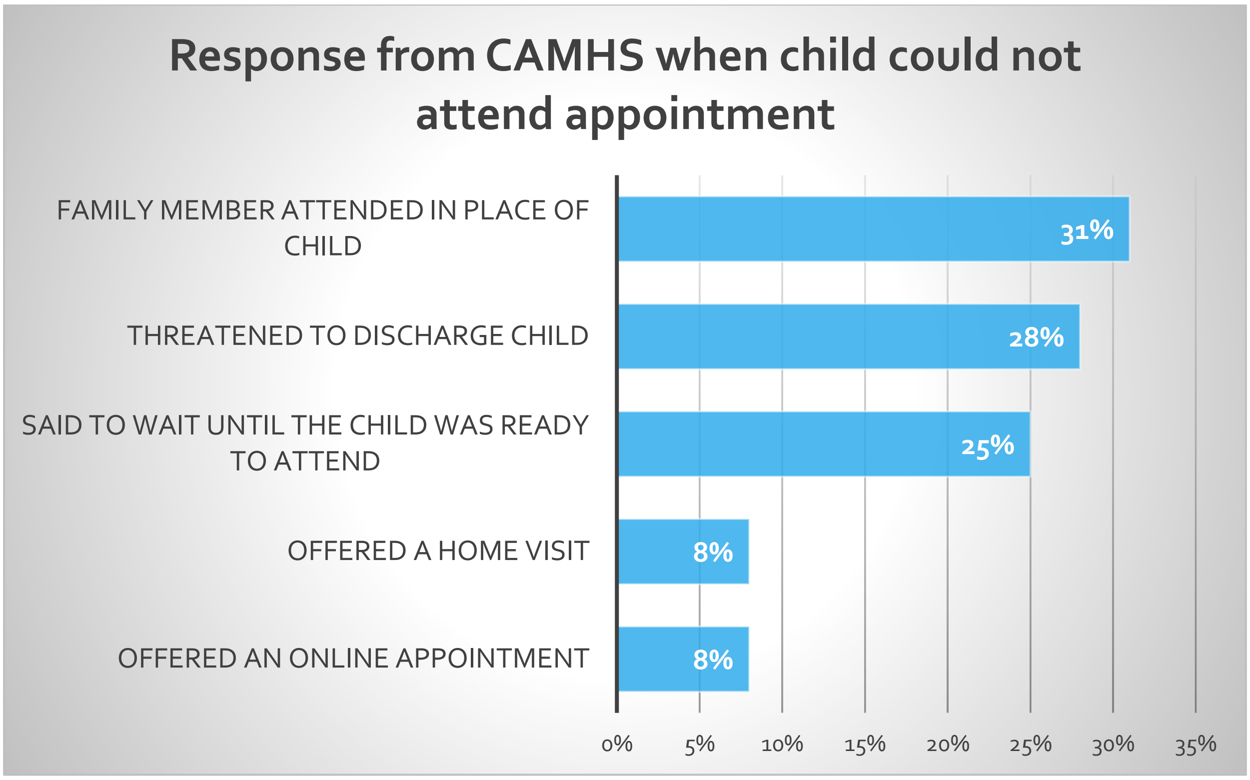


There was an inconsistent approach to how non-attendance of an appointment was dealt with by CAMHS teams.

Of the 44% of children who had struggled to attend a CAMHS appointment, 31% had a family member attend in their place; 25% were told to wait until they were able to attend; 8% were offered a home visit; and 8% were offered an online appointment. 28% were told they would be discharged if they could not attend.

Gratitude was expressed by families when more supportive approaches were offered and high levels of frustration and distress were expressed by those who felt dismissed and unsupported.

Figure 27: Response from CAMHS when a child could not attend an appointment



Families' voices: Struggling to attend an appointment

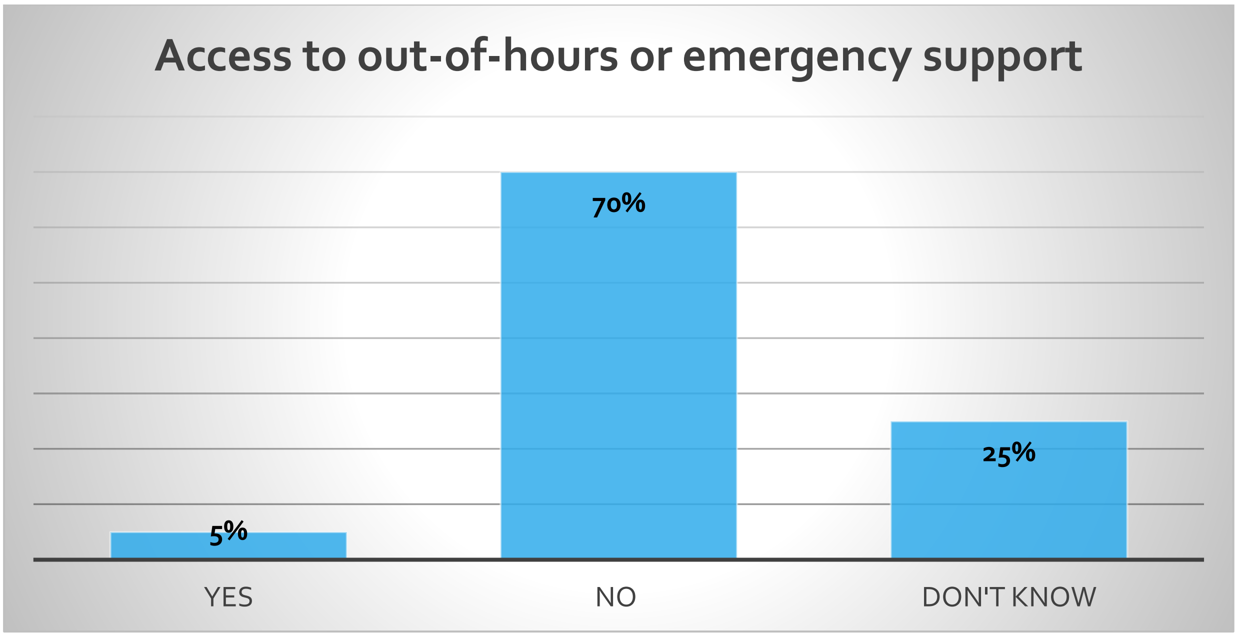
- *She attends, but she absolutely hates it. A different person every time, asking age inappropriate questions in an office setting.*
- *He hated how psychiatrists 'talked down ' to him, asked same questions every time.*
- *Very understanding about this. [not being able to attend]*
- *Staff turnover was so high, child felt unable to start from scratch over and over...*
- *At first appointment I was rudely ordered to leave the room, despite a clear arrangement having been made that I could stay for first appointment due to child's anxiety. Child became severely distressed. When mentioned later psychologist said nothing more than commenting on how he had disturbed other patients. He was unwilling to attend alone for subsequent appointments.*
- *CAMHs offer appointments at very short notice with no choice of day/time. Means that it is more likely we will not be able to attend, or struggle to arrange adequate childcare for other children, which is so stressful. If they get enough notice it would be so much easier.*
- *A new appointment was scheduled but all letters stated if refused to attend more than once would be discharged - not helpful with a child with anxiety.*

- *We haven’t attended yet since child became housebound. Referral indicated this. Parent told the intake person clinical coordinator. We won't know until the day of appointment if we can get the child out of the house. Coordinator advised to try but they only do home visits in extreme circumstances apparently!*
- *Had to go back on list*
- *They rescheduled*
- *I have now started to bring our dog whom is readily welcomed up the back steps to help relieve her anxiety at attending. I try have a phone call to update consultant before letting her so there is no talk about her in front of her and also I try arrive bang on time to avoid wait times.*
- *They discharged her*
- *We were really grateful that they made the effort to come to us when she wasn't well enough mentally to go to them.*
- *They did the meeting outside with my son when he had anxiety.*
- *New consultant threatened to discharge her but her psychologist stepped in told him her case he apologised and has since been meeting us monthly at our home and on zoom, we have been lucky.*
- *The approach varied depending on the person - one person did home visit , one offered on line and another offered parent visit.*
- *They discharged my son without telling us. If we want to be back in the system again we have to go through the GP again and wait. My son will be 18 in December. No point now.*
- *we got home visits from nurses. Home visits are great in my opinion, and should be an integral part of service not just for crisis.*
- *Removed from their service.*

2.4.5 Emergency Support

Respondents were asked whether they had access to out-of-hours or emergency support. Only 5% of respondents said yes; 70% said no and 25% said that they didn’t know.

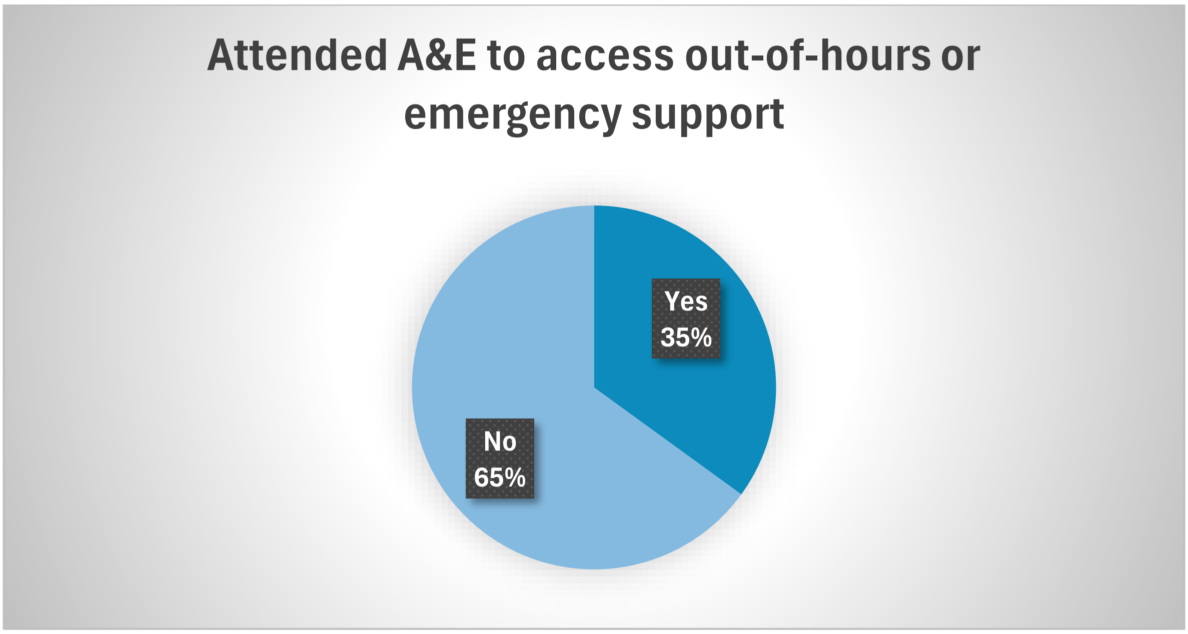
Figure 28: Access to out-of-hours or emergency support



Respondents were asked had they ever attended A&E in order to access out-of-hours or emergency support. 35% said that they had whereas 65% said that they had not.

Many comments were made about the stress and trauma that attending A&E as a means of accessing support can add to a child who is already distressed or having a difficult time.

Figure 29: Attended A&E to access out-of-hours or emergency support



Families' voices: Seeking out-of-hours or emergency support

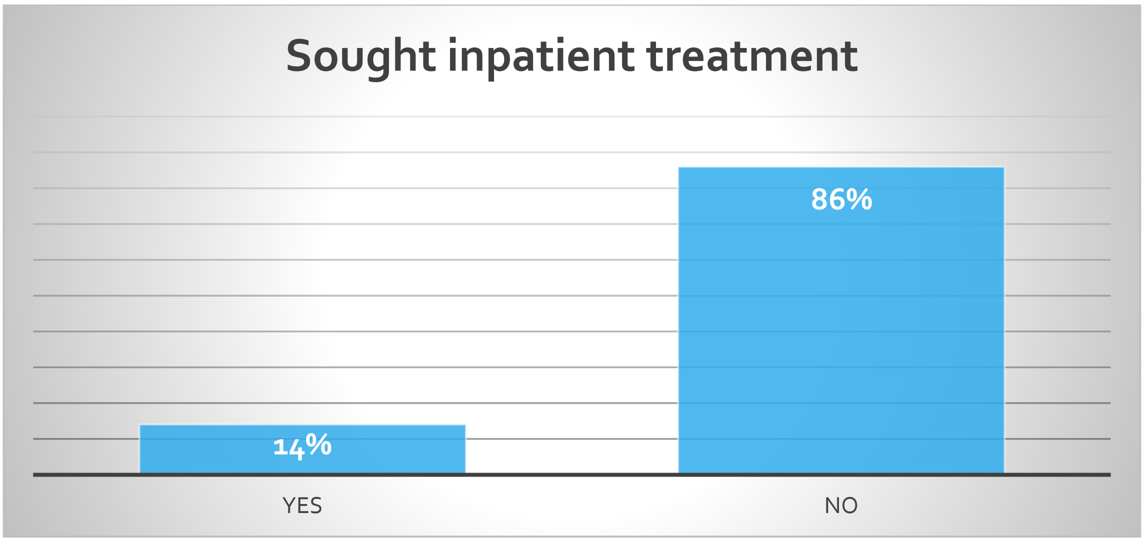
- *I have considered this [attending A&E] but felt it would be too distressing.*
- *Several times. Very traumatic way to try and access care.*

- *We had to take our daughter to A & E. Long waiting list. It added so much stress and made a bad situation worse. They did nothing at all for my daughter. Adult services available only and nothing for children or teenagers with mental health issues.*
- *Nursing staff [in A&E] were amazing.*
- *She stopped eating and we didn't know what to do as we were not getting any support from any services.*
- *Unless child was physically injured I would not bring our autistic child to A&E in UHK..and I'm a nurse that has worked there. It's in no way autistic friendly.*
- *Me, a widow, 2 kids on spectrum, told by GP bring him to A&E after she saw him in her office that day. My son was traumatised, terrible terrible experience*
- *Yes. First time told, this is a hospital for acute illness, not psychiatric illness, my child was acutely ill in a complete OCD breakdown, she was one of the most unwell children in there, they offered nothing, go home & attend CAMHS meeting. Which we did, which didn't help. Back in hospital.*
- *Had to attend multiple times but now that my child is 16 they are in adult A&E - went once after major self-harm and with suicidal thoughts but was told it wasn't the right environment for a 16 year old (they were very helpful but limited in what they could do).*
- *Yes a couple of times due to his medication been changed*

2.4.6 Inpatient treatment

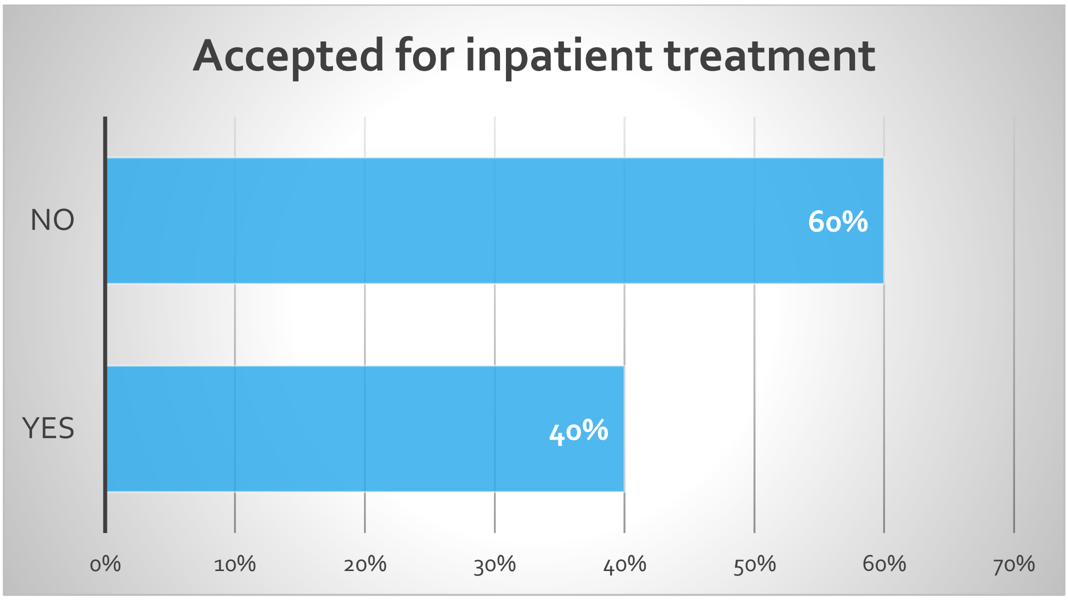
Respondents were asked whether they had ever sought inpatient treatment. 14% had sought inpatient treatment for their child and 86% had not.

Figure 30: Sought inpatient treatment



Of the respondents who had sought inpatient treatment, only 40% were accepted.

Figure 31: Accepted for inpatient treatment when sought



Families' voices: Reasons inpatient treatment was refused

- *No beds*
- *I believe they said it was "inappropriate"*
- *They said the kids in the inpatient treatment would make her worse, it was only for children with eating disorders.*
- *We were told she didn't have a psychiatric condition and wasn't suitable for the service. She took her own life within a month of this.*
- *Didn't believe he was suicidal and said the best place for him was home.*
- *Went private to Pats.*
- *[refused because of] Drug use*
- *1. The hospital doesn't treat mental illness 2. We have no private insurance so they have no place to keep them in and treat them 3. Linn Dara is the only place, its full and our kid would pick up worse habits there 4. St. Patrick's don't deal with ASD patients.*
- *They believed ASD was the underlying issue and would not consider admission until ASD diagnosis complete which took over 2 years.*
- *CAMHS said he didn't need inpatient care and he ended up in hospital on 2 more occasions in a space of 3 months after being referred to them. First for a week and then for 2 months.*

- *We were admitted for 5 days at the start of this month [April 2024] after the frequency of self-harming and talking of suicide increased...we were admitted on Wed night, seen by CAMHS Thurs (online psychiatrist) where my child was told that they have no service for her and that we could stay on a general ward. My child felt guilty and bad so asked to go home, despite telling the staff a few minutes earlier that she needed to stay...she also has issues with eating (that I have informed them of and they are escalating since the disclosure in Sept) and in the report they mention that she is overweight! I asked about medication for the ADHD to help reduce the impulsivity and intrusive thoughts...we won't be seen until May. We were offered an emotional literacy group (we have been offered this twice since Sept, when it was first offered, I discussed its suitability in light of her disclosure and CAMHS staff felt it wasn't appropriate and she needed 1:1 support, I'm still waiting.)*

2.4.7 Complaints process

Almost a quarter of respondents (23%) had submitted a complaint in respect of their experience with CAMHS.

Figure 32: Made a complaint

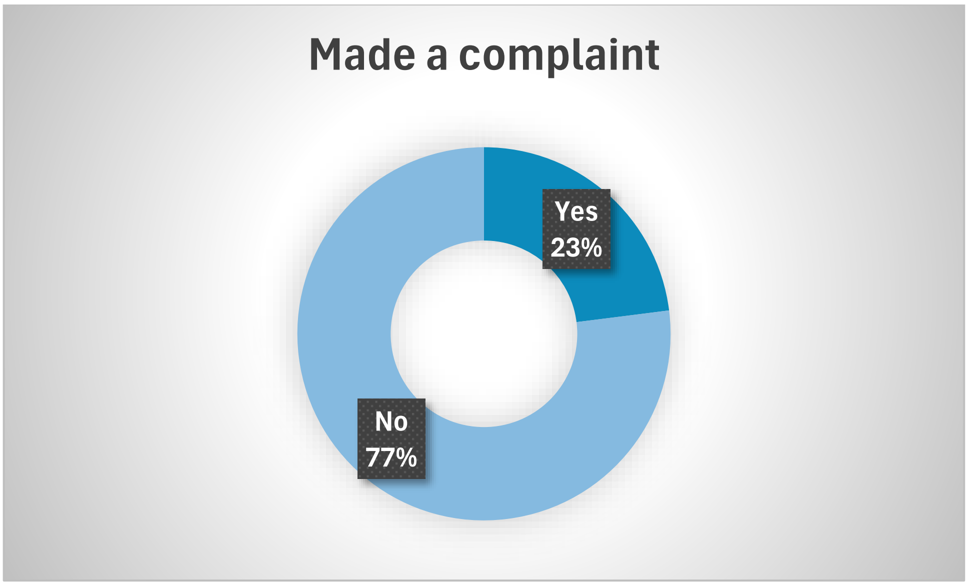


Figure 33: Experience of the complaints process

- **30% of those who made a complaint were satisfied with how the complaint was handled whereas 70% were not.**
- **28% were satisfied with the outcome of their complaint whereas 72% of respondents were not.**
- **27% found the complaints process clear and easy to navigate whereas 73% of respondents did not.**

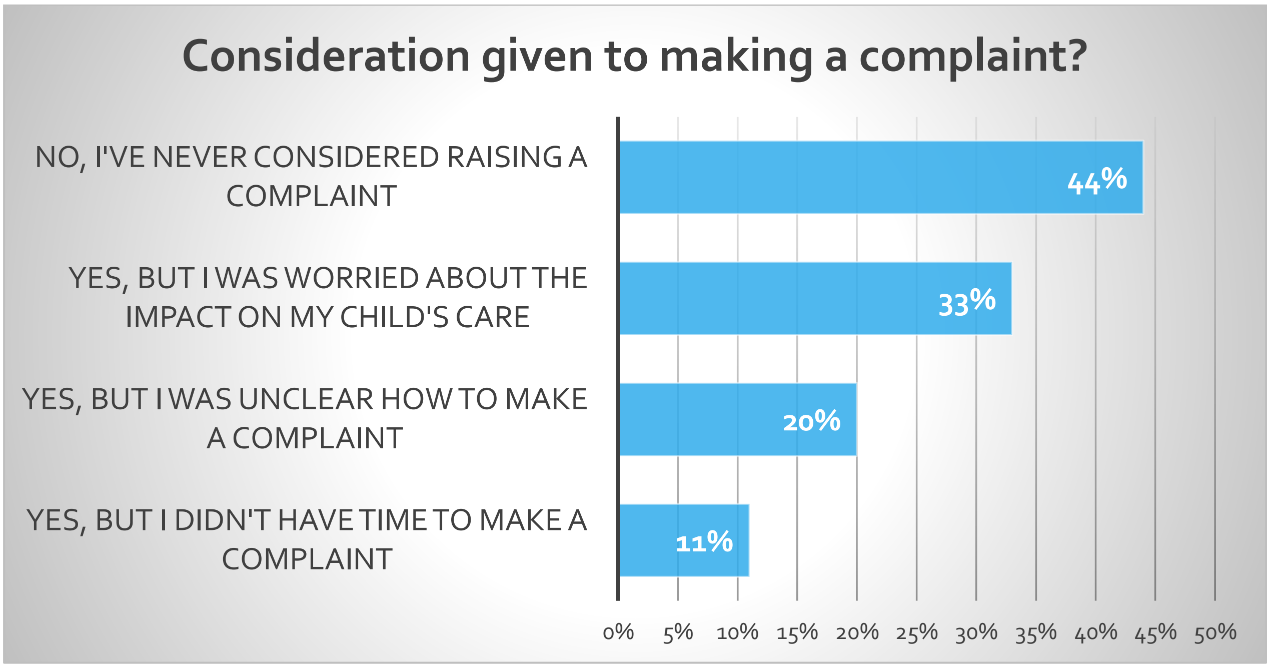
Families' voices: Experiences of the complaints process

- *Complaint September 2023, no reply.*
- *Lost documents. Being told correspondence not received until I said I had sent by registered post and also mentioned data protection. Then documents found. Went to 33 people for support in CAMHS.*
- *I complained about the poor treatment we got from a doctor and the call I got to find out more was from that same doctor. Then he sat in on all our appointments.*
- *We did not receive prior notice of complaints meeting so no warning - the letter was a normal appointment letter. The complaints meeting was with the 2 people we had complained about. There was no mediator. The room was set up with the 2 CAMHS staff (subject of complaint) at top of room in control while my husband and myself had 2 chairs pulled away down the room - as if we were the subject of a disciplinary procedure.*
- *We have escalated to the Ombudsman for Children and they are working on it now.*
- *We complained in writing directly to them in a detailed letter and they reversed their decision.*
- *Several times. Very traumatic way to try and access care.*
- *We had to take our daughter to A & E . Long waiting list. It added so much stress and made a bad situation worse. They did nothing at all for my daughter. Adult services available only and nothing for children or teenagers with mental health issues.*
- *Made a complaint to the Ombudsman for Children and HSE when she was denied a place in an inpatient unit. The HSE never responded, and the investigator at the Ombudsman for Children, while nice, said they could not make a medical facility accept someone.*

- *I was ignored, no reply.*
- *Took 6 months and eventually just come back with some comments written into our email responding to our complaints.*
- *Never heard back from HSE have your say or from the regional CAMHS manager despite being contacted many many times.*
- *Complained through HSE your say.ie. No response at all.*
- *We asked for records under FOI.*
- *We were brought into a room with 6 allied professionals and a consultant psychiatrist. After this there were always 2 people in a room one taking notes the other discussing our child. We were made feel like villains.*

Of the respondents who had not submitted a complaint, over half had considered submitting a complaint, however, 33% said they were worried about the potential impact on their child's care and 20% of respondents were unclear how to actually raise a complaint.

Figure 34: Consideration given to making a complaint



- *I strongly considered it in... Life got in the way, and I didn't.*
- *I knew how short staffed they were, and they were treating the most serious cases as a priority. Unfortunately, this meant that cases like my daughters became more serious due to no early intervention.*
- *I spoke to the social worker and they reminded me that I would be likely not to be able to get support elsewhere, even privately.*
- *Terrified of the impact since they discharged him straight away when I brought him in to speak to them about his medication.*
- *Concerned that this would further delay the referral.*
- *Decided to let it go as we had enough stress in our lives.*
- *No one cares. No system, no service, no staff.*
- *So much of our time was spent dealing with our child and the challenges we faced, we didn't have the mental energy to pursue a complaint. We gave them feedback while in meetings, but it was ignored or we were offered more forms to fill in. It was ridiculous.*
- *We spoke directly to the clinical nurse and said we never want to deal with him again and we immediately got an appointment to see a doctor in CAMHS after a year of useless advice and a referral for ASD assessment to a private therapist which turned out completely unnecessary.*
- *I wasn't mentally strong enough as all my energy was being used to care for all my children but most especially my child with ASD and anxiety.*
- *And I also believed that I would be wasting my time as nothing would be done*
- *We ended up taking legal action against Tusla regarding his overall care as he was a child in care.*
- *not so much that we didn't have time, but more that we felt it would be futile. And there was enough to deal with.*
- *I work in HSE mental health and know it is pointless*
- *Didn't believe it would make a difference*
- *Yes we have wanted to highlight the issues & challenge the 'flawed system' & what appear to be failures in just getting referral etc. But feel that it needs to be in this format, thousands of people coming together & lobbying for chance, united voices! That's why we joined Families for Reform of CAMHS*

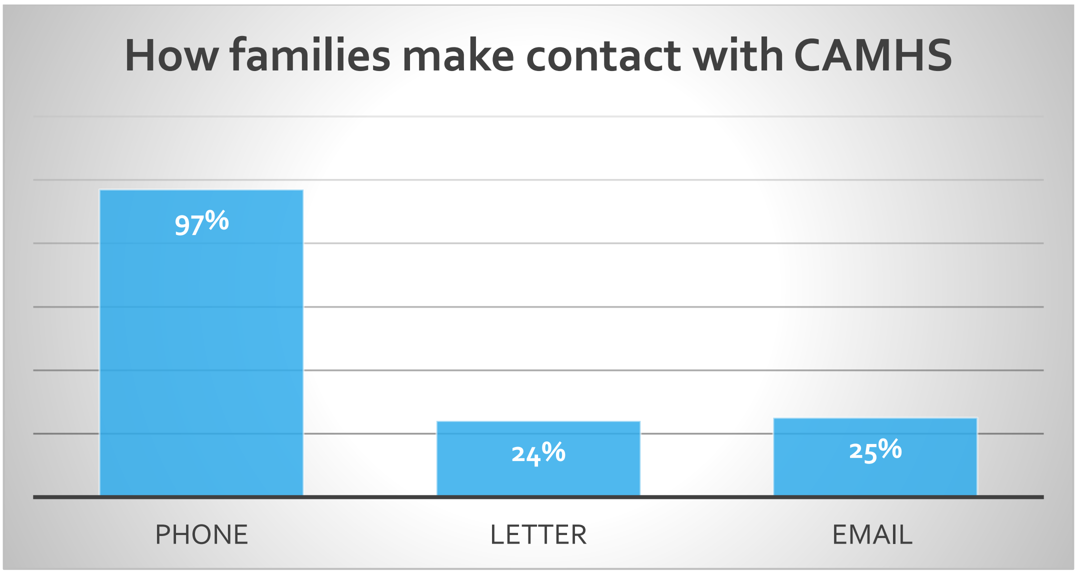
- *I have absolutely no faith in the HSE to provide any support for my children both are ASD/ADHD.*
- *I sent an email to the minister of children, his secretary replied but i am still waiting for him to reply.*
- *I am beyond exhausted and didn't feel capable to expend the energy it would have taken to fight a complaint.*
- *Afraid to rock the boat.*

2.4.8 Communication with CAMHS

This section was only asked to the 315 respondents currently with CAMHS.

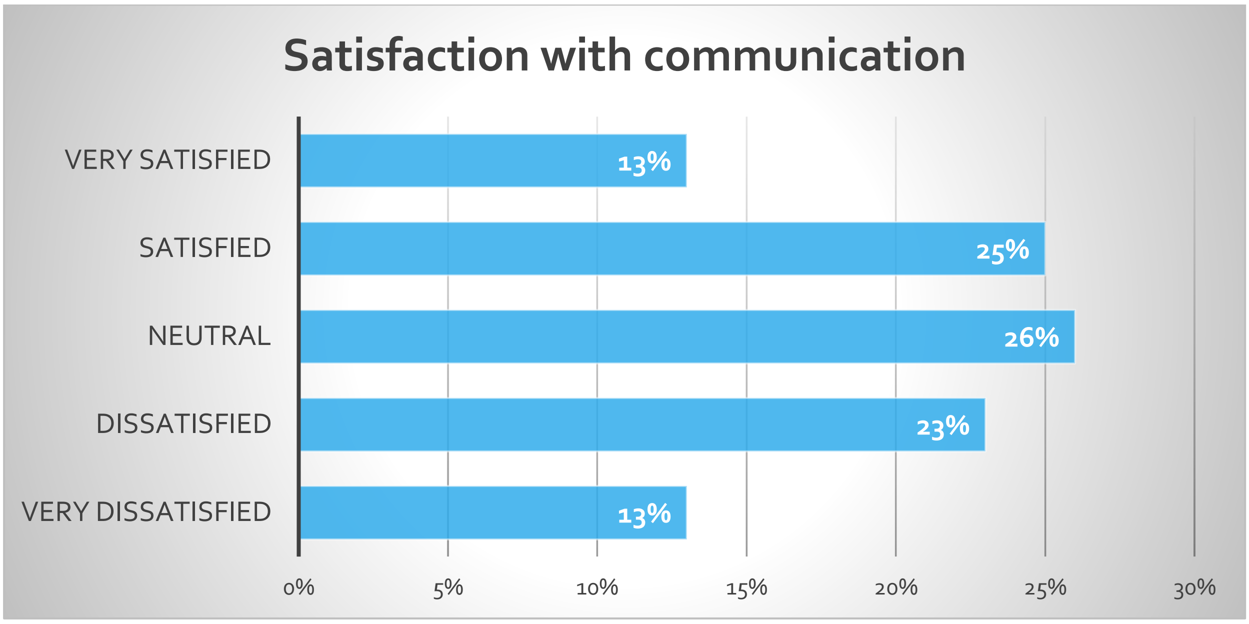
Respondents were asked how they communicated with CAMHS. The vast majority did so over the phone (97%), although it was frequently commented that it was often difficult to get through on the phone. A quarter of respondents communicated via letter and a quarter communicated via email. Many respondents mentioned that they did not have the option of email for their local CAMHS.

Figure 35: How families make contact with CAMHS



There were varying levels of satisfaction regarding communication with CAMHS, however 38% were satisfied or very satisfied; 26% were neutral; and 36% were dissatisfied or very dissatisfied.

Figure 36: Satisfaction with communication



Families' voices: Communication with CAMHS

- *I strongly considered it in.. Life got in the way and I didn't*
- *I cannot find an e-mail address and find calling on the phone frustrating as often diverted to a different office.*
- *I recently got a keyworker and their email address. In the past when I asked for the staff working with my child's email address, I was told they can't give it out because of GDPR. I know this is absolute crap as I also worked with the HSE and could guess their addresses quickly if I wanted to but I don't..*
- *I have number for key worker's mobile so I can text her*
- *Refuse to give email, even though I find this mode of communication easiest.*
- *Mostly voicemail and leaving messages for nobody to call back*
- *Can be hard to get an answer*
- *Often phone is unanswered*
- *Our CAMHS don't allow email*
- *You cannot send emails, I've asked and told I cant*
- *Have to leave a voicemail and it could be days before hearing back*
- *I can also text have one members mobile number very supportive and great at getting bk to me I would generally just ring the office*

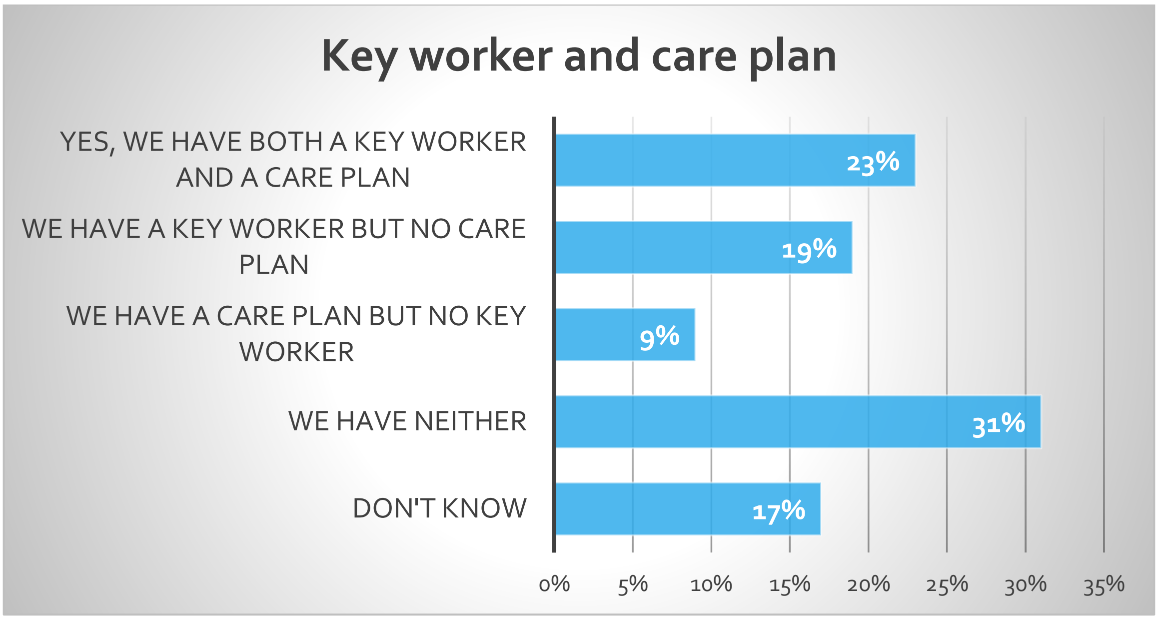
- *This varied from team to team. The original team were slow to respond. The current team are responsive*
- *When my child is unwell and was waiting to hear back from CAMHS I could only speak to the receptionist who was mostly unable to answer my questions.*
- *There is a lovely lady who works on the reception who is always very quick to answer my emails to say she will pass on to the team*

2.4.9 Key worker and care plan

This section was only asked to the 315 respondents currently with CAMHS.

Almost a quarter of respondents (23%) had a key worker and care plan and 28% had either a key worker or a care plan. 31% of respondents said that they had neither and 17% said that they didn't know if they had either.

Figure 37: Key worker and care plan



The 42% of respondents who had a key worker were asked whether the key worker assigned to their child fulfilled the role set out in the *CAMHS Operational Guidelines 2019* of coordinating care provided by the team and remaining in contact with the family. 68% said the key worker did not fulfil that role whereas 32% of families said they did.

Figure 38: Role of key worker

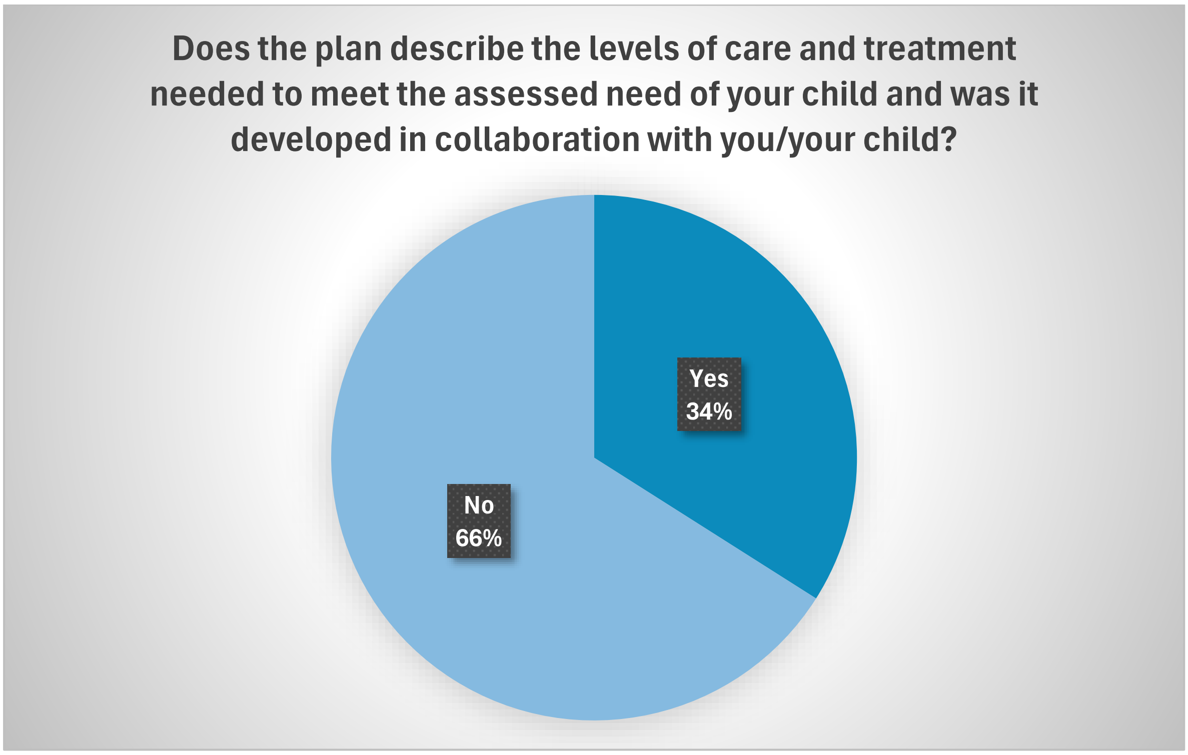
Families' voices: Role of key worker

- *We got our key worker in Mar (first one in 4 years with CAMHS). I think they told us we have a care plan, but I don't have a copy. I only got a copy of the safety plan for my child this week. We were meant to have one for months.*
- *I don't know if we have a key worker assigned.*
- *She doesn't contact me regularly, but I am able to contact her so I'm happy with that.*
- *We only see whatever doctor is in situ at the time.*
- *We are unaware of any key worker.*
- *Clinical nurse is key worker. Is up to date on all child's needs and meds etc.*
- *Never said anything about key worker or being able to contact him. Never heard anything about a care plan. Apparently, they just 'roll' without any reviews*
- *Never see them.*
- *No idea*
- *Not formally communicated but we find it very easy to access her care team.*
- *At first, we didn't know anything about a key worker till someone on a Facebook.*
- *group advised us. Since we complained we got sorted.*
- *I haven't talked to the keyworker in years.*
- *I think we have a key worker but I'm not sure.*

- *We didn't even know we had a key worker I asked at app who I can contact to support letters etc and the Dr said me I'm his keyworker. This was after a year I never knew*

The 32% of respondents who had a care plan were asked whether the care plan developed for their child described the levels of care and treatment needed to meet the assessed need of the child and was developed in collaboration with the family/child as set in the *CAMHS Operational Guidelines 2019*. 34% of respondents said their Care Plan did meet the description provided by the CAMHS Operational Guidelines and 66% said it did not.

Figure 39: Details and development of care plan

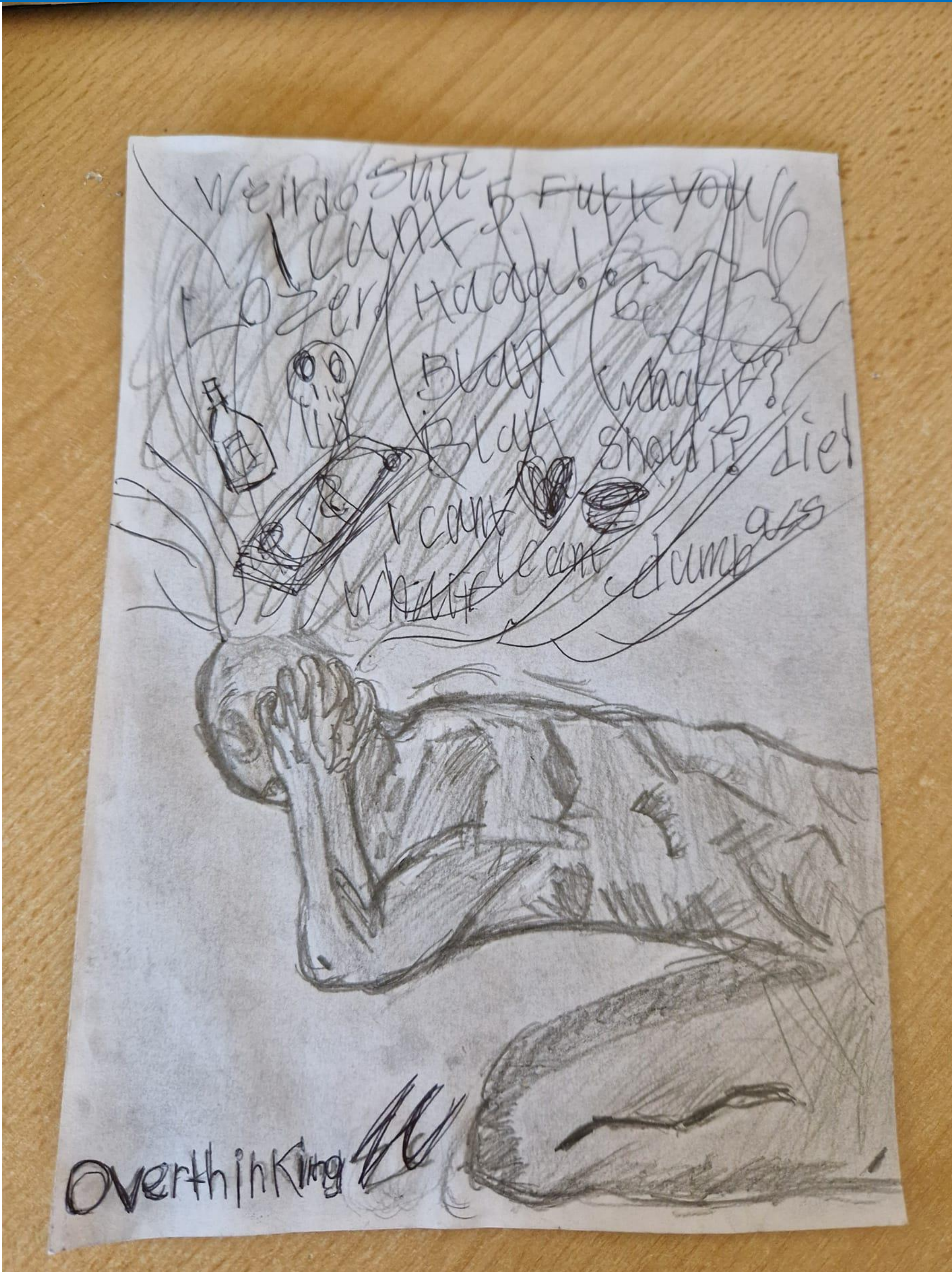


Families' voices: Care Plan

- *I have never seen a care plan.*
- *They made the plan and we signed. I was happy to follow what they thought was best.*
- *No, it's a standard care plan with just his name on it and for us to sign it.*
- *I don't know but I'll be finding out.*
- *If she has a care plan, I am not aware of one and have never seen one.*
- *We have not seen the care plan I'm assuming my child has one because my child been prescribed medication.*

- *Never heard of a care plan just monthly appointment*.
- *It is quite short and vague*.
- *A care plan was received after 3 months but recommend OT and SLT along which have not been given*.

Step 5: Leaving CAMHS

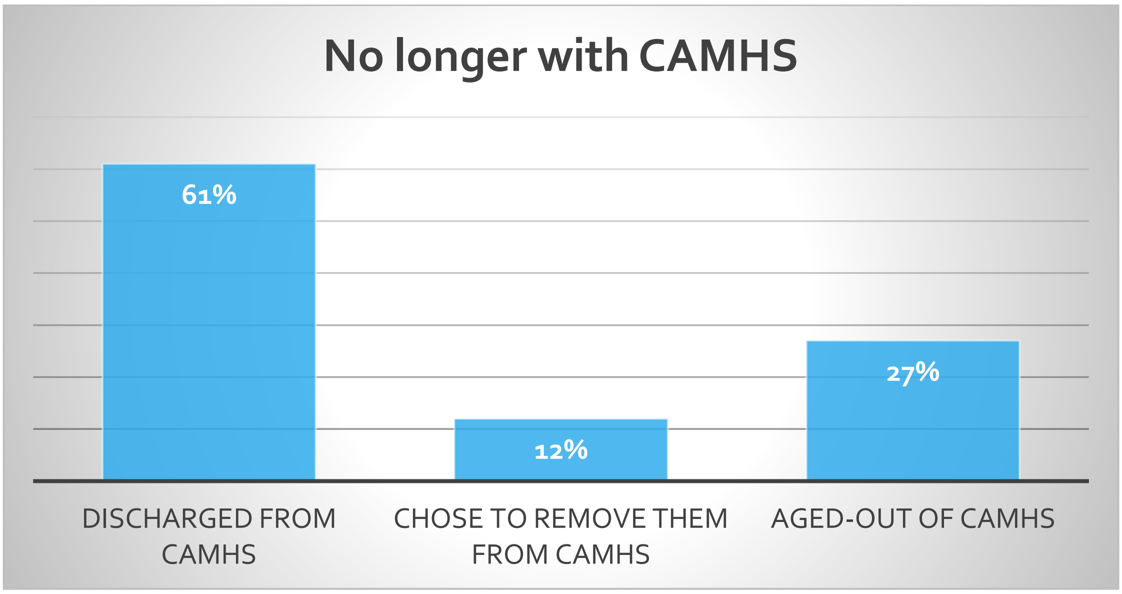


Step 5: Leaving CAMHS

This section details families' experiences of leaving CAMHS and is made up of information provided by 196 respondents. The children of 166 respondents are no longer with CAMHS and the children of 33 respondents used to be with CAMHS and are currently seeking support again.

61% of children who left CAMHS were discharged from CAMHS; 27% of children 'aged-out' and left the service when they reached the age of eighteen; and 12% of children and their families chose to remove them from CAMHS.

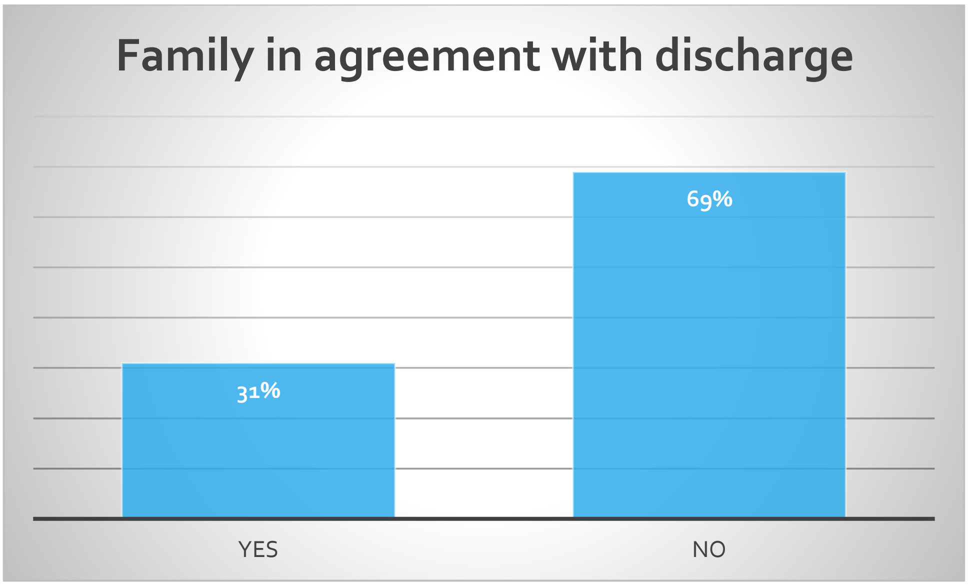
Figure 40: No longer with CAMHS



2.5.1 Discharged from CAMHS

Over two-thirds of respondents were not in agreement about their child being ready to be discharged from CAMHS (69%) whereas 31% of respondents agreed with the timing of their child's discharge.

Figure 41: Family in agreement with discharge



Families' voices: Discharged from CAMHS

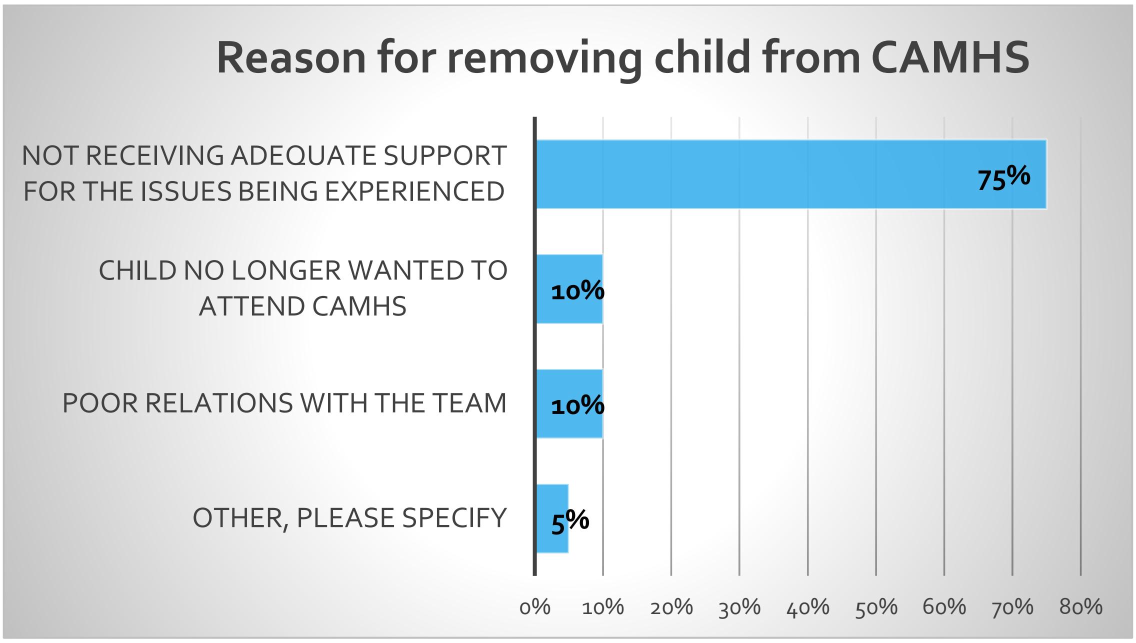
- *In hindsight I should have asked what support there would be going forward especially as we are now seeking help again for the same issue*
- *Against my pleas and they left me in bits and just didn't consider my child was high risk*
- *It didn't matter what we told the psychiatrist as she kept saying that everything was positive. We told her about eating difficulties (our CDNT psychologist described it as straying into eating disorder territory) and her developing agoraphobia. She just kept saying that our daughter was better and how wonderful it was to discharge her. It was as if she was following a script. She wore us down as we were so tired fighting for help which we never got in over 2 years.*
- *When they suggested he be discharged I agreed because I didn't think the service was much help.*
- *Discharged as suspected ASD. At the time my daughter then 10 was depressed, severe anxiety, school avoidance, suicidal ideation.*
- *We did not want to proceed with medication. We wanted more info. Child had completed MONTHS of PRIVATE therapy while waiting and was in a good place.*
- *We weren't given an option really. Once no medication, no appointments!!*
- *Discharged despite being referred this time for self-harming. Reason given was that autism is suspected.*

- *Was told that because I chose not to medicate my child there was nothing more, they could do for her.*
- *Discharged despite my objections.*
- *Discharged at 14 as we declined medication, nothing else offered in 3 years before that.*
- *Not at the time, as we knew there was nowhere else to go. Community psychology insisted CAMHS were the only service to deal with school-related anxiety. However shortly afterwards, on reflection, we were happy and relieved to be discharged as we were extremely dissatisfied with the service. In hindsight we were enduring a terrible and damaging service as we were desperate. The reasons given for the discharge did not make any sense.*
- *He did not want to participate from the beginning and they were not assisting, it felt like a mutual decision but we were unhappy that the services didn't do more to get through to him, it felt like they didn't try to help.*
- *We were told if she wouldn't take meds she was being discharged*

2.5.2 Removing child from CAMHS

Three-quarters of respondents who had removed their child from CAMHS said they did so as they felt their child was not receiving adequate support for the issues being experienced.

Figure 42: Reason for removing child from CAMHS



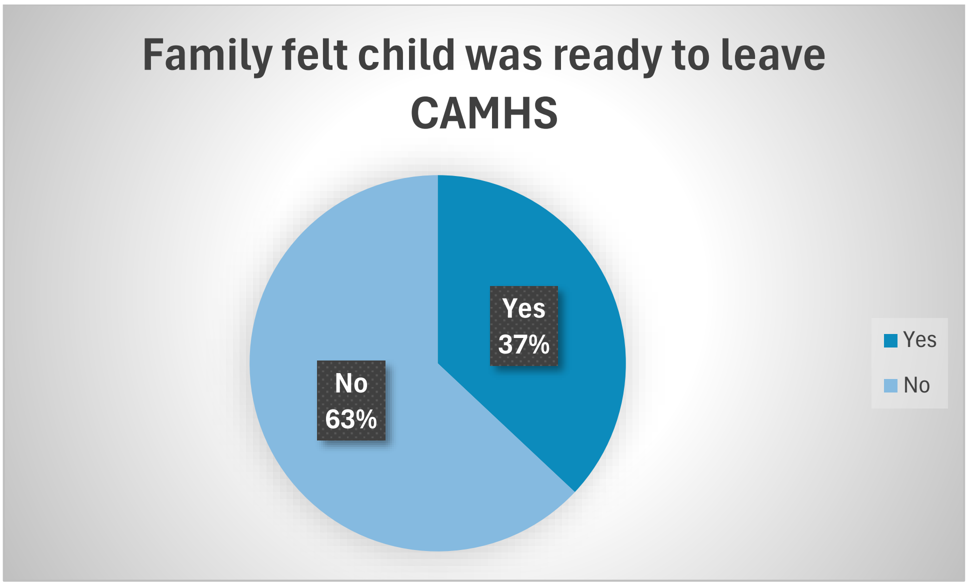
- *Out therapist was leaving we were happy to finish at same time. Did not want someone new.*
- *Child no longer wanted to attend. Therapy offered was inappropriate and ineffective.*
- *They refused to consider other reasons for his behaviour and self-harm.*
- *It became clear they were not going to do anything, and the meetings were leaving our daughter worse each time, so we had to leave.*
- *We could not see any benefit from our son attending CAMHS. Initially he was supposed to receive support from an OT and a speech and language therapist through CAMHS but learned that there were none available. My son had about 7 appointments all together with CAMHs and during this time was seen by 5 different members of staff which made it difficult for him to develop a relationship with them.*

2.5.3 Aging out of CAMHS

Respondents were asked did they feel their child was ready to leave CAMHS at the age of 18. 37% of respondents felt their child was ready whereas 63% did not. Respondents mentioned the disruption and impact that being discharged at eighteen had, especially as it often took place during the child's Leaving Cert year.

Half of children who aged-out of CAMHS went onto adult service and half did not. In some cases families were happy for their child to be discharged to the GP who would manage medication going forward. However, for a sizeable proportion of respondents they just haven't been able to access adult services and have been told there was "no transfer pathway", "they do not deal with ADHD patients", or they were on the waiting list for adult services.

Figure 43: Family's feelings about child leaving CAMHS at 18



Families' voices: Aged out of CAMHS

- *No details of these provided [adult services] and no referral given.*
- *Psychiatrist said not bad enough to need adult referral. That GP could manage medication going forward.*
- *Referred back to GP.*
- *One of my young adult children was refused adult services after a GP referral. My young adult children have been without support since aging out of CAMHS.*
- *Only just moved to adult services my child finds it extremely daunting and frustrating she feels she's starting again.*
- *Referred on to adult mental health services who later contacted me to say that they do not deal with ADHD patients and advised I go privately to a doctor who can continue to prescribe my daughter medication for her ADHD!!*
- *We have been on wait list for adult service and GP is now giving scripts for ADHD as my son is sitting his leaving cert. I begged to stay in CAMHS until he finished school and told no.*
- *CAMHS felt adult services were not needed and discharged them to the GP. One of my young adult children was refused adult services after a GP referral. My young adult children have been without support since aging out of CAMHS*
- *Still waiting [for adult services] ...5 months later and still have not heard anything. Medication not being monitored*

- *There are no Adult ADHD services in my area.*
- *Very disjointed, no proper handover and we returned to A&E after CAMHS discharge.*
- *Transfer to adult services was never an option, no predictability or consistency in term of personnel. No choice to ensure neuroaffirmative practitioner.*
- *The experience in AMHS has been exceptional.*
- *Awful [experience with AMHS]. She discharged herself. No understanding of eating disorders. Expected to adjust to adult services immediately and told she was too quiet.*
- *Had to wait nearly 1 year for follow on therapy… no file given to adult services.*
- *The transition was lengthy, we spent time without public care, and did some financially crippling private care. When we got into adult services they were, for the most part, obviously superior.*
- *AMHS has been excellent.*
- *Non-existent [transition to adult services], she was given all these diagnoses and then nothing just left to deal with it all.*
- *It was a straightforward transition but because of covid appointments were over the phone and my son was not able for it. So, he left.*
- *Wait was about 6 months to access adult services, having to ring them myself constantly plus a visit to A&E to access quicker. See a psychiatrist every few months, trying to access therapy plus the eating disorder team is the battle.*
- *Adult services have been much better than CAMHs.*
- *Better and safer [adult services]*
- *Just medication management has been offered [by adult services] no other supports.*
- *We had to go to the GP to get referred to adult services and in the meantime pay for a private psychiatrist.*

Section 3: Experiences of certain groups of children with CAMHS

Section 3: Experiences of certain groups of children

3.1 Experiences of autistic children

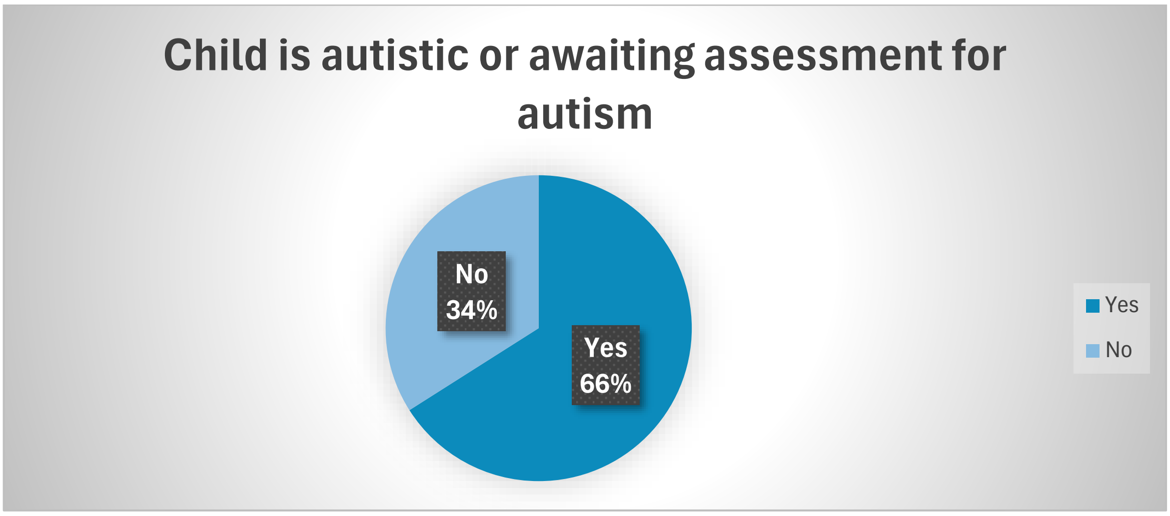
Information provided in this section is based on the experiences of 300 autistic children who are currently with or who have been with CAMHS.[16]

Out of all the children captured in the survey who are with or who have been with CAMHS, 66% are autistic.

The high representation of autistic children in the survey could potentially be explained by a number of overlapping factors, including:

- Autistic children disproportionately experience mental health issues with approximately 70% of autistic children having at least one co-occurring psychiatric condition[17]. Autistic children are also 28 times more likely to consider suicide[18];
- *Families for Reform of CAMHS* has been widely promoted and discussed amongst autism groups on social media; and
- Many of the members of *Families for Reform of* CAMHS believe their autistic child has been discriminated against in the provision of mental health services resulting in them potentially being more likely to join a campaign for reforming CAMHS and complete this survey.

Figure 44: Child is autistic or awaiting assessment for autism



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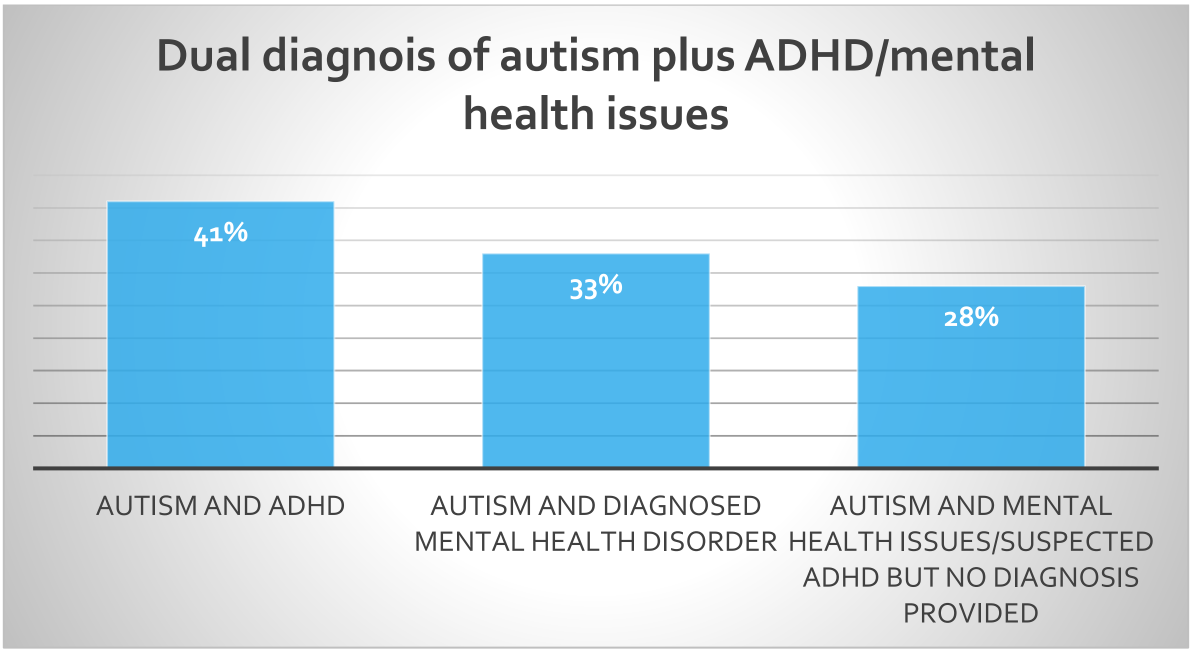
[16] While overall 439 children in the survey are autistic, only 300 of them have made it past the referral and waiting list process.

[17] 70% of autistic children will have at least one co-occuring psychiatric condition and 41% will have two or more: Young et al: *Guidance for identification and treatment of individuals with attention deficit/hyperactivity disorder and autism spectrum disorder based upon expert consensus, 2020* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7247165/#CR4; Autistic children are 28 times more likely to consider suicide Final Report of the Joint Committee on Autism June 2023

[18] Final Report of the Joint Committee on Autism June 2023

Amongst autistic children captured in the survey, 41% had a dual diagnosis of autism and ADHD; 33% had a dual diagnosis of autism and a mental health disorder; and 28% had suspected ADHD or mental health issues but had not received a formal diagnosis.

Figure 45: Dual diagnosis of autism plus ADHD / mental health issues

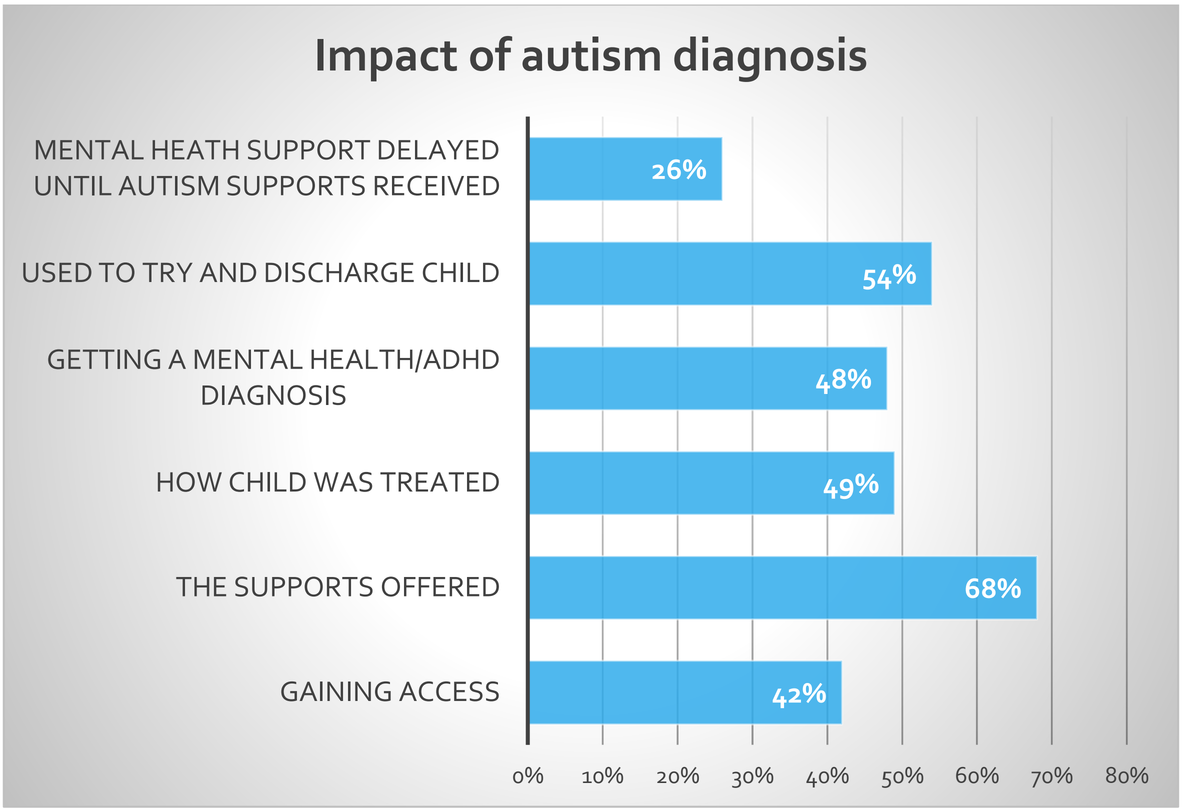


Families views on impact of having an autism diagnosis in CAMHS

70% of respondents with an autistic child felt that being autistic negatively impacted access to CAMHS and/or the mental health supports offered. When this was questioned further, respondents felt that a diagnosis of autism:

- impacted the supports received **(68%)**;
- was used to try and discharge the child **(54%)**;
- impacted how the child was treated **(49%)**;
- reduced the likelihood of getting a diagnosis of a mental health disorder or ADHD **(48%)**;
- prevented access to the service **(42%)**; and
- was used to delay receiving mental health supports until they first received autism supports **(26%)**.

Figure 46: How having an autism diagnosis in CAMHS was experienced by families



Key differences in the treatment of autistic children identified in the survey

A filter was applied to the overall survey results to differentiate the experiences of CAMHS between autistic children and children who are not autistic. A number of key differences were found:

- **It takes longer for a referral of an autistic child to be accepted by CAMHS:** 66% of the referrals of children who are not autistic were accepted on first referral compared with 50% of the referrals of autistic children.

- **An autistic child is more likely to end up in A&E while on the waiting list:** While both groups of children overwhelmingly experienced deterioration of their mental health while on the waiting list, a slightly higher rate of autistic children ended up in A&E while on the waiting list (40%) compared with children who are not autistic(34%).

- **An autistic child is less likely to be offered more than five therapy sessions:** While autistic children and children who are not autistic are as likely to be offered up to 5 therapy sessions, a lower number of autistic children were offered more than 5 therapy sessions (20%) compared with children who are not autistic (25%).

- **An autistic child is less likely to be offered CBT-E or FBT when dealing an eating disorder and families are likely to feel a lot less supported:**
  Despite higher proportions of autistic children experiencing an eating disorder (28%) compared to children who are not autistic (17%) only 32% of autistic children had been offered either CBT-E or FBT compared to 52% of children who are not autistic. 26% of families whose child is not autistic with an eating disorder felt adequately supported with their child's eating disorder compared with only 12% of families with an autistic child with an eating disorder.

- **Families are less likely to feel supported with their child's suicidal ideation/ intent if their child is autistic and an autistic child is more than twice as likely to be turned away from CAMHS than a non-autistic when experiencing suicidal ideation/intent:**
  33% of families of a child who is not autistic felt adequately supported with their child's suicidal ideation/intent compared to 23% of families of an autistic child. 18% of children who are not autistic had been turned away from CAMHS despite experiencing suicidal ideation/intent compared to 42% of autistic children.

Families' voices: Experiences of autistic children

- *"We don't deal with autism."*
- *Tried to refuse as ASD. GP kept re-referring.*
- *Passed back and forth between services - too autistic for one and too anxious for the other.*
- *I have been told that they don't 'do autism'.*
- *CAMHS point blank said 'we do not treat autistic individuals, you must 'fight' to get disability services'. Disability services had no counselling suitable for mental health issues being experienced.*
- *Told primary diagnosis is autism, so don't want to know what else is going on.*
- *We have queried ADHD but we're told 'not to complicate things'.*
- *Refused referral because told that my child needed better supports to learn and deal with his ASD diagnosis, but I had been bringing him to private OT and psychotherapy for 12 months and had provided a space to discuss and learn about ASD at home. Really felt like the ASD was being used against us.*
- *Putting issues down to autism without much investigation. Fighting tooth and nail just to get them seen, still not getting help or support, issues getting worse.*
- *Was told all her problems were ASD related.*

- *He’s autistic and it was ‘just his autism’.*
- *We are not telling them that we are getting autism assessment done.*
- *Once I paid and had assessment completed, we were told she had a disability not mental health issues and were discharged.*
- *It WAS used to discharge our child.*
- *I was told that my child needed support with issues caused by autism. I said the challenges he was facing were not autism, rather mental health, but I was told to seek support for his autism. I felt this was discrimination and wrote a complaint.*
- *They were not diagnosed when we accessed the service but as soon as it was suggested they told us they can’t support autistic children and ‘that was that’. Very poor of them.*
- *My middle child hasn't been assessed for any other mental health issues, everything is been put down to her been autistic. I believe there might be more. They will not assess for anything.*
- *We've been advised to just not mention it [autism diagnosis].*
- *It affected how the child was treated - in that they were handling things like it was all due to being an autistic person. They didn't get a diagnosis from CAMHS even though it was suspected. Diagnosis came from mental hospital shortly after leaving CAMHS.*
- *Hasn’t affected our access in any way.*
- *Psychiatrist kept saying ‘oh that’s the autism’.*
- *Every issue was blamed on ASD diagnosis and each appointment they tried to discharge us.*
- *From the first appointment everything was put down to autism. I demanded to see psychiatrist who then put everything down to normal anxiety due to autism, including hallucinations. On threatening to throw himself out a third- storey he advised finding a window company to lock the window from outside.*
- *No supports only medication. As he is autistic we are told that he should be receiving support from CDNT.*
- *Supports have been cut whilst awaiting autism assessment.*
- *When we moved, we were transferred to a new CAMHS Team. They tried to say the old CAMHS team had got it wrong and all my daughter’s behaviours were down to autism. This was very distressing for us.*
- *I feel it delayed psychology supports and had to fight for that. Ignored ADHD red flag traits. Everything was put down to autism.*

- *Told ASD was not diagnosed or treated in CAMHS even though it was anxiety and depression we sought help for.*
- *On the second referral to the ADHD clinic I explained regardless of the ASD they had a duty of care towards my child. She was pushed to the side for years.*

Within the responses provided for families' voices, some common themes are evident, with many families feeling that:

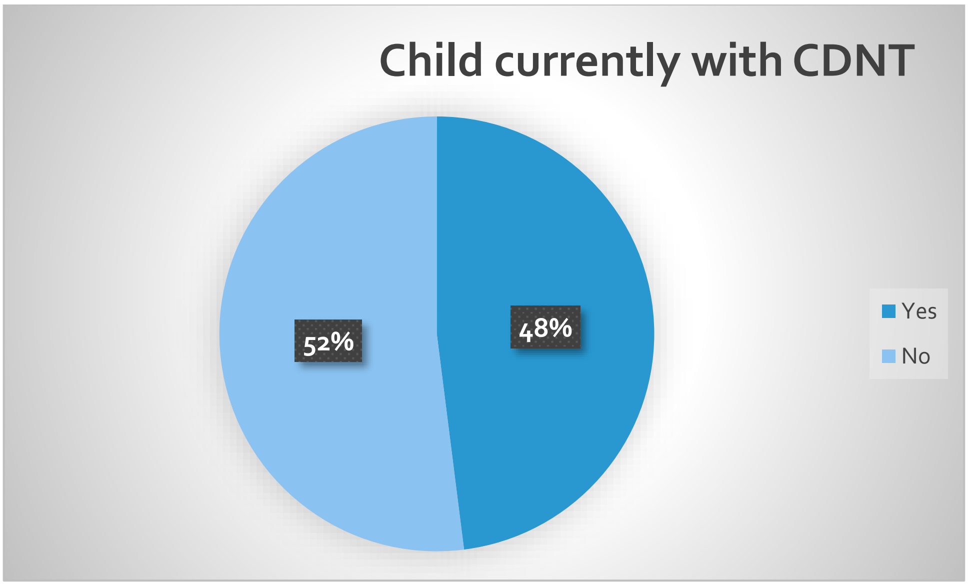
- the diagnosis of autism was used against their child to not offer supports or a differential diagnosis.
- CAMHS explained away anxiety/depression as just being 'part of ASD' rather acknowledging and offering support for the mental health issues being experienced.
- support was withdrawn once a diagnosis of autism was disclosed.

Similar to many experiences covered in this report, experiences varied widely and it is important to note that 30% of families reported that there was no negative impact or treatment based on their child being autistic.

Child and Disability Network Team

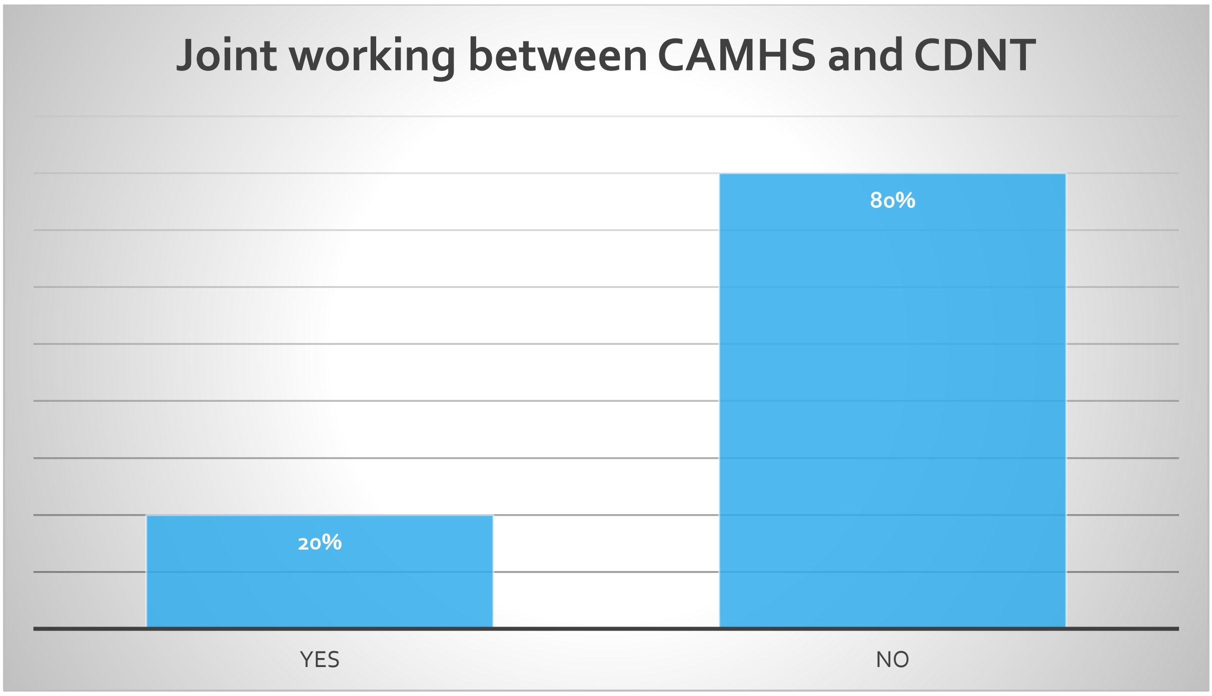
48% of autistic children whose experiences are captured in this survey were also with their local Child and Disability Network Team (CDNT) whereas 52% were not.

Figure 47: Child currently with CDNT



Of the families whose children were with both CAMHS and CDNT, only 20% had experienced any joint working between the two services.

Figure 48: Joint working between CAMHS and CDNT



Families' voices: CDNT and CAMHS

- *She's been awaiting CDNT for 6 years.*
- *They [CDNT] closed our case. Appealing for them to open again. CAMHS are 'advocating' he gets counselling around being autistic.*
- *Signed off from CDNT and referred to CAMHS. After a lengthy waiting list we received a letter from CAMHS saying child not a fit for CAMHS and they referred her to Child Psychology. Six month on that waiting list and received a letter from them saying 'not a fit for child psychology' and referred back to CAMHS. 18 months now and no appointment with either.*
- *CDNT have met him once. First referred 10 years ago.*
- *We've been left completely in the fog. I guess we're with CDNT as we know he's on a waiting list for psychological review - has been for more than 2 years.*
- *CAMHS currently advocating for my child to access CDNT services as CDNT said can't work with our child as with CAMHS.*
- *CDNT will not treat. St Patrick's won't admit. Primary care won't treat. We are totally left alone with a child intent on suicide.*

- *CDNT did see both of my daughters briefly but discharged them as they said that their needs were not 'complex' enough.*
- *CDNT did see both of my daughters briefly but discharged them as they said that their needs were not 'complex' enough.*
- *Discharged by CAMHS in November 2022 with reason that they suspect ASD diagnosis will come later and they knew we were on private waitlist for assessment. At this point my daughter was suffering from extreme anxiety, depression, suicidal ideation and school avoidance. Referred back to CAMHS three times for assessment for medication for anxiety by GP and refused. On waiting list for primary care. Refused by CDNT (would not accept referral from CAMHS for ASD assessment).*
- *We were constantly told that the other service needed to support him.*
- *I feel joint working has lessened since the Maskey report. We get quoted GDPR a lot as a reason they won't share info. They will give me a letter to share rather than send it themselves.*
- *We have tried through Meitheal process. Very unsatisfactory result. CAHMS discharged our child at the meeting (via Zoom).*
- *Both have been at multi-service meetings. Each service says the other service needs to do more.*
- *Our CDNT psychologist sought help for eating disorder and CAMHS sent information – but it was very scant and useless.*
- *The one psychiatrist who did the home visits was also the only one who engaged with CDNT and once she left after 12 months it all stopped.*
- *Despite claims of writing to each other, no such letters or correspondence exist on file.*
- *CAMHS and CDNT work well together in X. We have been to both and not discharged from CAMHS for doing so.*
- *[Worked together] through Meitheal process.*
- *CAMHS psychologist and CDNT psychologist met up with us as parents, said things would be put in place and nothing happened.*
- *Met but only for both to debate who is taking my son's case.*
- *Just one pushing our care onto the other leading to no support.*
- *On a few occasions I requested multi-disciplinary get-together to discuss my child but they declined saying that they don't work on a cross-over basis.*

- *There was previously, up until we moved. The new CDNT aren't great at engaging with CAMHS. I must stress that CAMHS have wrote to them several times to open the lines of communication.*
- *CDNT tried advocating for our teen, CAMHS refused to listen as they don't accept ADHD diagnosis from private and VHI.*
- *CAMHS had been trying to get a joint meeting with CDNT and EWO to help with her school avoidance issues but no answer from either service.*
- *Both services like to " blame " each other and we are bounced back and forth between services with no real support.*

3.2 Experiences of children with an intellectual disability

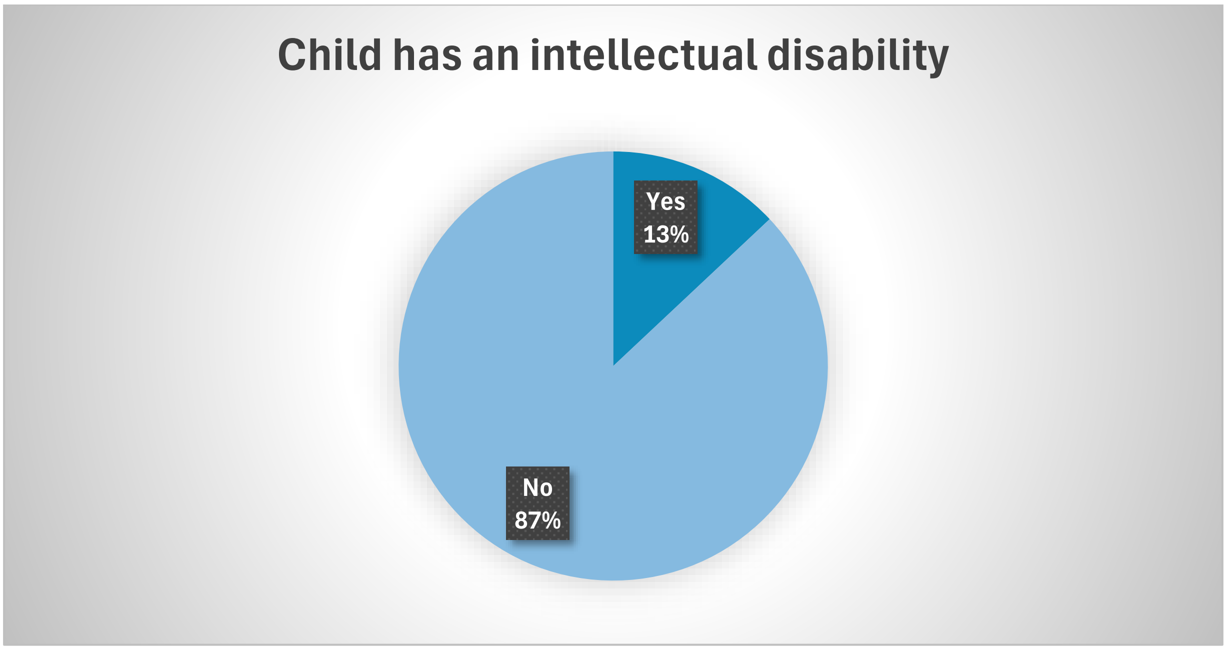
Information provided in this section is based on the experiences of 60 children with an intellectual disability who are currently with or who have been with CAMHS.[19] Out of all the children captured in the survey who are with or who have been with CAMHS, 13% have an intellectual disability.

While for the other groups of children captured in this survey it is clearer when a child is "with CAMHS", for children with intellectual disabilities it is less so. After a child with an intellectual disability makes it through the referral and waiting list process, they may then find themselves in a limbo of sorts and without access to mental health supports if they live in an area where there currently is no CAMHS-ID service in place.

The CAMHS-ID model was launched in September 2022 with the objective of setting up 16 teams across the country for children with intellectual disabilities. At present, there are only four to five partial teams. Each of the 16 teams should have 11 fulltime staff. The reality is that there are 10 consultant psychiatrists who either have no staff or only one/two team members.

The consequence of the lack of service is sorely felt by respondents. Children with intellectual disabilities are refused by CAMHS on the basis that their child should be seen by CAMHS-ID, even when there is no access to a CAMHS-ID service in their area.

Figure 49: Child has an intellectual disability



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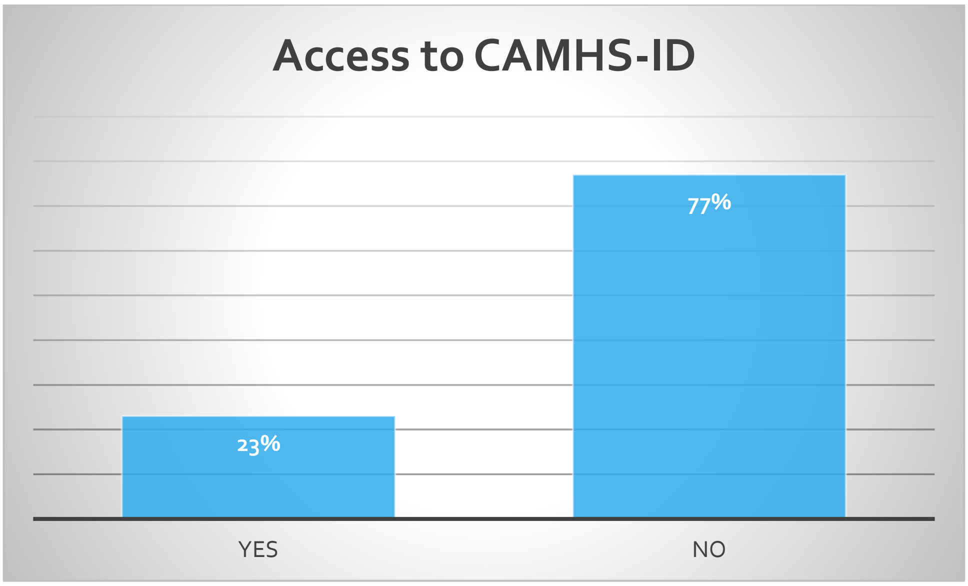
[19] While overall 76 children in the survey have an intellectual disability, only 60 of them have made it past the referral and waiting list process.

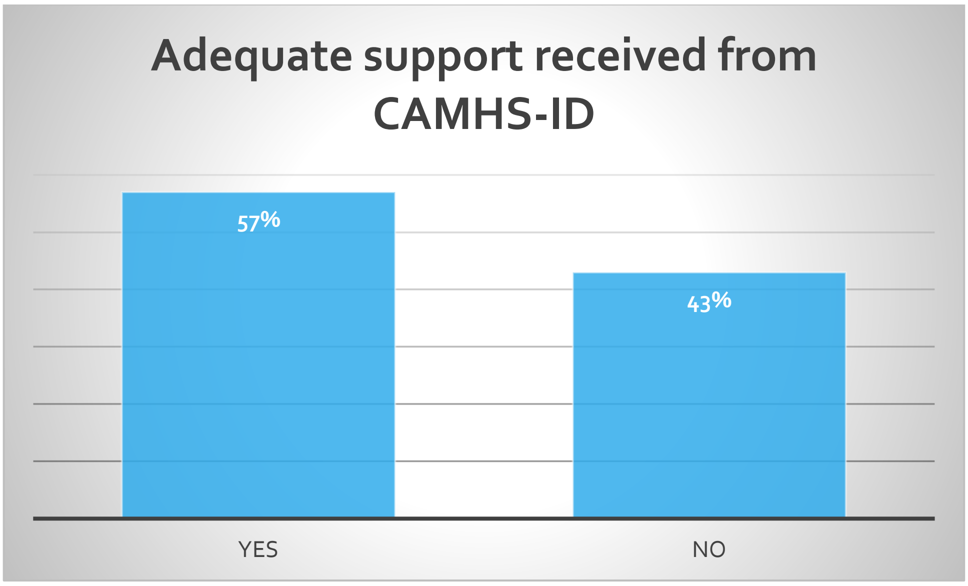
Out of the 60 children whose experiences are captured in this section, less than a quarter of them had access to a CAMHS-ID service. Over three-quarters of children had no access to a CAMHS-ID service.

Figure 50: Access to CAMHS-ID



Of the families who had access to a CAMHS-ID service, over half felt they were receiving adequate support (57%) and less than half felt that they were not (43%).

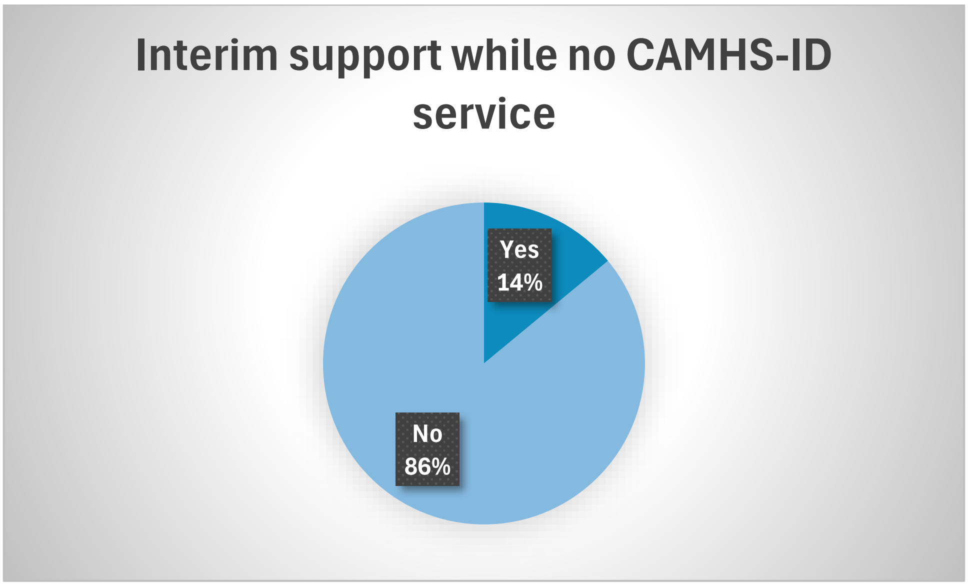
Figure 51: Support from CAMHS-ID



For those families who do not have access to a CAMHS-ID service, only 14% are receiving any interim support. 86% of families are receiving no support at all.

It is important to note that this is contrary to the position stated by the HSE: "*There are some areas where difficulties in staff recruitment have contributed to areas not fully developing CAMHS-ID team. In those areas, local arrangements are in place such as consultant psychiatrists providing a consultative service.*"

Figure 52: Interim support while no CAMHS-ID service



Families' voices: Intellectual Disabilities

- *Some very biased comments were used which I used to dwell on.*
- *You're very much on your own.*
- *The new CAMHS ID team were abysmal. After we complained, it was agreed we'd move back to our old CAMHS team, even though we are outside the catchment.*
- *Medication only.*
- *We were also told they have no-one who can see him due to his intellectual disability. There is no CAMHS ID in my county. So because of my child's ID diagnosis and where we live, basically his mental health is not being treated. This is a violation of his human rights and discrimination as far as I'm concerned.*

Key differences in the treatment of children with intellectual disabilities identified in the survey

A filter was applied to the overall survey results to differentiate the experiences of CAMHS between children with intellectual disabilities and those without. A number of key differences were found:

- **It takes longer for a referral of a child with an intellectual disability to be accepted by CAMHS.**
  46% of the referrals of children with an intellectual disability were accepted on first referral, compared with the overall average in the survey of 56% of first referrals being accepted.

- **With the lack of CAMHS-ID services in place, families who have a child with an intellectual disability are twice as likely to go their local politician or to go to the media to try and access support for their child.**
  30% of families with a child with an intellectual disability have sought support from a local TD, councillor or senator compared to the overall average in the survey of 15% of families. 10% of families with a child with an intellectual disability have gone public in an attempt to access support compared with the overall average of 5%.

- **For those children with an intellectual disability who are autistic, there were higher reports of negative impact arising from an autism diagnosis than reported by families of autistic children without an intellectual disability.**
  Three-quarters of children with an intellectual disability in this survey are autistic. Of this group:
    - 58% reported difficulty gaining access to CAMHS due to having an autism diagnosis compared with 42% of families who have an autistic child without an intellectual disability.
    - 59% reported difficulty getting a mental health/ADHD diagnosis compared with 48% of families who have an autistic child without an intellectual disability.
    - 65% reported autism being a reason used to try and discharge their child compared with 54% of families with an autistic child without an intellectual disability.

- **Children with an intellectual disability are more likely to be discharged from CAMHS in their first six appointments compared with children without intellectual disabilities.**

42% of children with intellectual disabilities were discharged from CAMHS within the first six appointments, compared with 30% of children without intellectual disabilities.

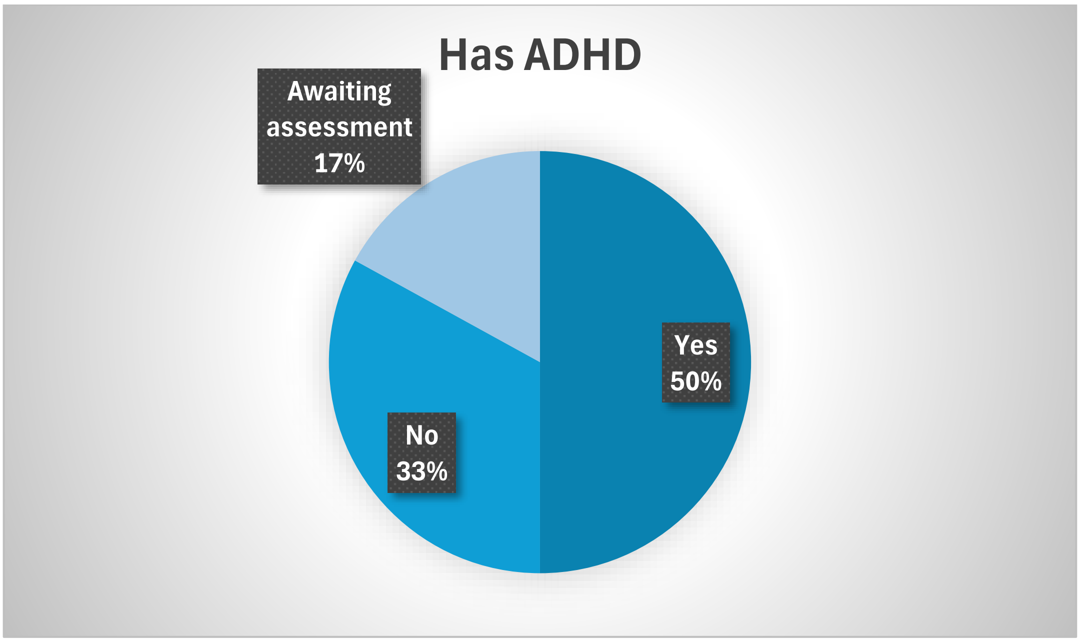
- **Families are less likely to be in agreement with their child's discharge from CAMHS if their child has an intellectual disability.**
  90% of families who have a child with intellectual disabilities did not agree their child was ready to be discharged at the time they were discharged, compared with 69% of families with a child without an intellectual disability.

3.3 Experiences of children with ADHD

Information provided in this section is based on the experiences of 303 children with ADHD or awaiting assessment for ADHD who are currently with or who have been with CAMHS.[20]

Out of all the children captured in the survey who are with or who have been with CAMHS, 50% have been diagnosed as having ADHD and 17% are awaiting assessment from CAMHS.

Figure 53: Child has ADHD



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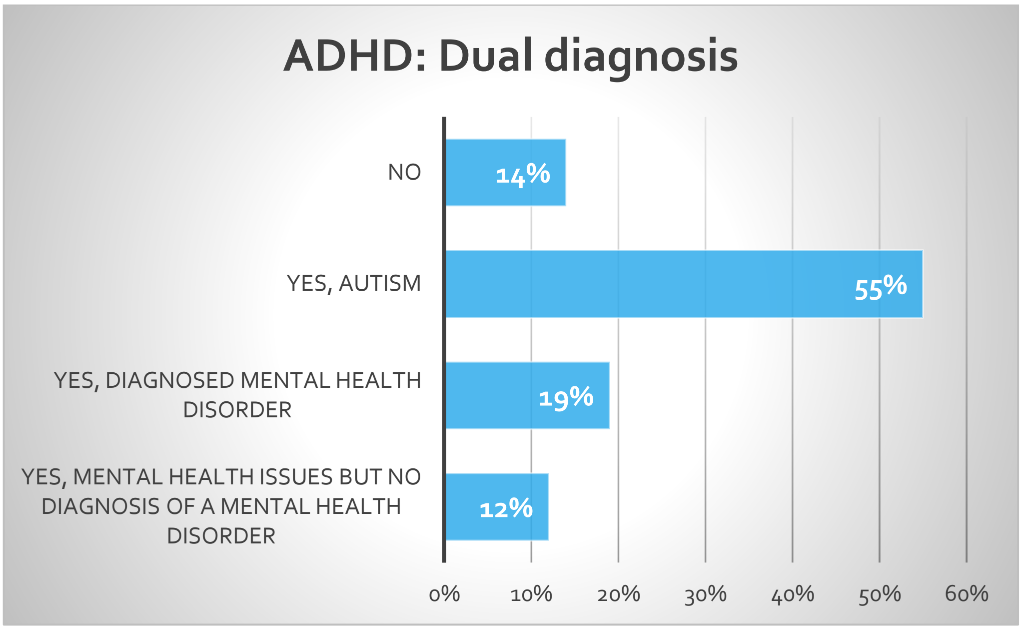
[20] While overall 405 children in the survey have ADHD/suspected ADHD, only 303 of them so far have made it past the referral and waiting list process.

Amongst children with ADHD/suspected ADHD captured in the survey, 55% were also autistic; 19% also had a diagnosed mental health disorder; and 12% also had mental health issues but had not received a formal diagnosis.

Figure 54: ADHD: Dual diagnosis

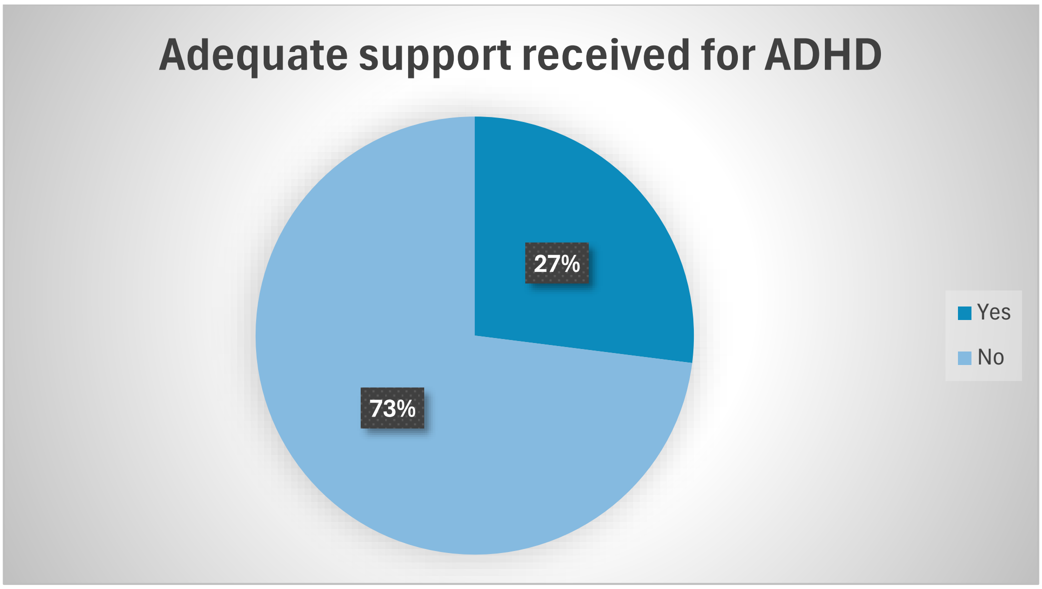


When respondents were asked whether they felt their child was receiving adequate support for their ADHD, almost three-quarters stated no.

Within the families' voices, the main issues of frustration related to:

(i) long delays to receive any support, despite CAMHS being the only public service who can assess or support ADHD. Delays in support were seen as having a lasting and damaging impact on the child;
(ii) the lack of supports offered or provided beyond medication;
(iii) not close enough monitoring of medication; and
(iv) lack of information or education provided by CAMHS to families with ADHD.

Figure 55: Support received for ADHD from CAMHS



Families' voices: ADHD

- *Should have been seen and diagnosed five years ago when first referral sent in.*
- *All that is offered is medication and told to go on the ADHD Ireland website.*
- *Medication without multidisciplinary supports which our child needed.*
- *Medications was what was offered. Not properly monitored, not explained to my daughter. She stopped taking it, no one cared.*
- *I feel we're just a number.*
- *Could be a bit more done on the education side of things, for example allowing the school to know about movement breaks or how sometimes my child works better alone than in a classroom.*
- *Medication reviews not frequent enough and no idea of when next appointment will be.*
- *Offered medication, nothing else.*
- *I have had to learn a lot myself through services like ADHD Ireland/ Middletown Centre for Autism to support my children. I have also had to seek out training on trauma to better help my child and have had to fight to get the PTSD diagnosis acknowledged by CAMHS.*
- *Severe lack of supports due to staff shortages.*
- *Different doctor every time we attend CAMHS, so feels like it's going in circles.*
- *He was diagnosed by psychologist but psychiatrist said she didn't believe the diagnosis as he looked calm and discharged us after meeting with us for six minutes.*

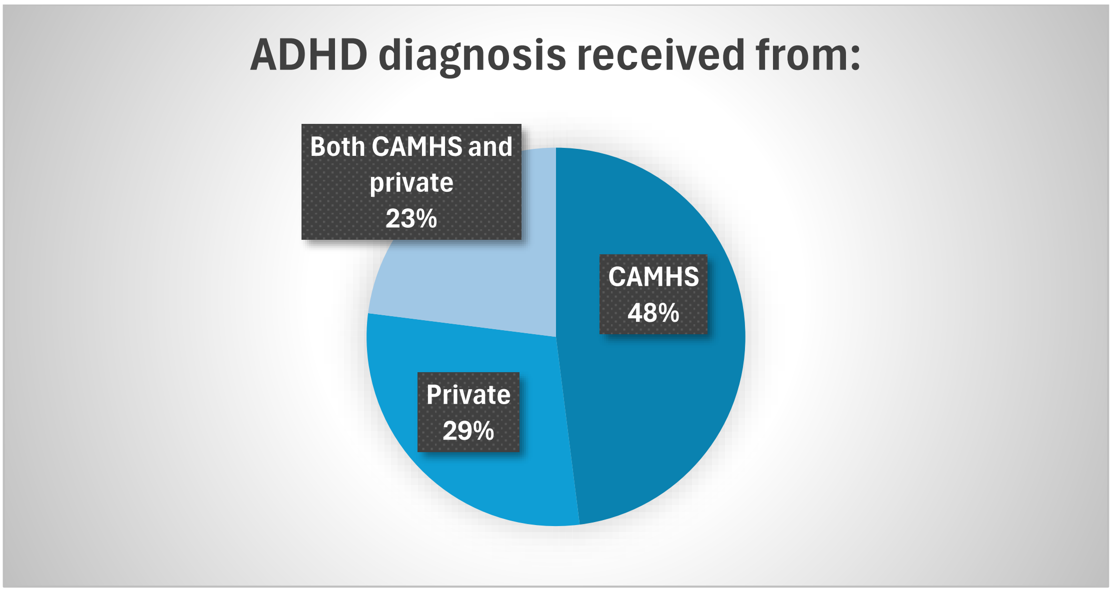
- *I wish CAMHS offered individual therapy and/or coaching. He is given medication, but learning how to navigate a world made for neurotypicals and how to adapt his daily life would have been highly beneficial. I don't know who to turn to to get help.*
- *It's sad that medication seems to be the only support available.*
- *Her medication was not monitored closely. I was not made aware of how high risk girls of her age with ADHD are for self-harming and suicidal ideation.*
- *I think there is poor understanding of co-morbid disorders, medication for them, how to deal with therapeutic intervention for kids like this.*
- *Medication is the only support offered. I would like other non-med supports as well.*
- *Tried two medications for ADHD but mental health had gotten so bad that didn't see benefits of taken ADHD meds, so stopped them and they haven't offered anything else. Still on anxiety medication.*
- *After seven years of being on one medication that worked, they took him off it and our lives were hell for two years. The stress and devastation it had on him and us as a family I will never forget.*
- *We wanted to be given or at least told exactly what therapies would help our child along with medication but CAHMS had nothing to offer. We cannot afford even the subsidised rate for occupational therapy.*
- *OT requested numerous times and refused.*

Obtaining an ADHD diagnosis

Many families resort to obtaining a private ADHD diagnosis to improve the chances that their referral will be accepted by CAMHS; or because the waitlist for CAMHS support is so long; or because their child's ADHD traits are being dismissed as traits of autism.

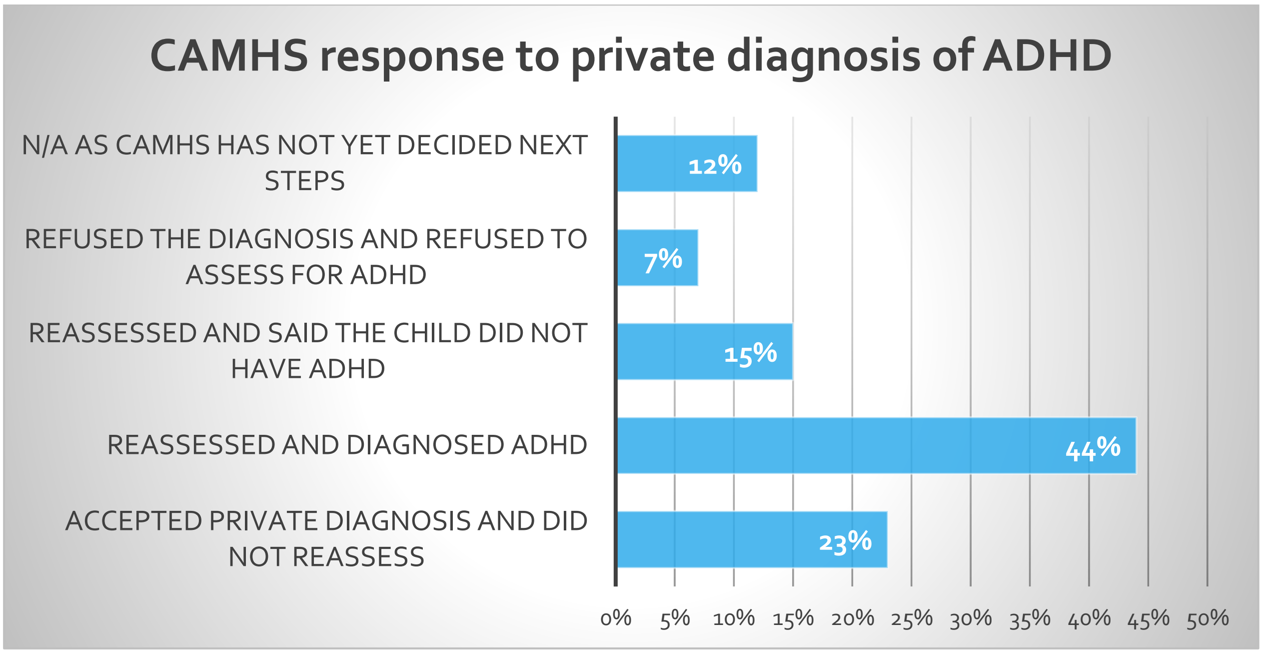
52% of the children of respondents had a private diagnosis of ADHD. Of that group 23% had both a private diagnosis and a subsequent diagnosis from CAMHS. 48% of respondents had a diagnosis from CAMHS alone.

Figure 56: Where ADHD diagnosis was obtained



When asked how CAMHS responded to a private diagnosis there was a wide variety of approaches. Almost half of respondents said that CAMHS re-assessed and diagnosed ADHD; almost a quarter accepted the private diagnosis and did not reassess; 15% re-assessed and said the child did not have ADHD; and in 7% of cases CAMHS refused to accept the diagnosis and refused to re-assess the child.

Figure 57: CAMHS response to a private diagnosis



- *Only attended one appointment. Private diagnosis was not accepted. Child was going to have to go through assessment again and drop all medication in order for CAMHS to assess them.*
- *Was told they wouldn't have accepted him onto their waitlist without a formal diagnosis, but during their diagnosis said he wasn't 'bad enough' for them to keep him on their list.*
- *Accepted private assessment but also went to school to observe.*
- *CAMHS readily accepted autism diagnosis and refused ADHD diagnosis. VHI diagnosis was a year ago and psychiatrist there wanted to know how it got so bad. Told them no one would listen.*
- *We were lucky with the people we met at the very beginning of our CAMHS journey and I made it known to them that I didn't want our private diagnosis dismissed as I had heard from others. They were very understanding and thorough in their assessment and agreed with private diagnosis.*
- *They said he did not have ADHD first day they saw us. My child ended up in A&E shortly after and they then listened to us.*

Key differences in the experiences of children with ADHD identified in the survey

A filter was applied to the overall survey results to differentiate the experiences of CAMHS between children with ADHD and those without. A number of key differences were found:

- **Referred at a younger age**
  58% of children with ADHD in this survey had been referred to CAMHS by the age of 8 years old, compared to the overall average of 44% in the survey or only 17% of children who do not have ADHD.

- **Longer wait times for a referral to be accepted**
  While the number of referrals that had to be made was in line with the average, the amount of time waiting for a referral to be accepted was longer for children with ADHD. 33% of families who have a child with ADHD had to wait over 18 months to have a referral accepted, compared with the overall average of 27%, and 22% for children who do not have ADHD.

- **Longer times spent on the waiting list**

  18% of children with ADHD had spent over 18 months on the waiting list compared to the overall survey average of 14%, and 9% of children who do not have ADHD.

- **More likely to seek private support while on the waiting list**

  76% of families with a child with ADHD/suspected ADHD sought private support while on waiting list compared with the overall survey average of 69% and 57% of families of children who do not have ADHD.

- **Less likely to be discharged in early appointments**

  77% of children with ADHD were kept on beyond six appointments compared with the overall average of 69%, and 62% of children who do not have ADHD.

- **Main supports include medication and parenting courses**

  74% of children with ADHD were offered medication compared with the overall average of 69% and 67% of children who do not have medication.

  Lower numbers of children with ADHD (17%) are offered over five sessions of therapy compared with children without ADHD (31%).

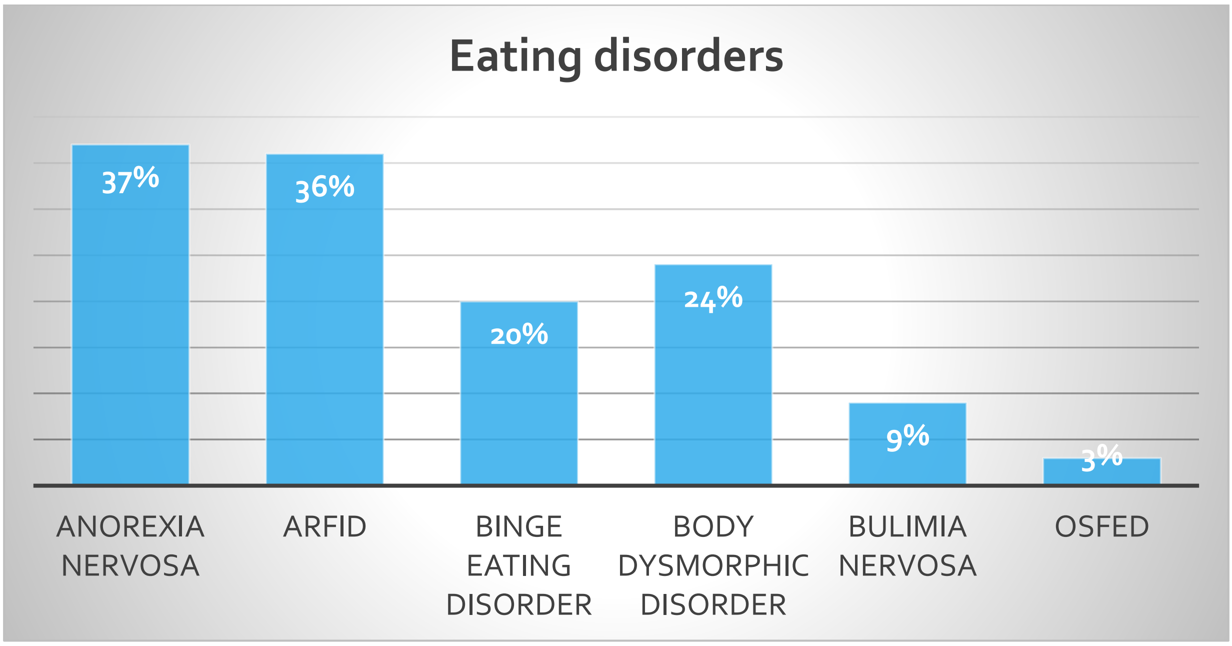
3.4 Experiences of children with eating disorders

Information provided in this section is based on the experiences of 107 children with an eating disorder.

Out of all the children captured in the survey who are with or who have been with CAMHS, 24% have an eating disorder.

Anorexia nervosa and ARFID were the two most common eating disorders experienced by the children of respondents, followed by body dysmorphic disorder; binge eating disorder; bulimia nervosa; and OSFED.

Figure 58: Eating disorders

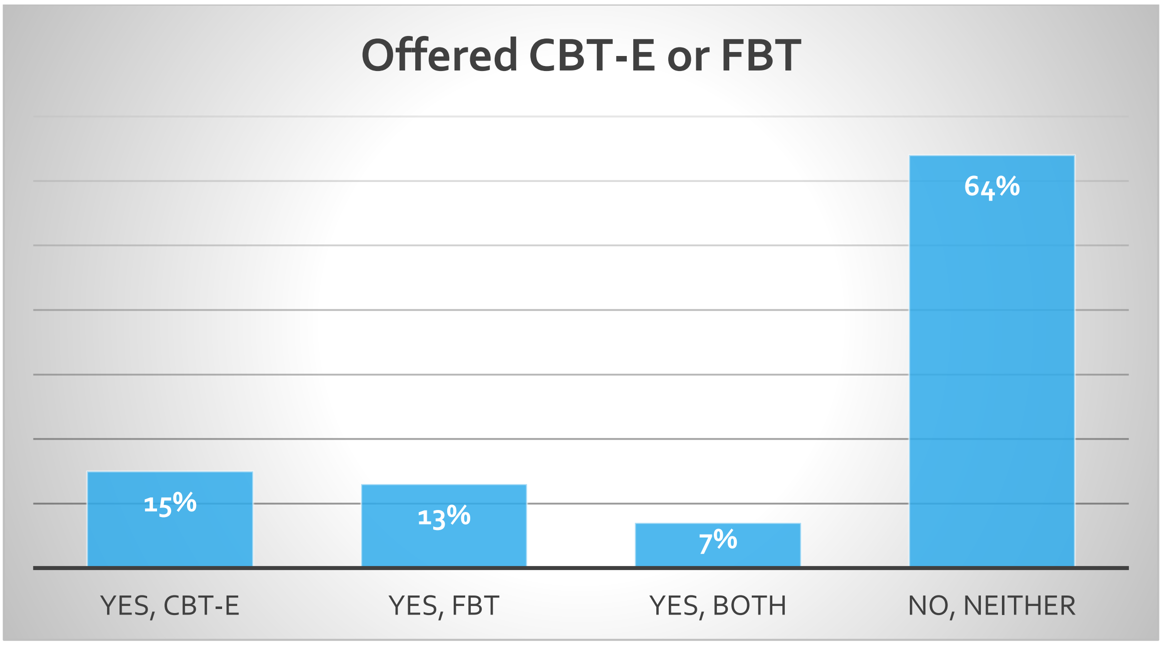


When asked whether their child had access to an eating disorder team or specialist team, only 23% of children did. 77% of children did not.

Figure 59: Access to an eating disorder team or specialist staff member

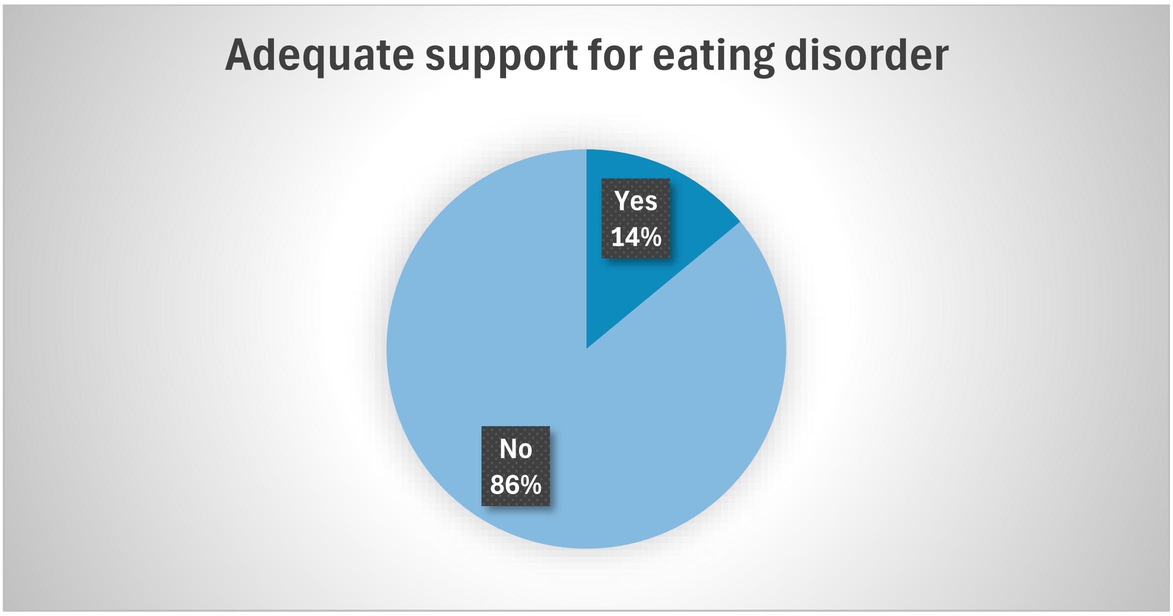
Respondents were also asked whether their child had been offered enhanced cognitive behaviour therapy (CBT-E) and/or family based treatment (FBT). 36% of children had been offered CBT-E and/or FBT, whereas 64% of children had been offered neither.

Figure 60: Offered CBT-E or FBT



When asked whether they felt their child was receiving adequate support for their eating disorder, only 14% of respondents believed they were. 86% of respondents did not feel their child was receiving adequate support.

Figure 61: Adequate support for eating disorder



Families' voices: Eating disorders

- *We went private couldn't wait for CAMHS she would be dead.*
- *This is escalating and I am left to manage it alone. Again, because of my background I have more knowledge than a lot of parents but I'm still mom. I am exhausted and it is impacting on all of us.*
- *Although we were grateful for the support we received during lockdown, I felt it was a struggle to be seen, for the eating disorder to be recognised and to get ongoing help because of my child's autism diagnosis. There should have been follow up and linking in of services. There has been extremely limited therapy for my child from any services since autism diagnosis 5 years ago.*
- *No dietician available and inadequate experience and knowledge on team of how to deal with ARFID. Despite this I feel CAMHS team are trying very hard and exploring all options available to them to support.*
- *CAMHS told us that they wouldn't see her until she started eating again, it was a very difficult meeting and left us all confused*
- *At the moment she has enough support as she is in a much better place in recovery, but she has never been offered therapy so we went private.*

- *I have sought help from my GP, private counselling (I counted 12 services I have tried to access who won't see her as she is 'too complex too young or we don't have the funding'). I have done my own training/ research and talked with colleagues with professional knowledge. We were in hospital a few weeks ago for self-injurious behaviour and suicidal ideation, something I have been flagging with CAMHS since 2019. I had discussed with both in patient and outpatient CAMHs about the fixation on controlling food and fasting, binging and purging. We have heard nothing from them since. They offered us a safety plan (we got a written copy of this, first time ever) an emotional regulation group and a letter to Pieta*.
- *She has a private psychiatrist in London and attends an eating disorder centre as an outpatient weekly.*
- *CAMHS referred to a private dietitian.*
- *Treatment was based on anorexia which is the opposite approach needed to ARFID. CAMHS try to treat her but have very limited knowledge and focus on weight- no dietician available.*
- *No they are literally learning from treating my child about ARFID.*
- *She is currently attending the CAMHS Ed clinic.*
- *Received family based therapy after discharge from hospital for eating disorder so we could restore weight which was helpful but the child was told that once weight was restored one to one therapy would start to work on what was driving the eating disorder. This is where they failed in delivery of that support*.
- *Over a few months her weight went way down she was not eating and purging when she did eat . Meds started and she started eating again so as soon as she went to healthy weight that was their job done*
- *She has never been offered therapy so we went private. When first accepted into CAMHS she was not offered any therapy despite being in a very bad place mentally. At one stage she was put on a list for occupational therapy, but was back in children's hospital before the therapist was even available.*
- *It's very difficult to get specialised service I do know we are lucky as in we have a full CAMHS team and don't have a lack of service but anorexia needs very specialised service as in its own service separate to CAHMS in my opinion.*

3.5 Experiences of children with suicidal ideation/intent

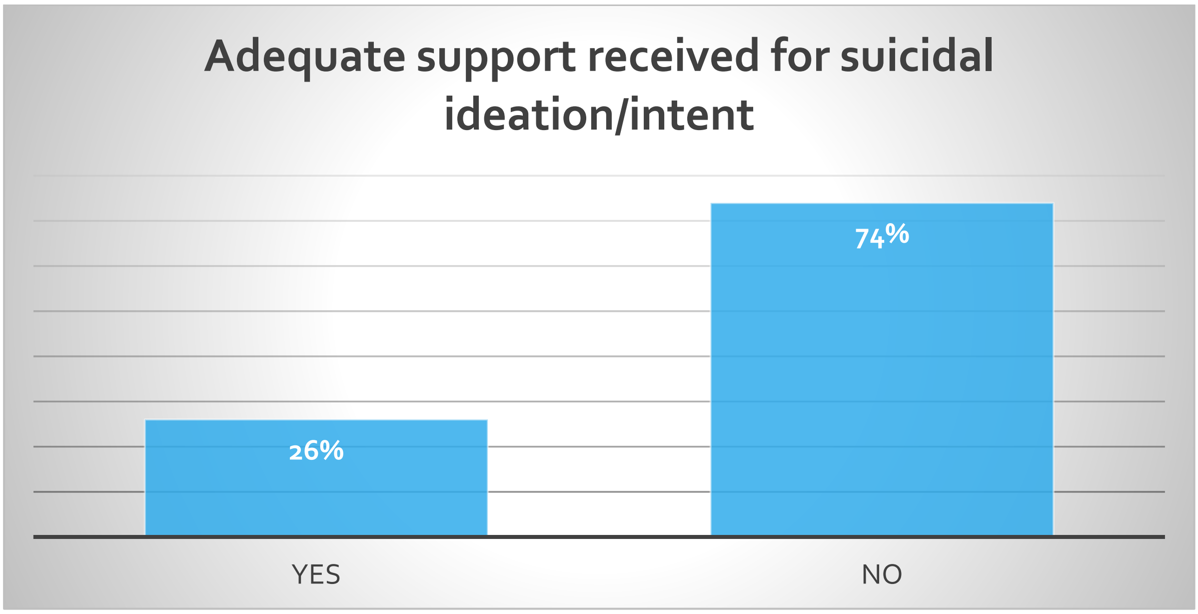
Information provided in this section is based on the experiences of 259 children who have experienced suicidal ideation/intent.

Out of all the children captured in the survey who are with or who have been with CAMHS, 58% had experienced suicidal ideation/intent.

When asked whether they felt their child was receiving adequate support for suicidal ideation/intent, 26% of respondents believed that they were. 74% of respondents did not feel their child was receiving adequate support.

Those respondents who were receiving adequate support spoke very highly about their CAMHS teams and the support they had been offered. Whereas respondents who could not access adequate support for their child expressed great distress and frustration.

Figure 62: Adequate support received for suicidal ideation/intent



Families' voices: Support with suicidal ideation/intent

- *Yes. AFTER she tried to take her own life*
- *No longer with CAMHS but had support at the time.*
- *Once he had a plan, after 2 years of no support, he was referred to Linn Dara hospital for 4 weeks as he was a threat to himself.*
- *My child is talking about killing herself, has left a suicide note and cut deep enough that she needed steri-stitches to keep closed. I brought her to A&E and in patient thinking something would change and she would get help. It hasn't helped. She has all the signs*

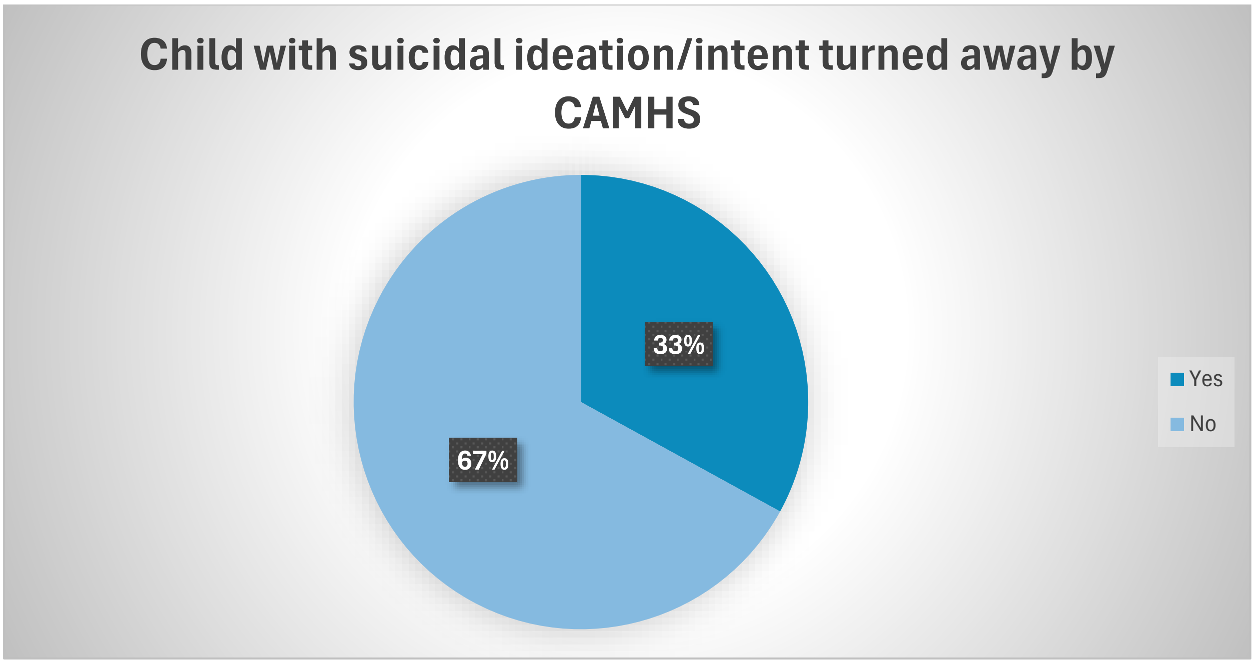
of ideation and intent. I rang pieta out of desperation and she will be seen soon. CAMHS offered to write a letter to Pieta after we had been assessed already by them.

- *Just put it down to autism behaviours.*
- *He was refused readmission to CAMHS after being referred back in to the service from A&E.*
- *Unbelievable support and monitoring.*
- *Meeting every 2 weeks for the past 2 yrs.*
- *Absolutely not. Have to go to A&E where after age 16 only choice is an adult psych ward. CAMHS just pass responsibility back to parent and had no suggestions.*
- *Advice was lock away knives and watch the child. Bring into A&E if child harms themselves or others.*
- *They say she is not going to do anything even though she threatens or hurt herself/says she wants to die on a regular basis. I hope they are right as I'm extremely worried.*
- *Due to complexity of FASD diagnosis we were passed between CAMHS psychology & ID services & none would take on his care.*
- *I called the psychiatrist (not the one he is currently seeing) because my son was constantly crying and saying he wanted to kill himself and he told me that no, my son was not experiencing depression. He then said he would follow up but never did.*
- *Support only received recently- having been in system for 6 years.*
- *Was told to hide sharp objects and go to A&E if required.*
- *Was told to lock up medication and anything sharp and just not leave them alone.*
- *No, my child took their own life, CAMHS did everything they could to discharge her and didn't believe her.*
- *When he was actively trying to kill himself CAHMS would not refer him to a children's unit to keep him safe. We got our GP, again with referral from Pieta to refer him to John of gods in Dublin privately.*
- *I ended up in A&E twice & second time refused to leave. I told them they'd have to contact Tusla as I was not taking my child home. I'm actually still in the hospital due to have a meeting tomorrow. But to have to literally beg & go down this route to get my child some help is beyond unacceptable.*
- *No therapy offered, had to go private. That being said, the two clinical nurses that work with my daughter are very good with her, and she is quite honest with them when she has ideation or intent.*

- *A&E visits constantly refer back to CAMHS who immediately discharge due to autism. We are getting no help at all from CAMHS even after a recent suicide attempt.*
- *Discharged him literally the day after he came home from two days in hospital after taking an overdose.*
- *CAMHS provides excellent support to us.*
- *The support we received in person and over the phone was 2nd to none.*

Respondents were asked whether their child had ever been turned away from CAMHS while they were experiencing suicidal ideation/intent and 33% of respondents indicated that they had.

Figure 63: Child with suicidal ideation/intent turned away by CAMHS



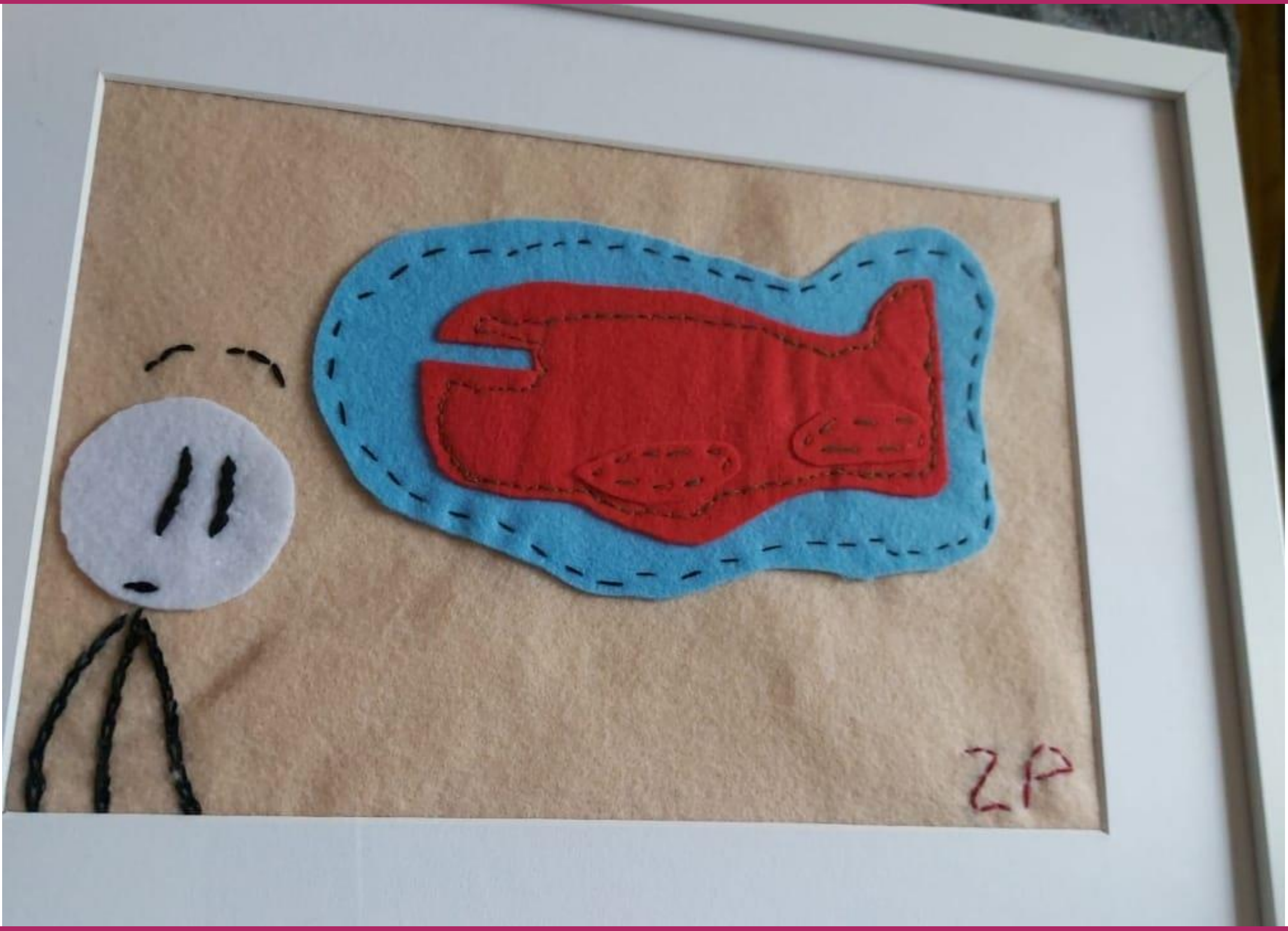
Families' voices: Support with suicidal ideation/intent

- *Because she is autistic they tried to refuse us but I demanded help when I said it's her depression that's causing the thoughts of suicide and hopelessness*
- *Referred back to AON*
- *Told me he did not understand and would not act on it. On a phone call one time I was told to "hide any knives".*
- *Suggested Pieta House while on waitlist.*

- *At 5 years old when he 1st described wanting to jump in front of traffic to die. He was refused by CAMHS stating he needed to be assessed for autism.*
- *Had one triage appt when child was 7- said she wasn't bad enough/must have heard things from somewhere. Didn't take them seriously.*
- *Told by letter not an urgent case, go back to GP.*
- *Not sufficient evidence - the child was standing on a two-story windowsill threatening to jump and was still refused.*
- *First CAMHS appointment 2022 they made a referral to CDNT. No further mental health support given until this January 2024 when they carried out ADHD assessment and prescribed medication No other treatments offered.*
- *They said it was emotional dysregulation due to ASD.*
- *On the 24th of March my child took a serious overdose, we attended A&E. The CAMHS reg came to assess my child who was clearly saying she would try again, and she did not want to live. We were told we were being discharged with a follow up appointment for her psychiatrist in a few days. I refused to take my child home in such distress and such high risk until she was assessed by a psychiatrist. We stayed in A&E for 36 hours until she was seen. The hospital psychiatrist gave his recommendations and said he would contact her doctor. We then travelled to see her CAMHS psychiatrist who dismissed and disagreed with the other doctor's recommendation. We were sent home unmedicated, exhausted, distressed and my daughter with a clear intent on trying to kill herself again.*
- *We were told she didn't have a psychiatric condition and didn't fall under their care.*
- *Was turned away from Psychiatrist on duty who said he didn't believe he was suicidal. We had to stay up day and night to watch him, lock all the doors, he was extremely agitated.*
- *We wanted to start with pieta and CAMHS discharged us.*
- *Because he was autistic this was deemed as normal for a child on the spectrum.*
- *Refused by GP referral.... had to go to A&E*
- *'This behaviour is line with their ASD diagnosis'.*
- *As they were serious attempts this is how we manged to get into CAMHS in the first place. Crumlin wouldn't discharge until they agreed to take her and confirmed her as our request. We stated we wouldn't take her home unless we had confirmation from team.*
- *The response I was given was that "all children with ASD say they don't want to be here".*
- *We had to have her assessed for autism. No help during the 3 months wait period. My child as mentioned earlier had made many attempts on her life.*

- *Apparently, it’s because of ASD and primary care or CDNT psychologist should deal with them instead.*
- *They are blaming autism.*
- *Was told it wasn't a serious intent.*
- *He was discharged with it being linked to autism.*
- *Never turned away but left waiting to be seen when in turmoil.*
- *We wanted him to be assessed for ADHD but after two years of them refusing to accept him on their waiting list, we wrote that he wants to kill himself (which he has said during massive meltdowns) and then he was finally accepted in their emergency list, which took 9 months before they finally saw him for the first time.*

Section 4: Supports received outside of CAMHS



Section 4: Supports received outside of CAMHS

This section was open to all 736 respondents.

79% of respondents had sought mental health supports outside of CAMHS as captured in the table below:

Figure 64: Support sought and received outside of CAMHS

Private psychiatrist	41%
Private psychiatrist abroad	4%
Private psychologist/therapist	49%
Private OT	33%
Private Speech and Language therapist	16%
Support from Jigsaw, Pieta House, BodyWhys, Turn2me or Barnardos	37%
Primary care therapy/supports	38%

Respondents also mentioned getting support from: ISPCC, Foroige, Tusla, St. Patrick's Mental Health Services, National Eating Disorder Clinic, Mindspace Mayo, Insync Youth Counselling Service, Brill Family resources centre.

Furthermore, families sought support from GPs, private consultant paediatricians, dieticians, art therapists, music therapists and equine therapists.

Families' voices: External supports

- *I have counted 12 different organisations that I have tried to get support for my child since Sept 2023..either she is too complex, too young or they don't have the funding to take on new clients. We have just been offered therapy with pieta which is a relief.*
- *Jigsaw not available for my address*
- *We were discharged from CAMHS in X as we broke policy by attending Pieta at the same time as them. Interestingly CAMHS in X don't have any issue with that and encourage it.*
- *Contacted a local psychiatrist too but too long waiting list to be of any real use to us*
- *I have completed 2 parenting courses with Barnardo's and my child was in attendance with Pieta house for therapy until 2 weeks ago*
- *Private eating disorder clinic. Also now considering psychiatric support abroad.*
- *Haven't found a psychiatrist that will take on a child*
- *He is on waiting lists with 2 private psychiatrist to be assessed privately for ADHD*

- *Primary care removed us from their waitlist due to his issues being too extreme for them to deal with*
- *Pieta are brilliant*
- *Couldn't find a private psychiatrist that would treat. All I could find was people to do assessments for ADHD*

Section 5: Impact on family and school attendance

Section 5: Impact on family and school attendance

This section was open to all 736 respondents of the survey.

5.1 Impact on family

In order to look after a child experiencing mental health issues a parent/guardian in:

(i) 33% of families had to leave employment;
(ii) 16% of families had to take carer's leave;
(iii) 32% of families had to take sick leave or annual leave; and/or
(iv) 32% of families had to take other unpaid leave from work.

Figure 65: Impact on the mental health of parents/guardian

81% of all respondents said their mental health was definitely impacted by trying to battle the system and secure mental health supports for

Families' voices: Impact on family

- *Stress worry sleepless nights. Worry about affording private care*
- *So disheartening to be unable to access appropriate support and be unable to help a distressed child.*
- *It is bizarrely circular - I left work to look after my daughter. As I am not in paid employment, I find I am often not taken seriously and that has impacted my mental health[...]. I feel that the lack of supports really can force families into poverty and a position of instability.*
- *I can't understate this enough. It's hard enough to support our child as a parent without having to fight for help for them as well, at every turn being invalidated, unheard and patronised*
- *I'm broken and my family are broken.*
- *By the 3rd year of seeking help and not getting it, I was a mess, crying daily. Damaged the whole family.*
- *I felt helpless as a parent. She was repeatedly denied inpatient treatment, and there was no care plan for her other than to leave her in the children's hospital,*

which is not an appropriate place for a child with a mental illness. I missed a lot of work, and both my physical and mental health have been damaged

- *The constant ringing and emailing and chasing is exhausting. It takes time and energy that I could use for my children's care*
- *Fighting for my son to get supported has broken us as parents, I can’t even imagine how our son feels.*

5.2 Impact on school attendance

Most children of respondents had missed school due to mental health issues with:

- 27% of children missing over 1 year;
- 9% missing between 6-12 months;
- 13% missing between 3-6 months; and
- 22% missing between 1-3 months.

Appendix I: Infographics

Families voices

"The lack of support from a CAMHS was very unexpected, we thought getting an appointment would help us make progress, and it turned out to be the complete opposite. I still don't know how we survived as a family, it was an unbearable time. We have since sourced private support, costing thousands over 2 years, but we are making progress. I still get upset thinking about happened and for all the families that don't have the financial means to get private help."

"It breaks my heart to think what kind of life she could have had if she wasn't thrown on the scrap heap because her parents couldn't afford an earlier diagnosis, maybe that could have made a difference we will never know"

"I am a camhs professional for more than 18 years myself. But my own 5 year old in an acute crisis is left"

"So disheartening to be unable to access appropriate support and be unable to help a distressed child"

"Stress worry sleepless nights. Worry about affording private care"

"This country is a DISGRACE for our youth if today regarding mental illness! Things need to change soon or we will continue to see the rise in young suicidal deaths it's so unfair on them it makes me so angry"

"Don't know how to fix it but the way the system is now is cruel by design"

"Kids get worse while waiting. Existing staff doing the best they can. The system is broken"

"Why do they not accept GP referrals, why is it so hard to get our children the help they need and help we the parents are not qualified to give, we can only do our best and feel like we are letting our kids down. Heartbroken parent"

"Constantly fighting with CAHMS to secure an appointment. They are accountable to nobody and failing our children. Tackling waiting lists by dismissing ASD children without any contact. Discrimination by definition. Disgraceful"

"I feel like our government is letting down the most vulnerable people in the whole country. Which affects their future and their whole lives really."

"i feel like every day im advocating for my child to get help and im banging my head of a wall with the public system."

Seeking mental health support for our children

Step 1: Referral

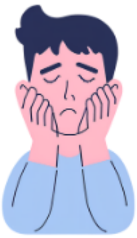
- 44% of children required multiple referrals before being accepted
- For 41% of children the referral process took longer than 1 year
- 92% of families felt their child's mental health deteriorated during the referral process

Step 2: Waiting list

While on the waiting list:

- 69% of famlies sought private support
- 39% of children had to go to A&E
- 15% of families sought political support
- 5% of families went public/to the media

74% felt their child's mental health deteriorated while on the waiting list. Those who did not think so, generally commented that they were paying for private support



Step 3 – Initial appointments with CAMHS

- 8% of children discharged at triage on the first appointment
- 10% of children discharged after 3 appointments
- 13% of children discharged after 6 appointments
- 70% of children kept within the service for a longer period of time

Step 4 - interventions/support

- 69% of children offered medication
- 19% of children offered 1-5 therapy sessions
- 22% of children offered more than 5 therapy sessions
- 20% of children offered OT sessions
- 13% of chidlren offered speech and language therapy
- 25% of families offered parenting courses
- 14% of children had received no interventions

Step 5 - Leaving CAMHS

- Discharged from CAMHS

69% of families were not in agreement that their child was ready to be discharged.

- Aged out of CAMHS

63% of families did not believe their child was ready to leave CAMHS at the age of 18.

CAMHS SUPPORTS FOR...

AUTISTIC KIDS

66% of the children in the survey are autistic.

70% of families felt that being autistic negatively impacted access to CAMHS and/or the mental health supports offered

·48% of children were also with their local CDNT but only 20% had experienced any joint working between CAMHS and CDNT.

KIDS WITH AN INTELLECTUAL DISABILITY

13% of children in the survey have an intellectual disability

77% of these children have no access to mental health support through a CAMHS-ID serivce as the service has not been set up in their area

Only 14% of this group are receivng any interim support

KIDS WITH SUICIDAL IDEATION/INTENT

58% of children in the survey had experienced suicidal ideation or suicidal intent

·74% of respondents did not feel their child had received adequate support for suicidal ideation/intent

KIDS WITH ADHD

50% of the children in the survey have ADHD and 17% are waiting for an assessment

Only 27% of families felt their child was getting adequate support for ADHD

For families joining CAMHS with a private assesement, 60% of children were reassessed by CAMHS, 23% had the private diagnosis accepted and 7% were refused a reassessment

KIDS WITH AN EATING DISORDER

24% of children in the survey have an eating disorder

Only 23% children had access to an eating disorder team or specialist team member

36% of respondents children had been offered CBT-E and/or FBT whereas 64% had been offered neither

·86% of families did not feel their child was receiving adequate support for their eating disorder

Based on survey results from the April 2024 survey held by *Families for Reform of CAMHS*. 736 responses were received nationally. The above stats were gathered from the 511 responses from families who had seen CAMHS.

Appendix II: Areas where experiences of autistic children differed

	Children who are not autistic	Autistic children
What support was being sought at point of referral to CAMHS	- ADHD (50%) - Anxiety (50%) - Depression (27%) - OCD (9%) - Suicidal ideation/intent (31%) - Self-harming (25%)	- ADHD (55%) - Anxiety (73%) - Depression (33%) - OCD (14%) - Suicidal ideation/intent (35%) - Self-harming (32%)
Accepted on first referral	- 66%	- 51%
Accepted by	- 2 referrals: 83% - 3 referrals: 92%	- 2 referrals: 68% - 3 referrals: 88%
Ended up in A&E while on the waiting list	- 34%	- 40%
Offered more than 5 therapy sessions	- 25%	- 20%
Has an eating disorder	- 17%	- 28%
Types of eating disorder	Anorexia Nervosa (65%) ARFID (15%) Binge eating disorder (15%) Body dysmorphic disorder (10%) Bulimia (10%) OSFED (5%)	Anorexia Nervosa (29%) ARFID (45%) Binge eating disorder (18%) Body dysmorphic disorder (29%) Bulimia (8%) OSFED (3%)
Offered either CBT-E or FBT	- 52%	- 32%
Feels adequately supported with eating disorder	- 26%	- 12%
Experienced suicidal ideation or intent	- 55%	- 61%
Felt received adequate support for suicidal ideation/intent	- 33%	- 23%
Turned away despite suicidal ideation/intent	- 18%	- 42%