



Families for Reform of CAMHS

<https://www.families-for-reform-of-camhs.com/>



@Reform_of_Camhs



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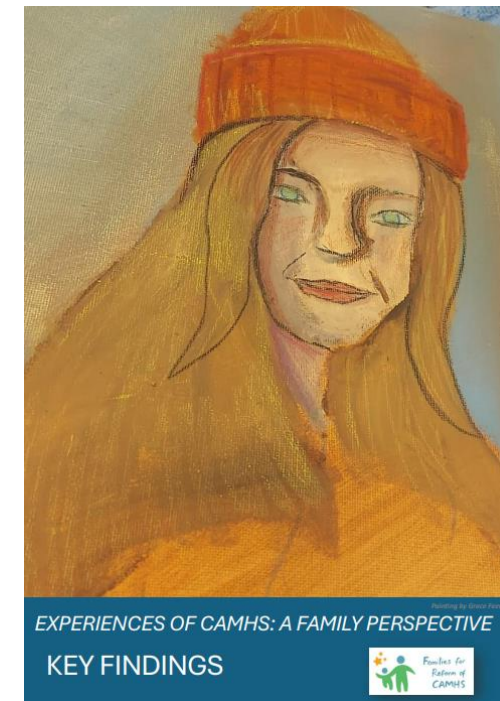
Experiences of CAMHS: A Family Perspective Survey Report

- Survey open for 3 weeks over the month of April
- 736 responses
- Over 80 questions to capture quantitative and qualitative findings



EXPERIENCES OF CAMHS:
A FAMILY PERSPECTIVE

JUNE 2024



EXPERIENCES OF CAMHS: A FAMILY PERSPECTIVE

KEY FINDINGS



Today

1. General respondent information



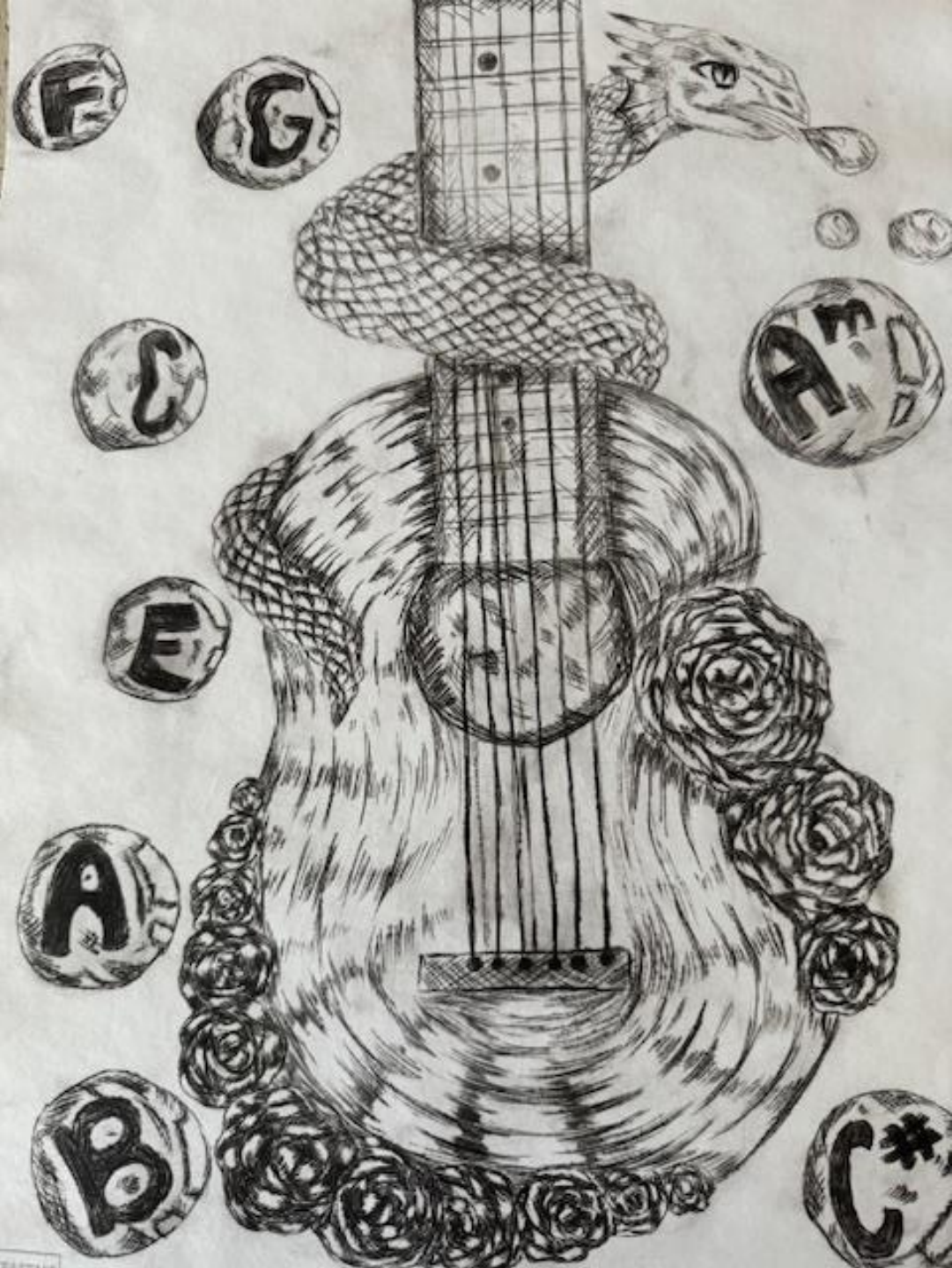
2. Journey through CAMHS

- the referral process
- time spent on the waiting list
- Experience and supports while with CAMHS
- Experience of moving on from CAMHS



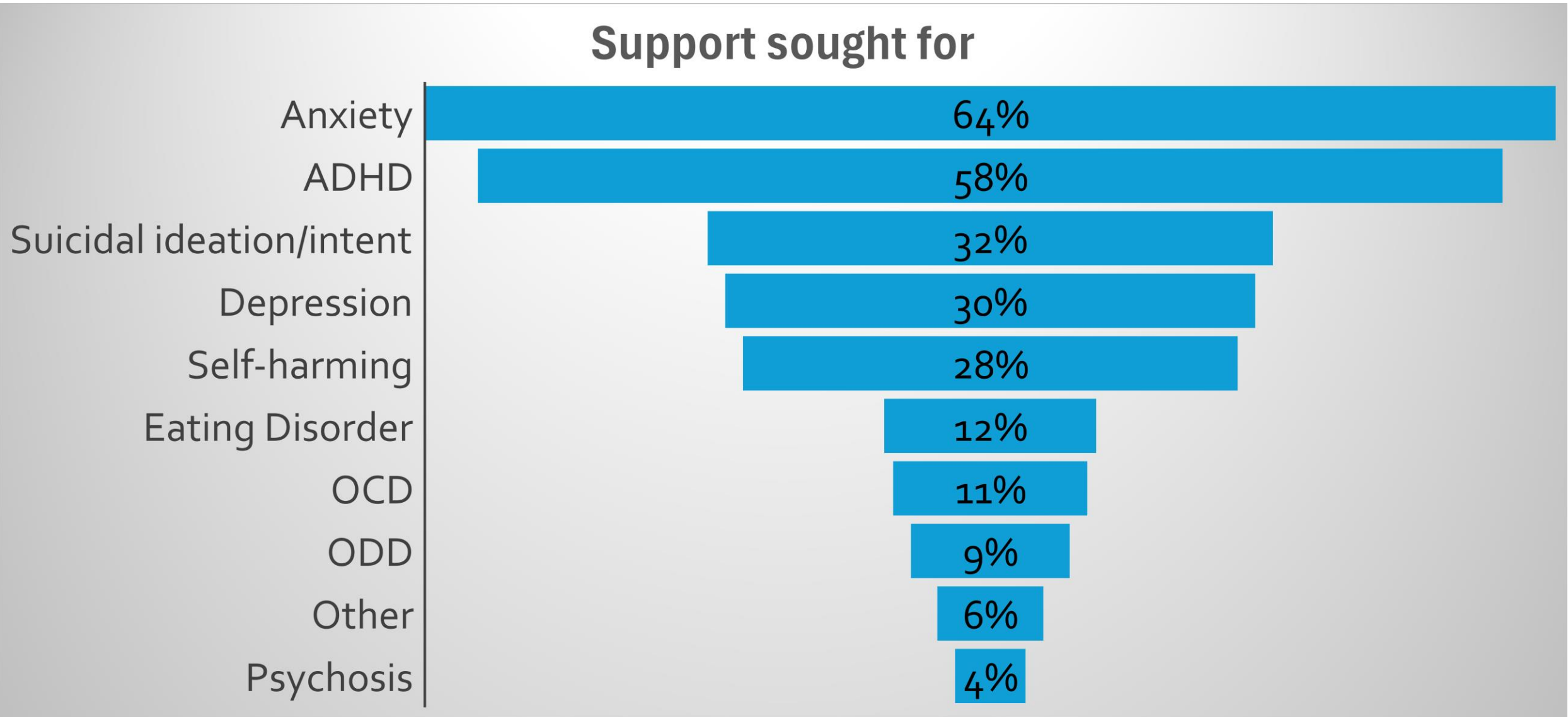
3. Experiences of certain groups:

- Autistic children
- Children with an intellectual disability
- Children with ADHD
- Children with an eating disorder
- Children who have experienced suicidal ideation/intent



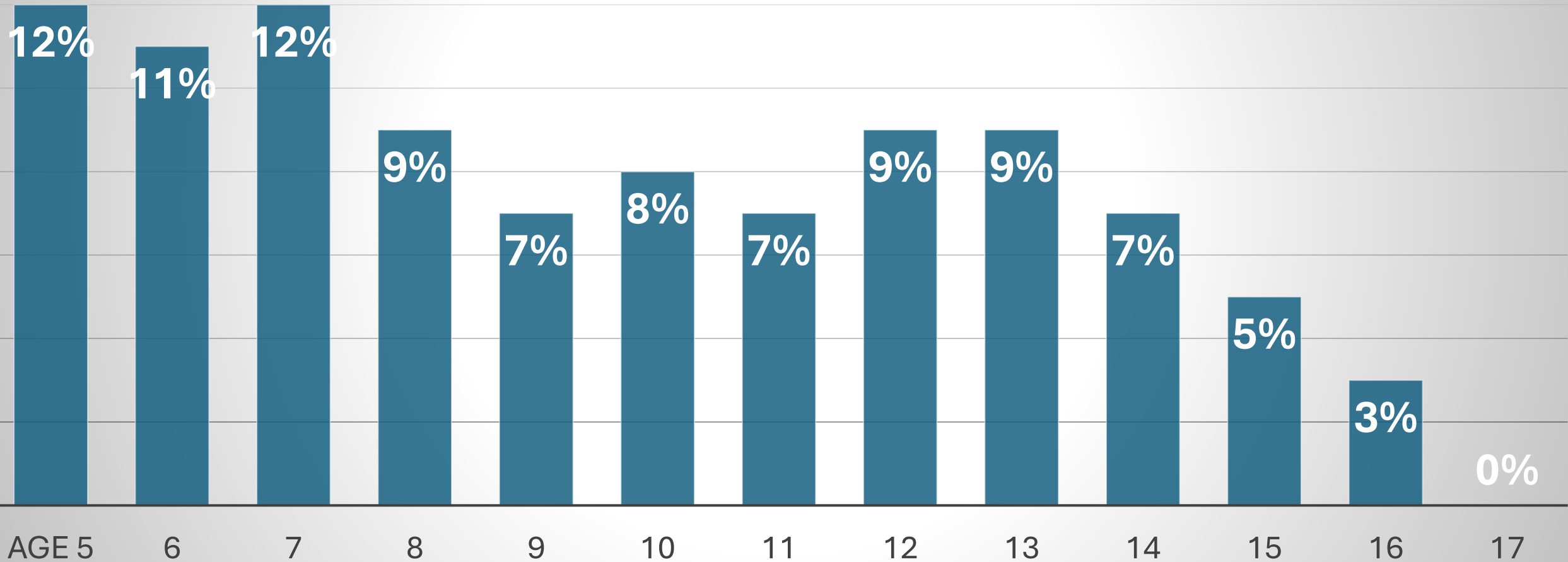
1. General Respondent Information

General Respondent Information



General Respondent Information

Age at first referral



General Respondent Information

Reasons support sought:

Referral at age 5-9

(384 respondents - 52%)

ADHD (74%)

anxiety (59%)

suicidal ideation/intent (20%)

depression (20%)

self-harm (17%)

Referral at age 10 – 16

(352 respondents – 48%)

anxiety (69%)

suicidal ideation/intent (44%)

depression (40%)

ADHD (39%)

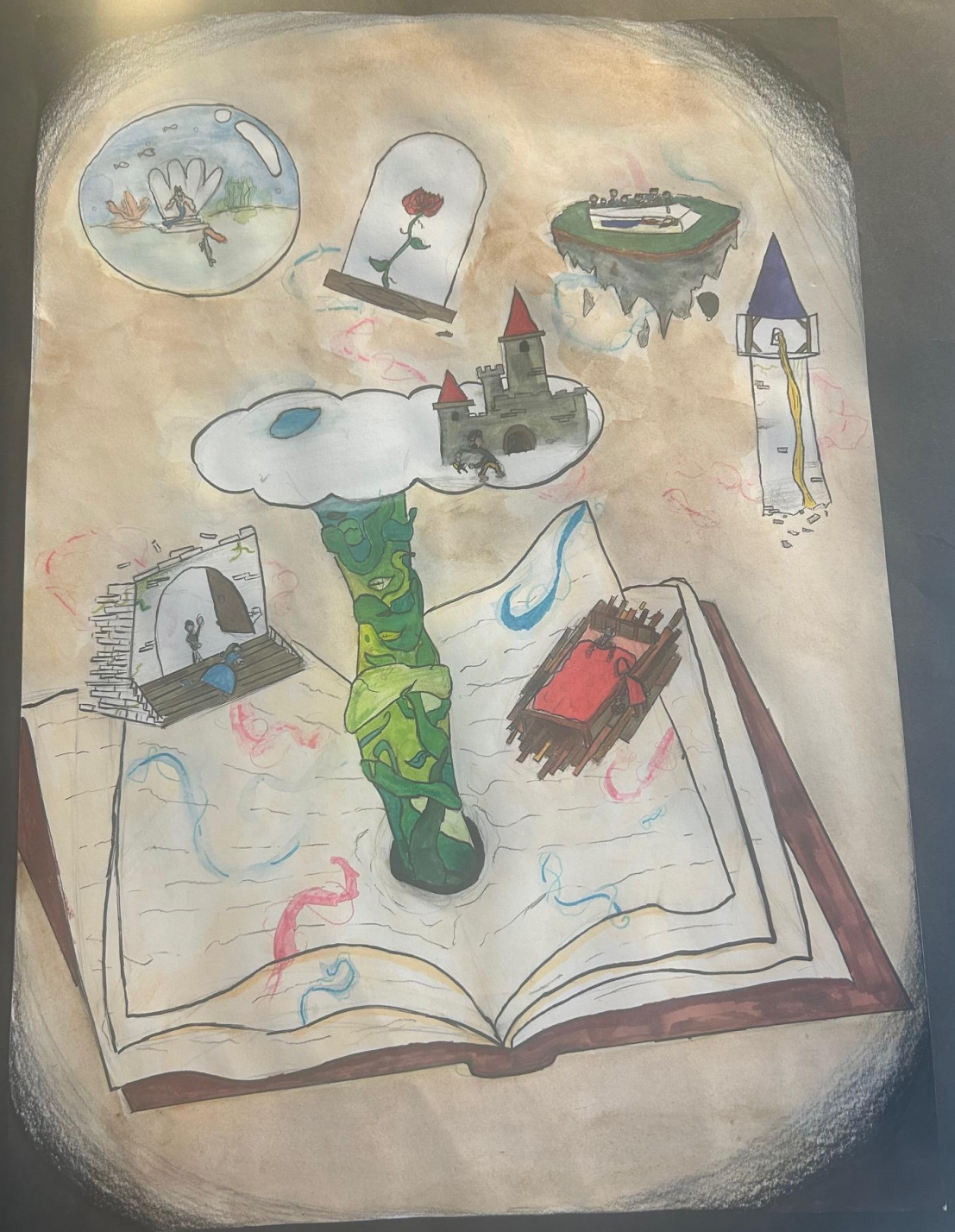
self-harm (39%)

"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 great
friends. Friends needed
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

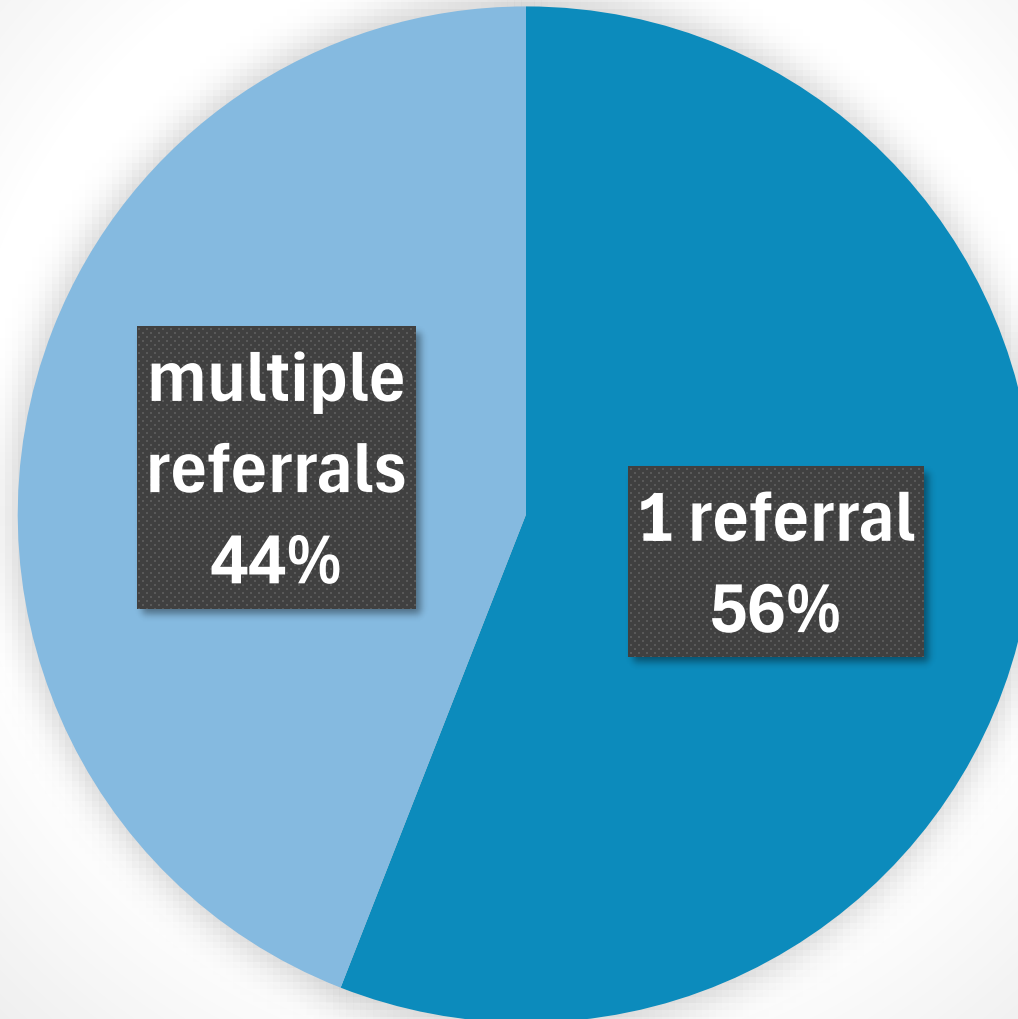
2. Journey through CAMHS



Step 1: Referral Process

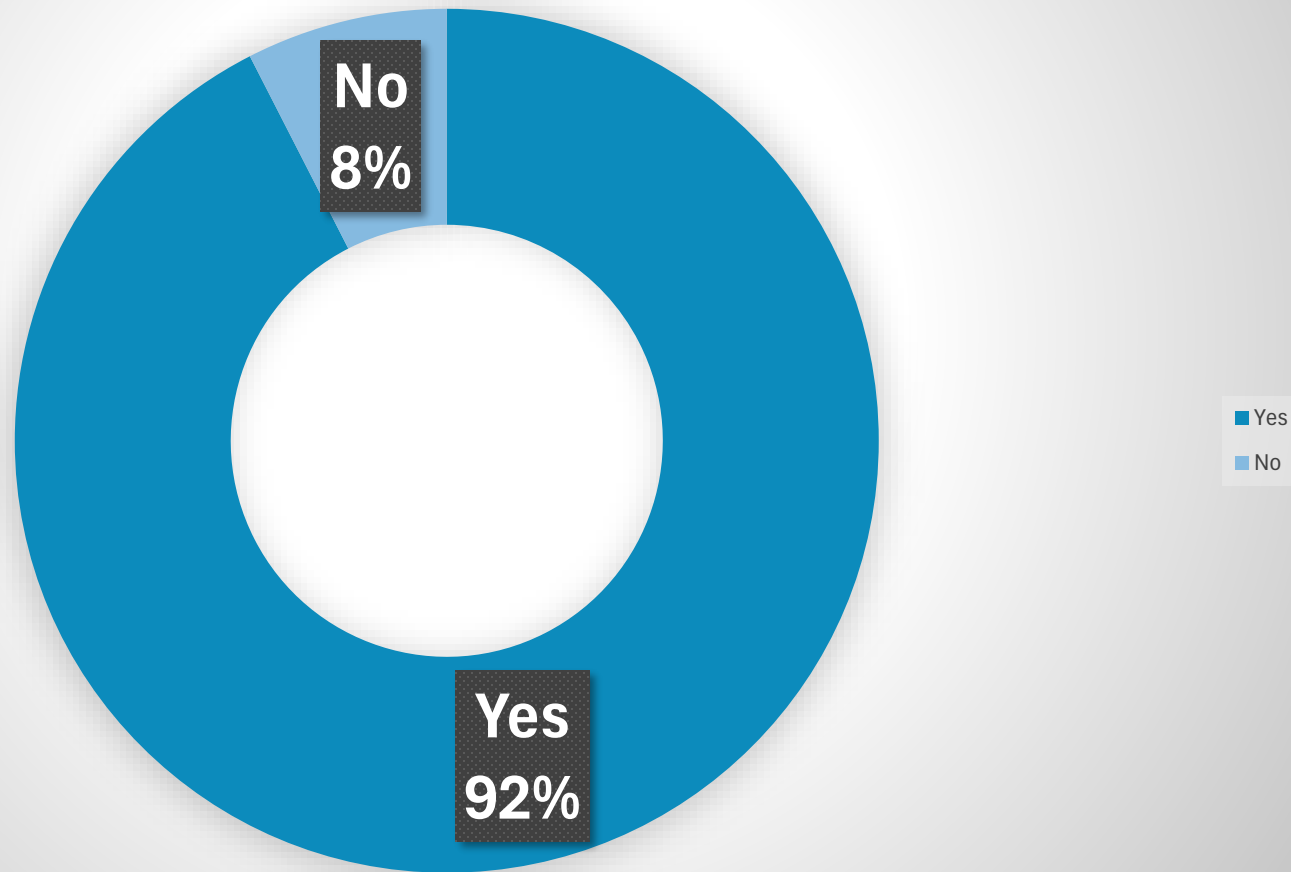
1. Referral Process: Trying to gain access

Referral accepted: Number of referrals



1. Referral Process: Trying to gain access

Mental health deterioration during referral process



Multiple referrals

Of the group of children who required multiple referrals:

- 40% required 2 referrals,
- 37% required 3 referrals;
- 16% required 4 referrals and
- 5% required 5 referrals.

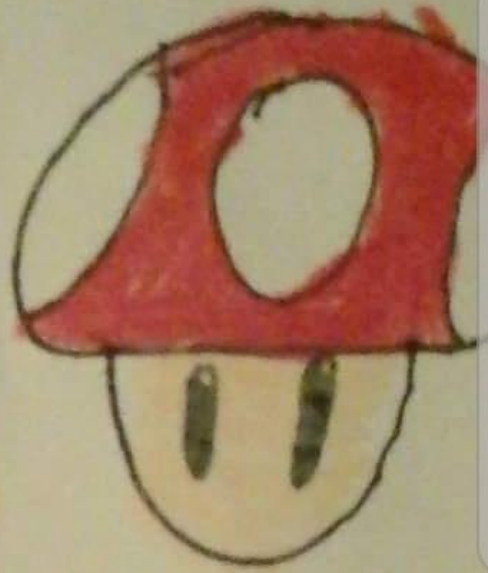
Families Voices: Referral Process

- *“Didn’t see him until he actually self-harmed. And attempted suicide.”*
- *“CAMHS said “Autism, try CDNT”. CDNT would reply with “ADHD, try CAMHS”. This went on for years until he was terrified he’d kill himself.”*
- *“In the end they took her case because we ended up in A&E in a complete crisis.”*

Let's go!



Mario

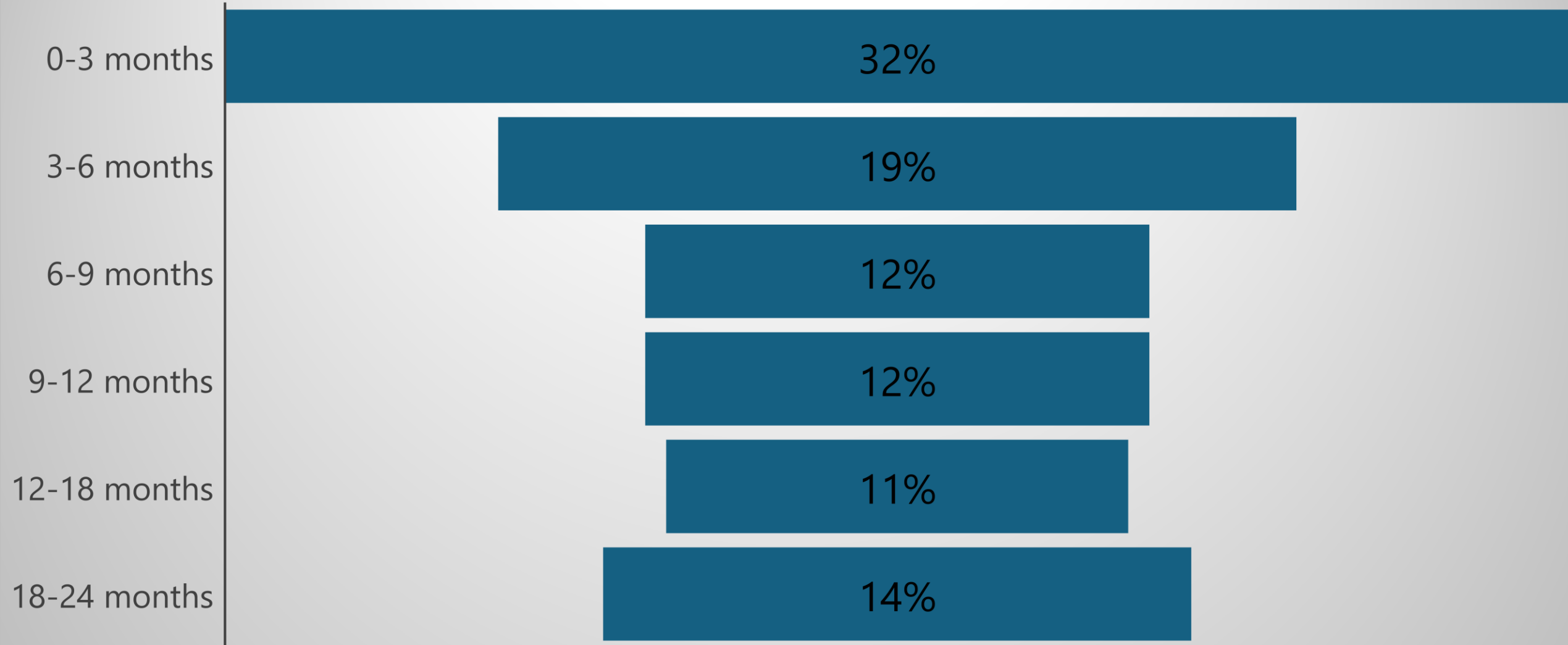


R.B.

Step 2: Waiting List

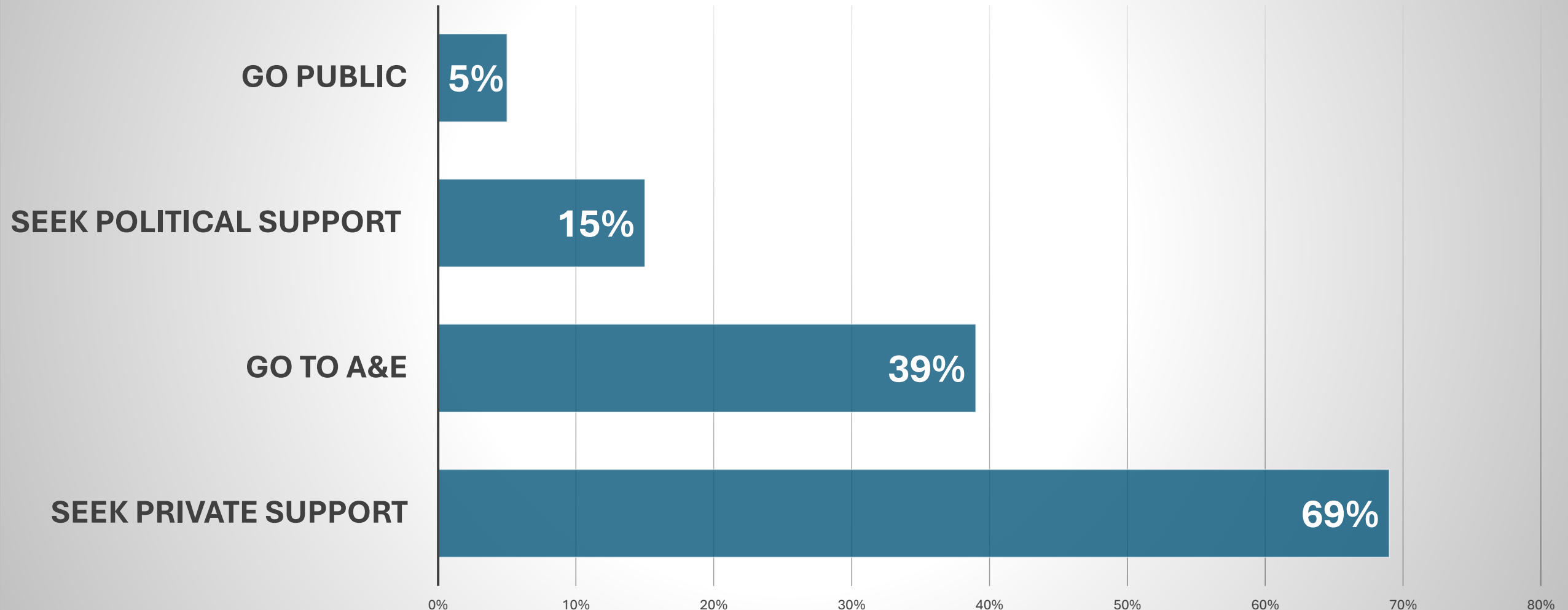
2. Waiting list: Waiting for support

Time on waiting list



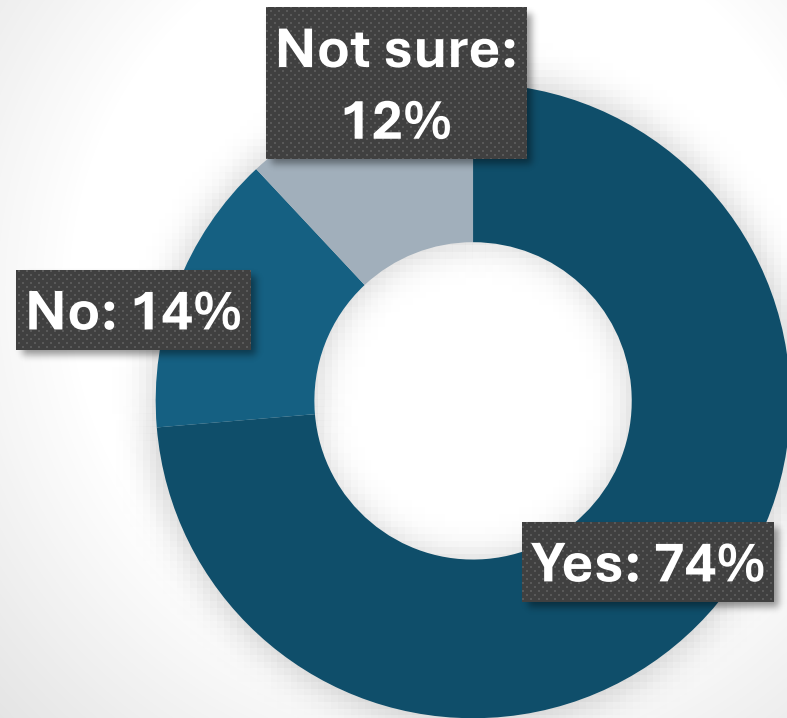
2. Waiting list: Waiting for support

Action taken to try and shorten time on waiting list or to access support while on it



2. Waiting list: Waiting for support

Mental health deterioration while on waiting list



If mental health did not deteriorate, families generally indicated that it was usually because the family was accessing private support.

Significant barriers to accessing private support: cost, availability and complex needs.

Impact on Family

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

- 33% of families had to leave employment;
- 32% of families had to take other unpaid leave from work;
- 16% of families had to take carer's leave

“Stress worry... sleepless nights. Worry about affording private care”

“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”



**Step 3:
With CAMHS -
Initial
Appointments**

3. Initial Appointments: with CAMHS

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

“We thought getting an appointment with CAMHS was the beginning of getting help, how wrong we were.”



**Step 4:
With CAMHS
– Support /
intervention**

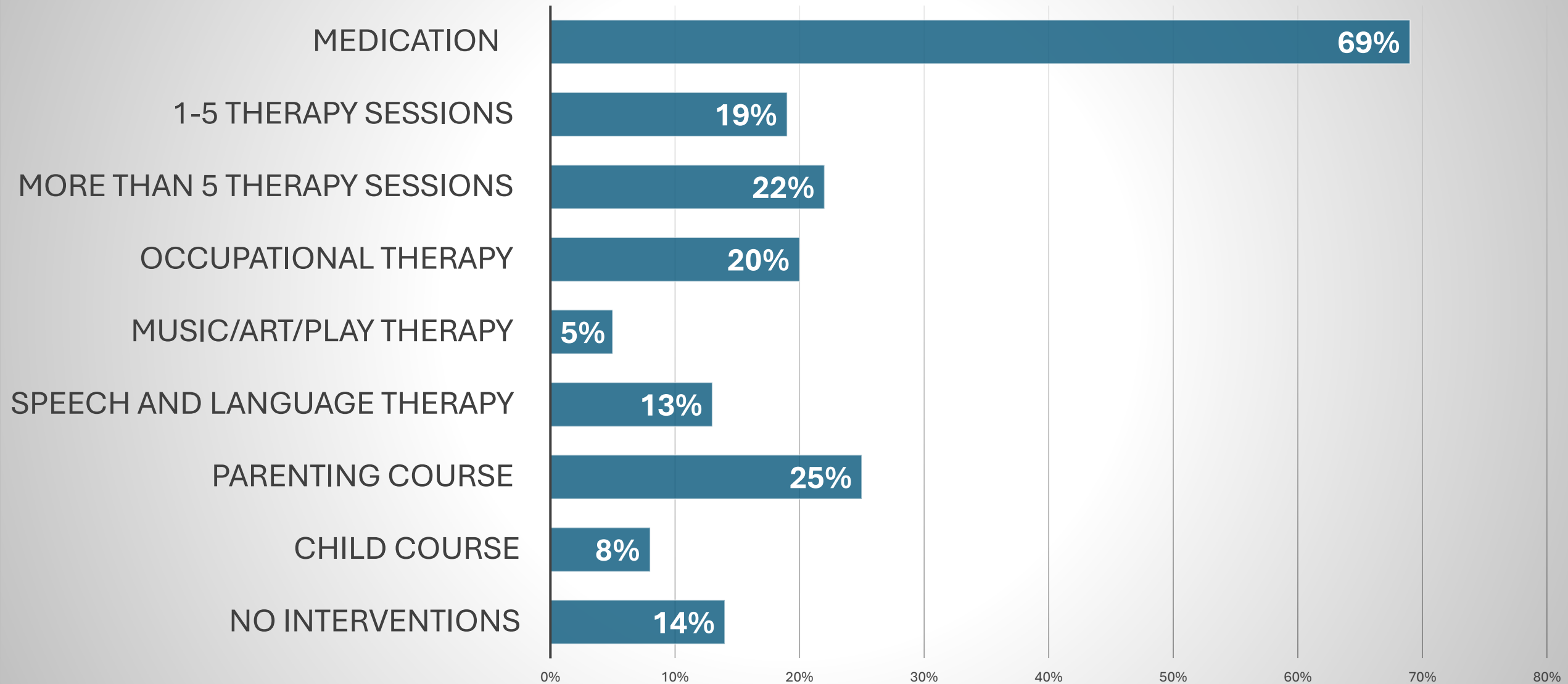
4. With CAMHS: Top Support received

- Individual staff members: being listened to, believed and validated, feeling empathy and care made all the difference
- Access to medication
- Access to interventions

However, a clear lack of consistency with experiences

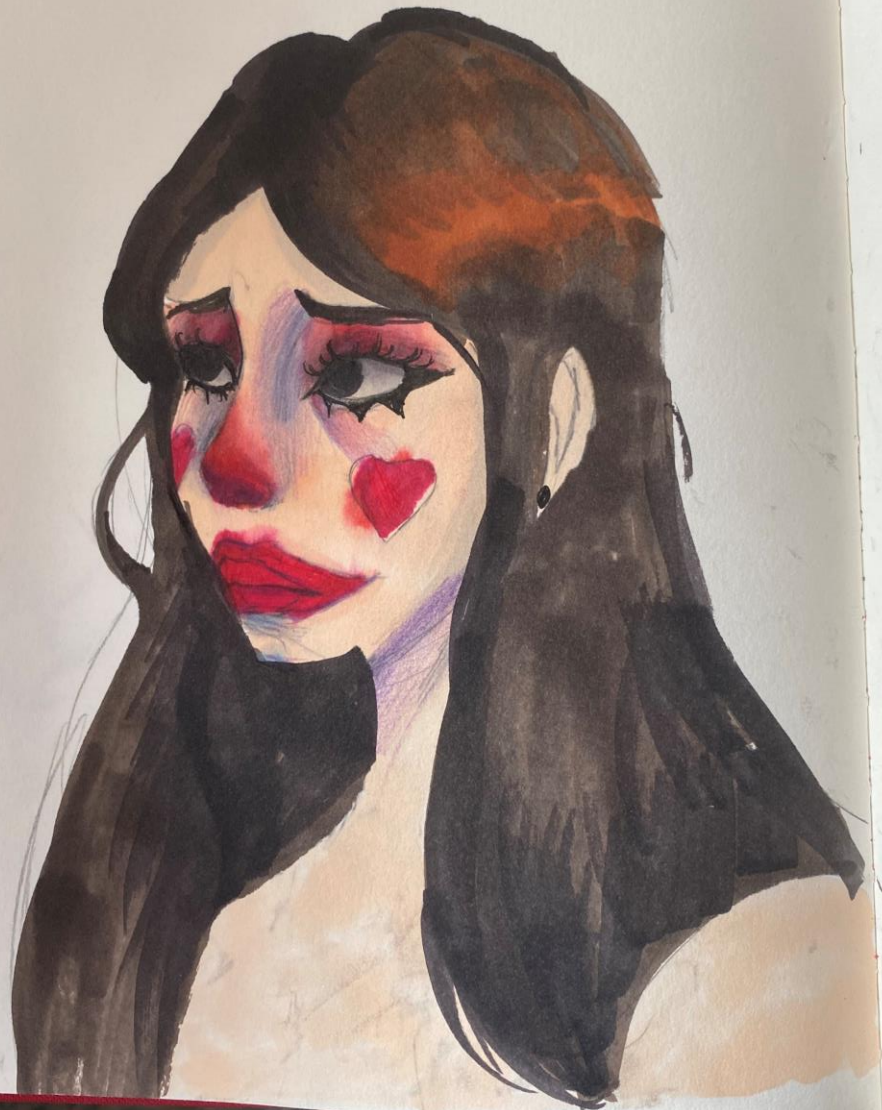
4. With CAMHS: Support/interventions

Interventions offered by CAMHS



4. With CAMHS: Complaints process

- 23% of respondents had submitted a complaint.
 - 70% were not satisfied with how the complaint was handled
 - Only 27% of respondents found the complaints process clear and easy to navigate
- Of the 77% of respondents who had not submitted a complaint, over half had considered submitting a complaint but:
 - 33% were worried about the potential impact on their child's care.
 - 20% were unclear how to do so



**Step 5:
Leaving
CAMHS**

Discharged from CAMHS

- 69% were not in agreement that their child was ready to be discharged

- *“[Discharged] Against my pleas and they left me in bits and just didn’t consider my child was high risk”*
- *Discharged as suspected ASD. At the time my daughter then 10 was depressed, severe anxiety, school avoidance, suicidal ideation”.*
- *“We were told as she wouldn’t take meds she was being discharged.”*

Aged-out of CAMHS

- 63% did not feel their child was ready to leave CAMHS at aged 18
 - 50% of young people moved onto adult services and 50% did not.
- *We have been on the waitlist for adult services...I begged to stay in CAMHS until he finished school and told no”.*

Key Findings : Journey through CAMHS

- Difficulty at *every* stage of the process for families
- The door tends to only open for children who have to become critically unwell first
- Negative impact when child cannot access or afford private support
- Additional steps often required to get support including going to A&E, going to a local politician, going public /to the media with their experience.
- Lack of supports or intervention beyond medication when in the door. And availability of interventions varied hugely across different CAMHS teams

- Acknowledgement of the huge strain staff were under and the positive impact that an individual staff member could make.
- 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.
- The real possibility of being discharged before being ready, led to a large sense of distrust amongst respondents. This was amplified by the fact that if the child needed help again in the future families knew how difficult it would be to get back in the door.



3. Experiences of certain groups

NEURO DIVERSITY

IS

We think
DIFFERENTLY!



- ★ Dyslexia
- ★ Dyspraxia
- ★ Dyscalculia
- ★ Dysgraphia
- ★ Hyperlexia
- ★ ADD, ADHD
- ★ ASD, AUTISM
- ★ GIFTED.

Fun Fact!

Up to 30% of
the population
are neuro diverse!

SAD Fact ☹️

90% of neuro diverse
have been bullied!

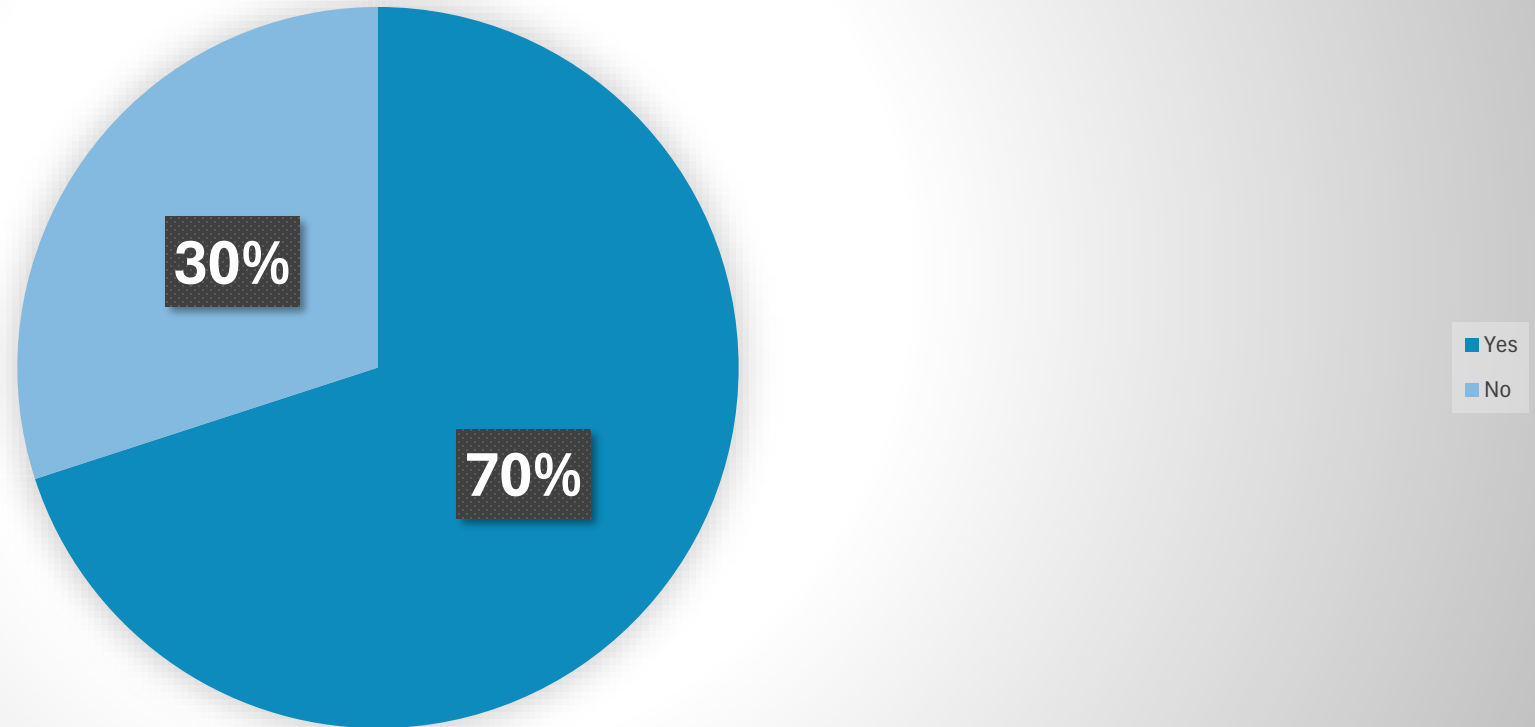


Support Neurodiversity

Autistic children

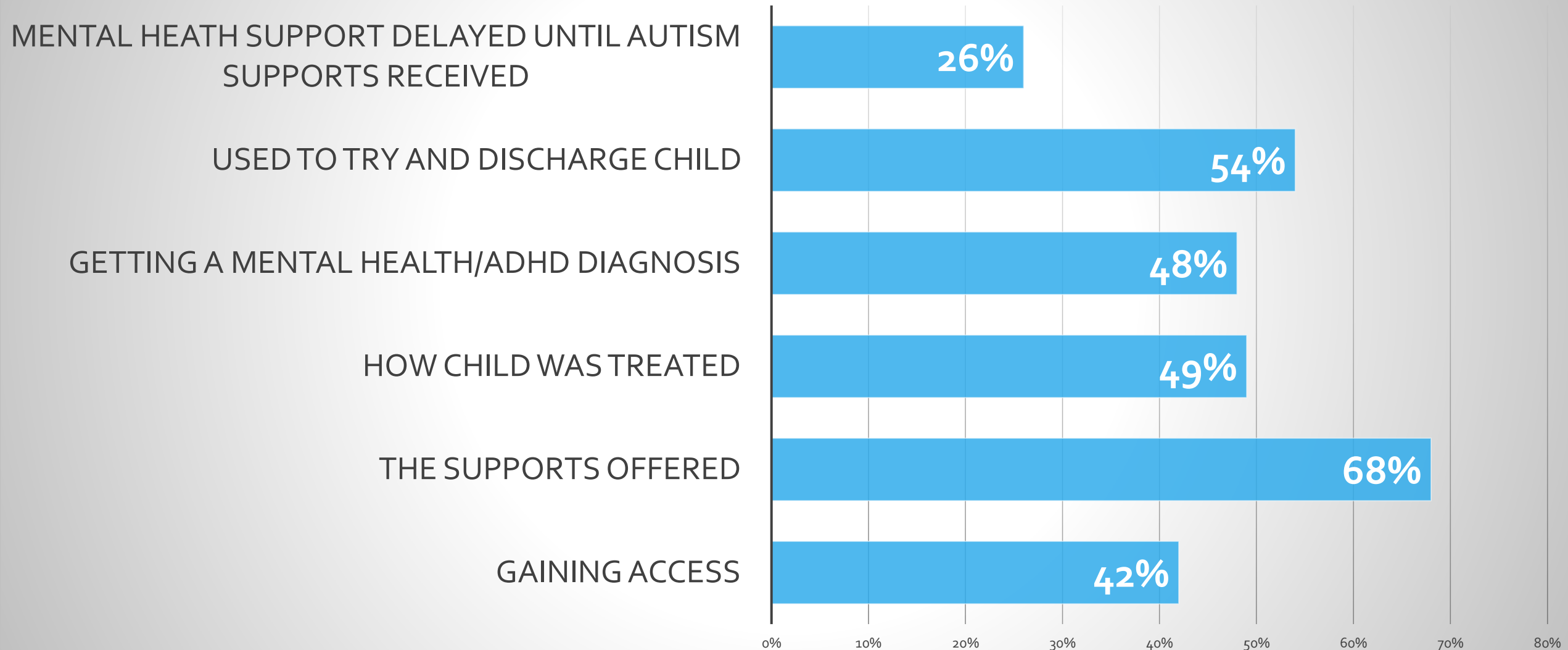
- **40% of autistic children were looking for support with ADHD; 60% with mental health issues**

Being autistic negatively impacted access to CAMHS or the mental health supports received



Experience of autistic children

Impact of autism diagnosis



Key Findings : Experiences of autistic children with CAMHS

- **Takes longer for a referral to be accepted by CAMHS**

First referral accepted: 51% of autistic children versus 66% children who are not autistic

- **More likely to end up in A&E while on the waiting list**

40% of autistic children versus 34% of children who are not autistic

- **Less likely to be offered more than 5 therapy sessions:**

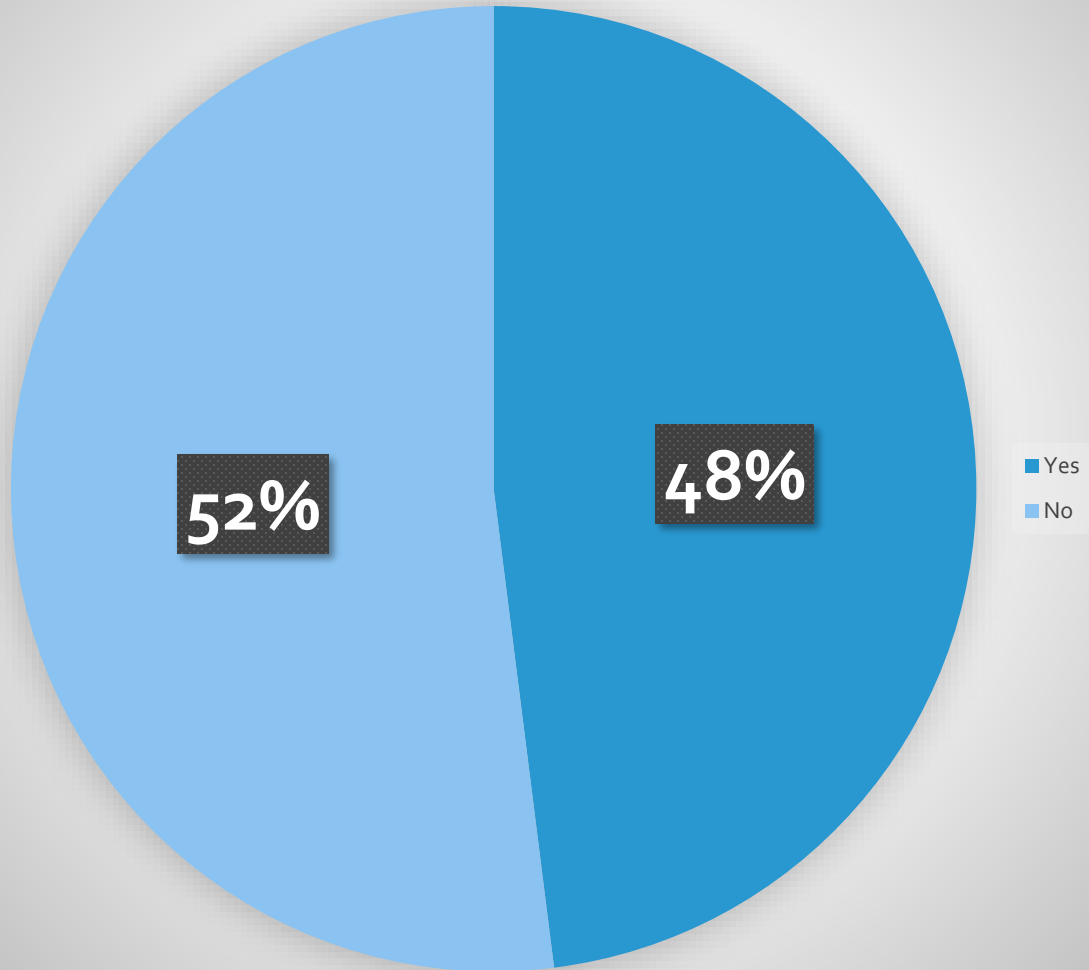
20% of autistic children versus 25% of children who are not autistic

Key Findings : Experience of an autistic child

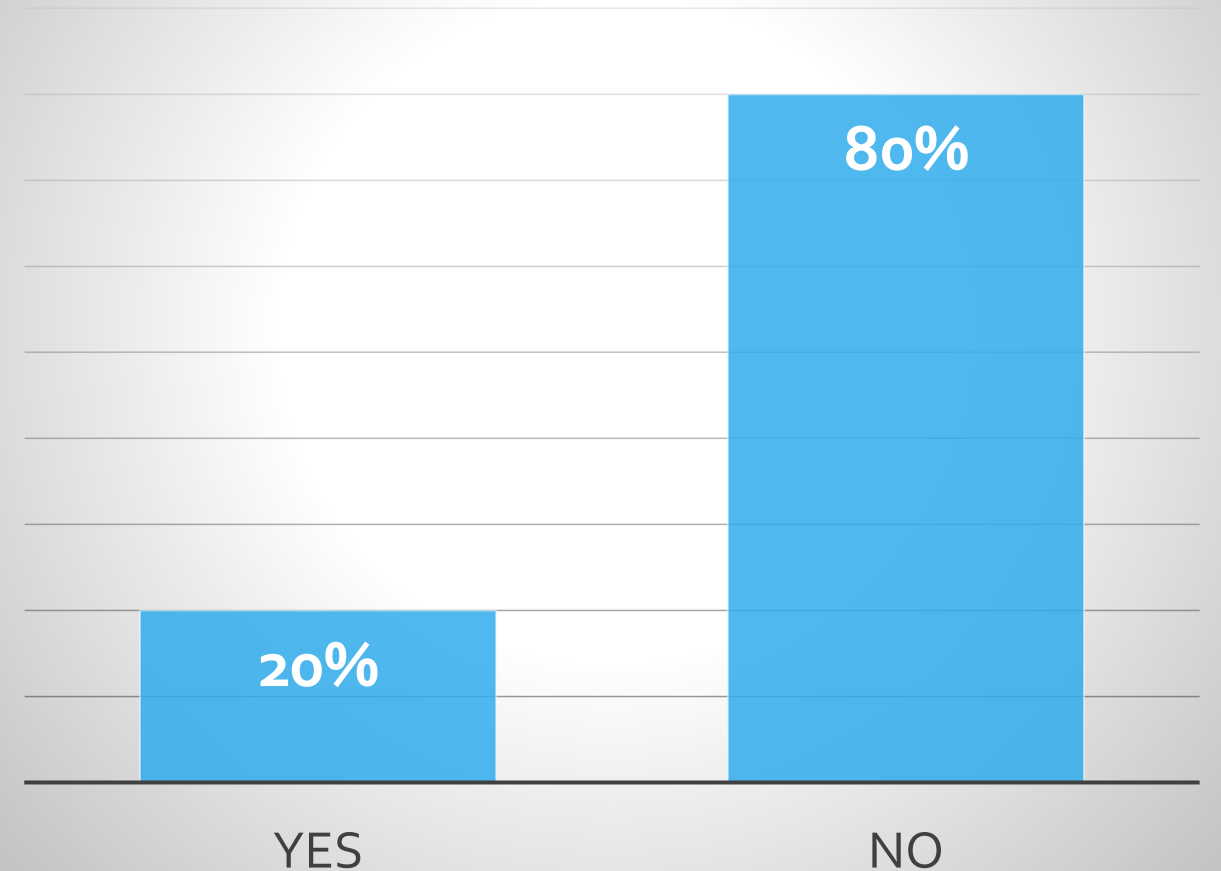
- **Less likely to be offered CBT-E or FBT when dealing with an eating disorder and families feel less supported:**
32% offered CBT-E or FBT compared to 52% of children who are not autistic
Only 12% of families with an autistic child feel supported with an eating disorder compared to 26% of families of children who are not autistic.
- **More than twice as likely to be turned away from CAMHS when experiencing suicidal ideation/intent:**
42% of families reported their autistic child being turned away from CAMHS when experiencing suicidal ideation or intent compared to 18% of children who are not autistic.

Experience of autistic children

Child currently with CDNT



Joint working between CAMHS and CDNT



Families Voices: Experiences of autistic children

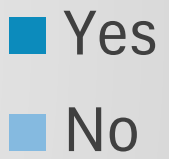
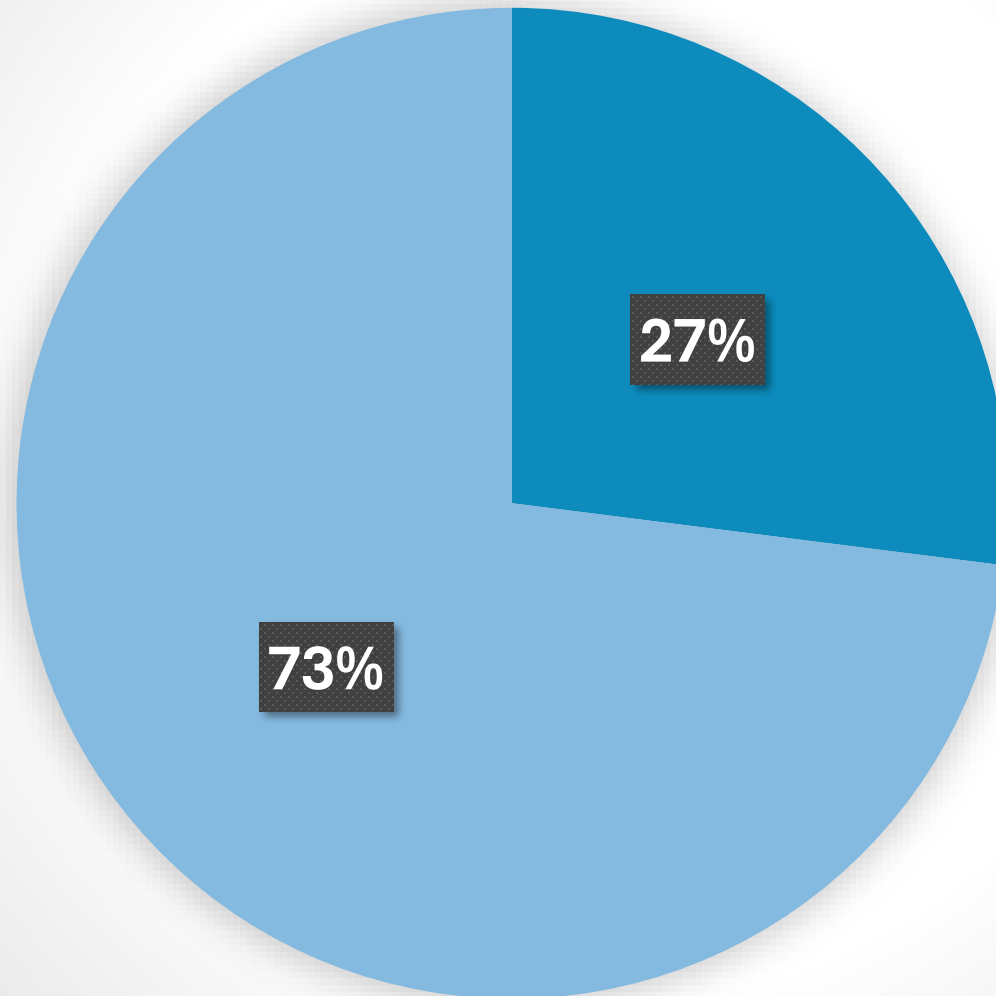
- *Passed back and forth between services too autistic for one and too anxious for the other.*
- *CAMHS point blank said 'we do not treat autistic individuals, you must 'fight' to get disability services....Disability services had no counselling suitable for mental health issues being experienced.*
- *Every issue was blamed on ASD diagnosis and each appointment they tried to discharge us.*



**Children
with ADHD**

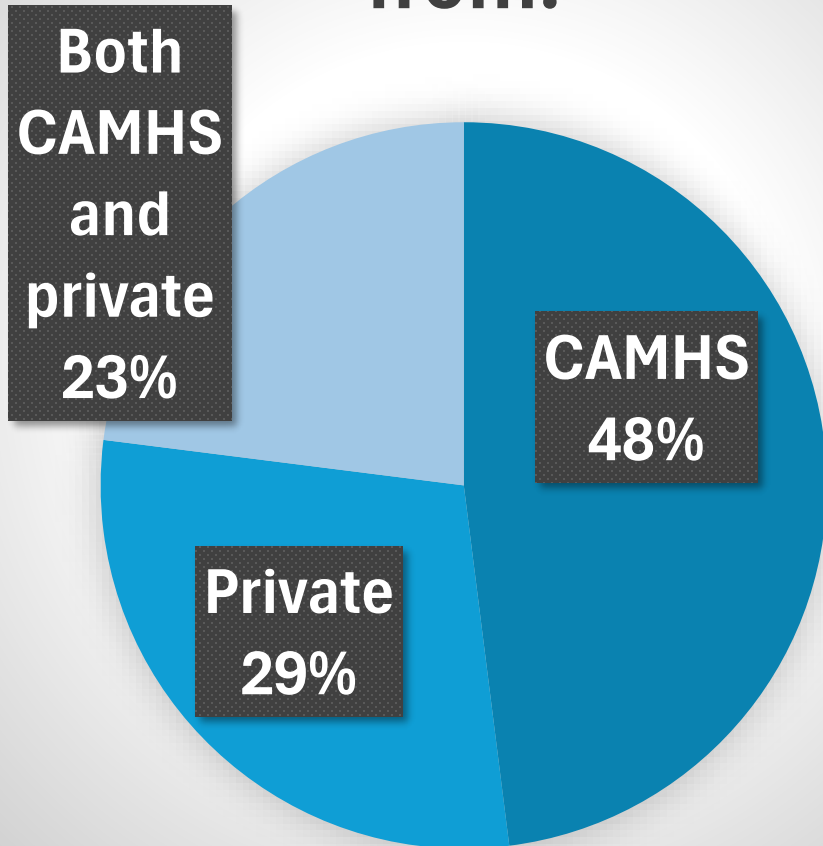
Experience of children with ADHD

Adequate support received for ADHD

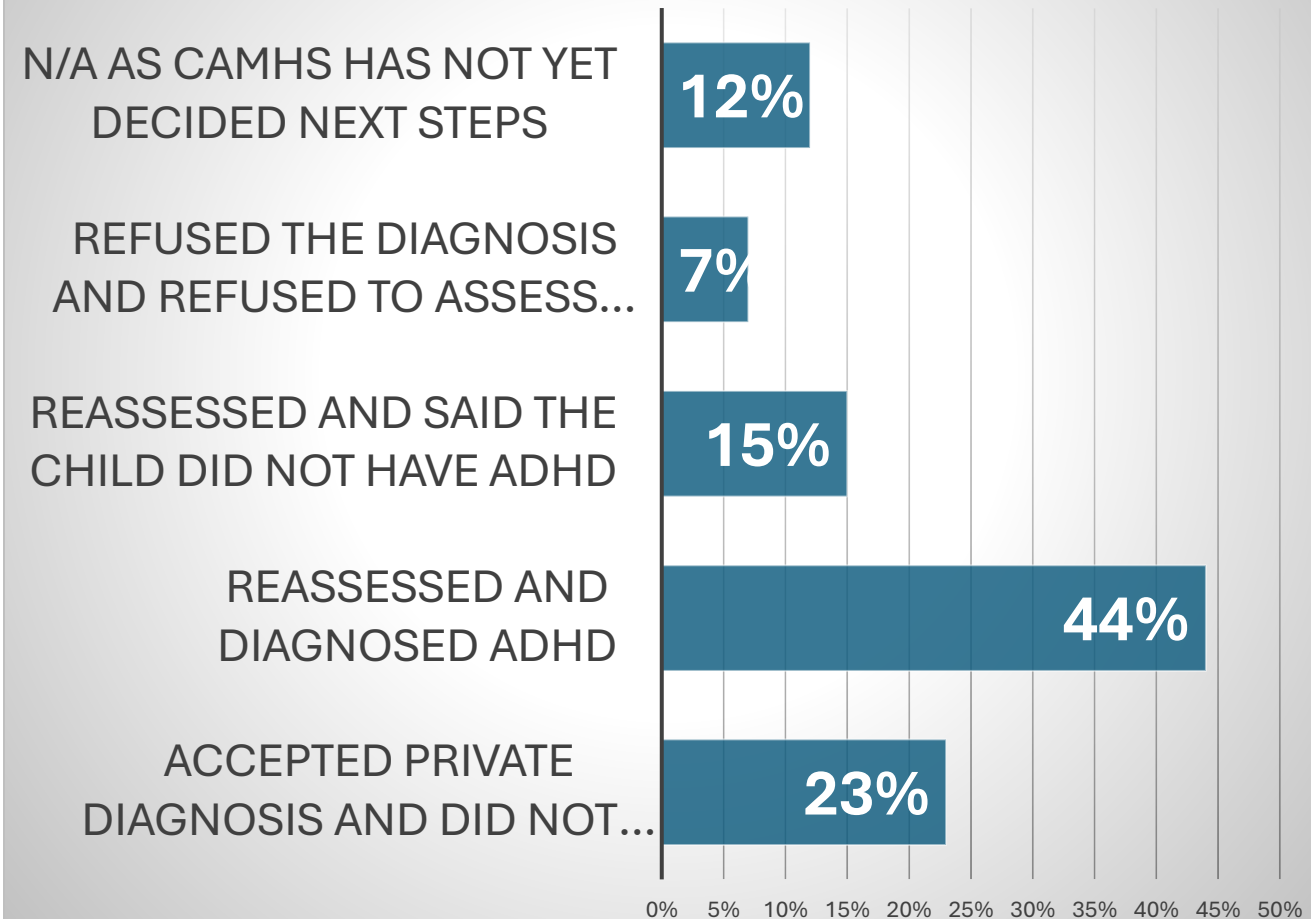


Experience of children with ADHD

ADHD diagnosis received from:



CAMHS response to private diagnosis of ADHD



Key Findings : Experience of a child with ADHD

- **Longer wait times for a referral to be accepted and spent on the waiting list**
33% of children with ADHD had to wait over 18 months to have a referral accepted, compared with 22% for children who do not have ADHD. 18% of children with ADHD also had spent over 18 months on the waiting list compared to 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 seek private support compared with 57% of families of children who do not have ADHD
- **Main supports include medication and parenting courses**
Lower numbers of children with ADHD (17%) are offered over 5 sessions of therapy compared with children without ADHD (31%)

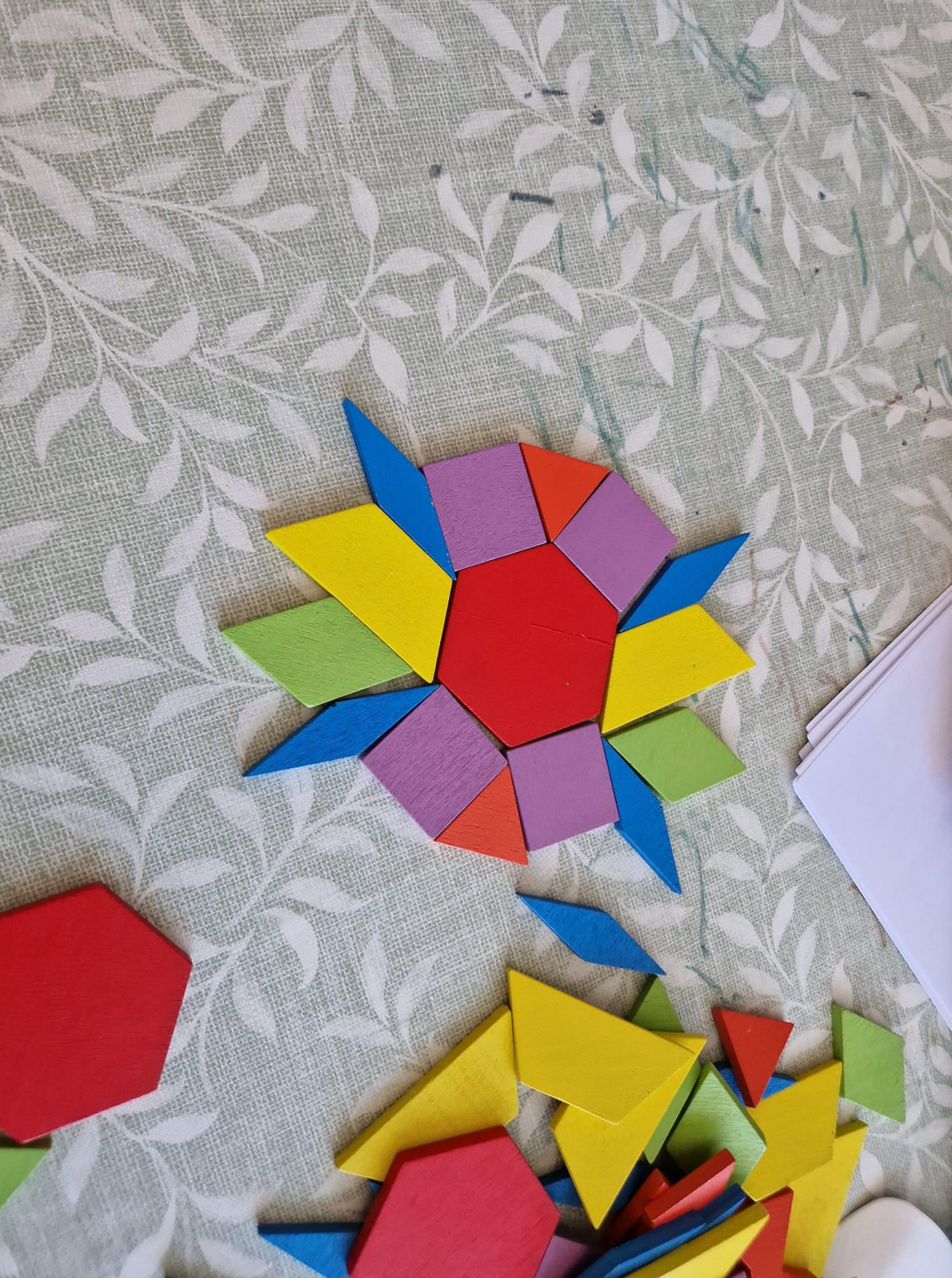
Families Voices: Experiences of children with ADHD

Should have been seen and diagnosed 5 years ago when first referral sent in

I feel we're just a number.

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.

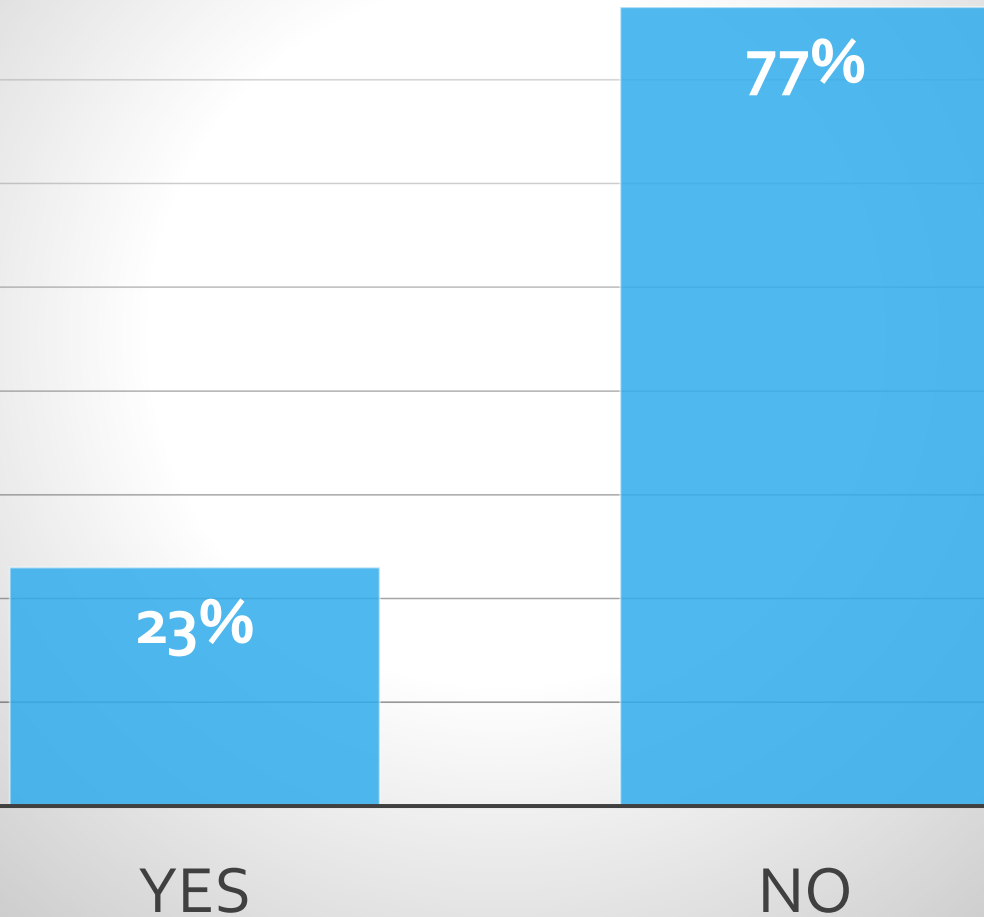
CAMHS are the only public service that can diagnose ADHD, but refuse to meet with a child who is presented to them displaying all symptoms.



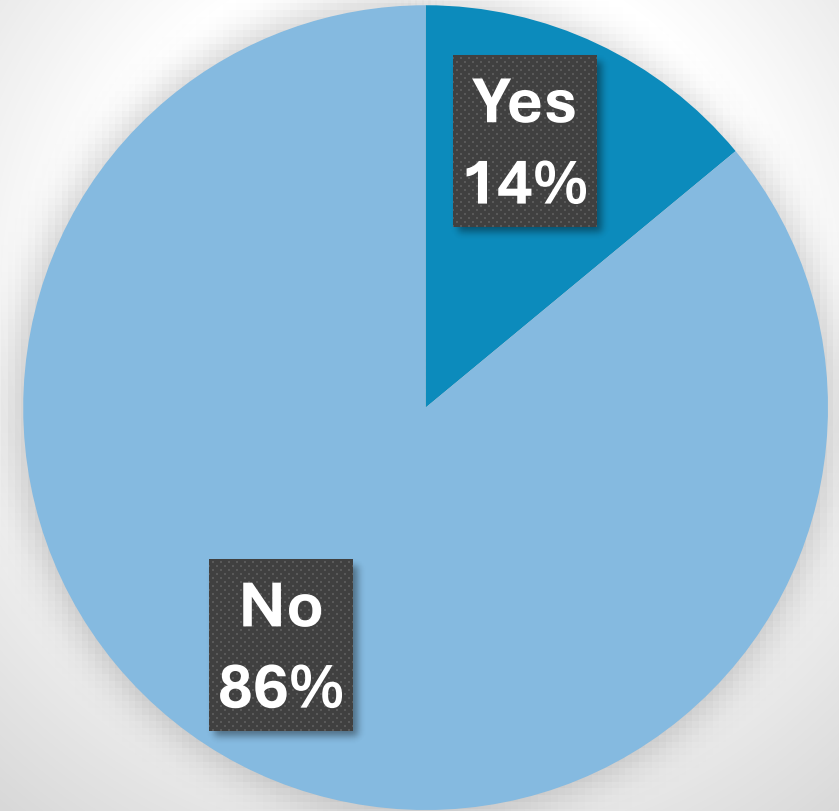
Children with intellectual disabilities

Experience of children with intellectual disabilities

Access to CAMHS-ID



Interim support while no CAMHS-ID service



Families Voices: Experiences of children with intellectual disabilities

- *We were 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.*
- *You're very much on your own.*

Key Findings : Experiences of children with an intellectual disability

Families twice as likely to go their local politician or to go to the media to try and access support for their child

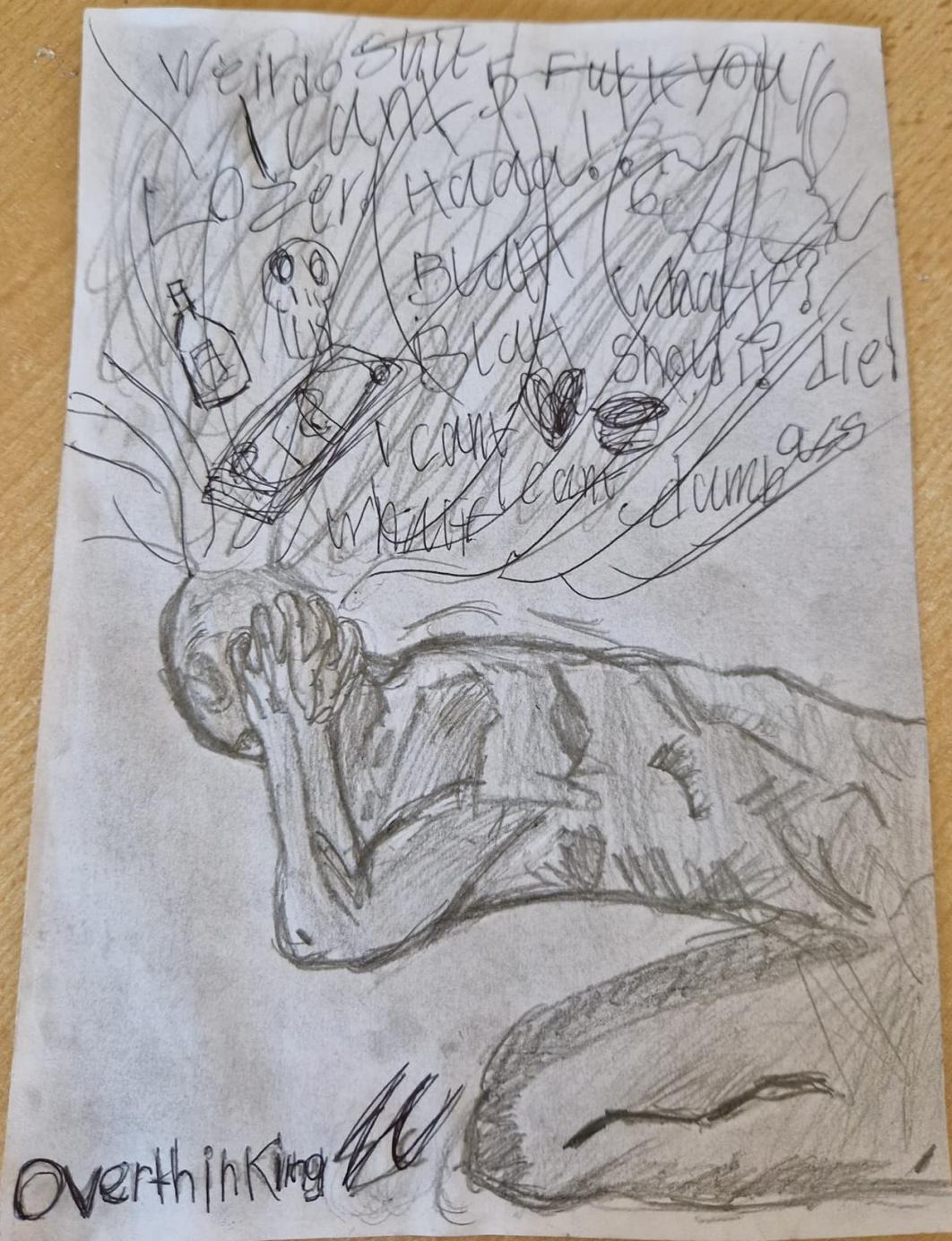
30% of families who have a child with an intellectual disability have sought support from a local politician and 10% have gone to media compared to the overall average in the survey of 15% and 5% respectively.

More likely to be discharged from CAMHS in their first 6 appointments

42% of children with intellectual disabilities are discharged from CAMHS within the first 6 appointments compared with 30% of children without intellectual disabilities.

Families less likely to be in agreement with their child's discharge from CAMHS

90% of families who have a child with intellectual disabilities did not agree their child was ready to be discharged compared with 69% of families with a child without an intellectual disability

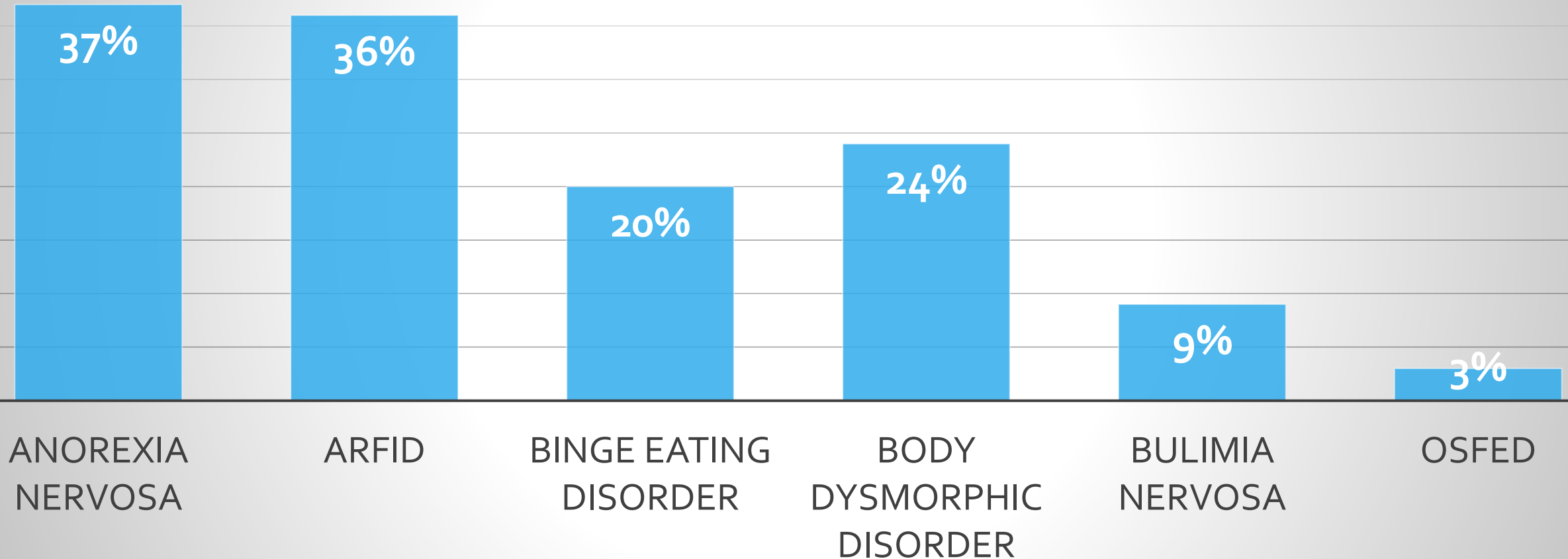


Children with an eating disorder

Experience of children with an eating disorder

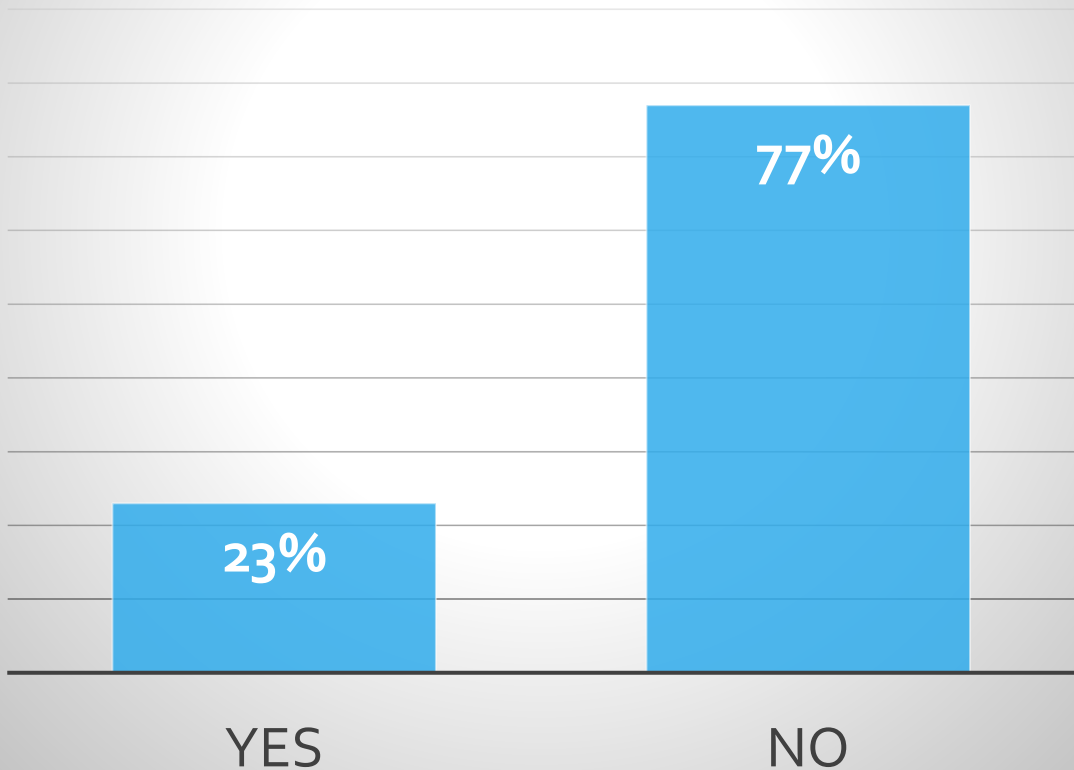
- A quarter of kids with CAMHS or who have left CAMHS has an eating disorder

Eating disorder being experienced

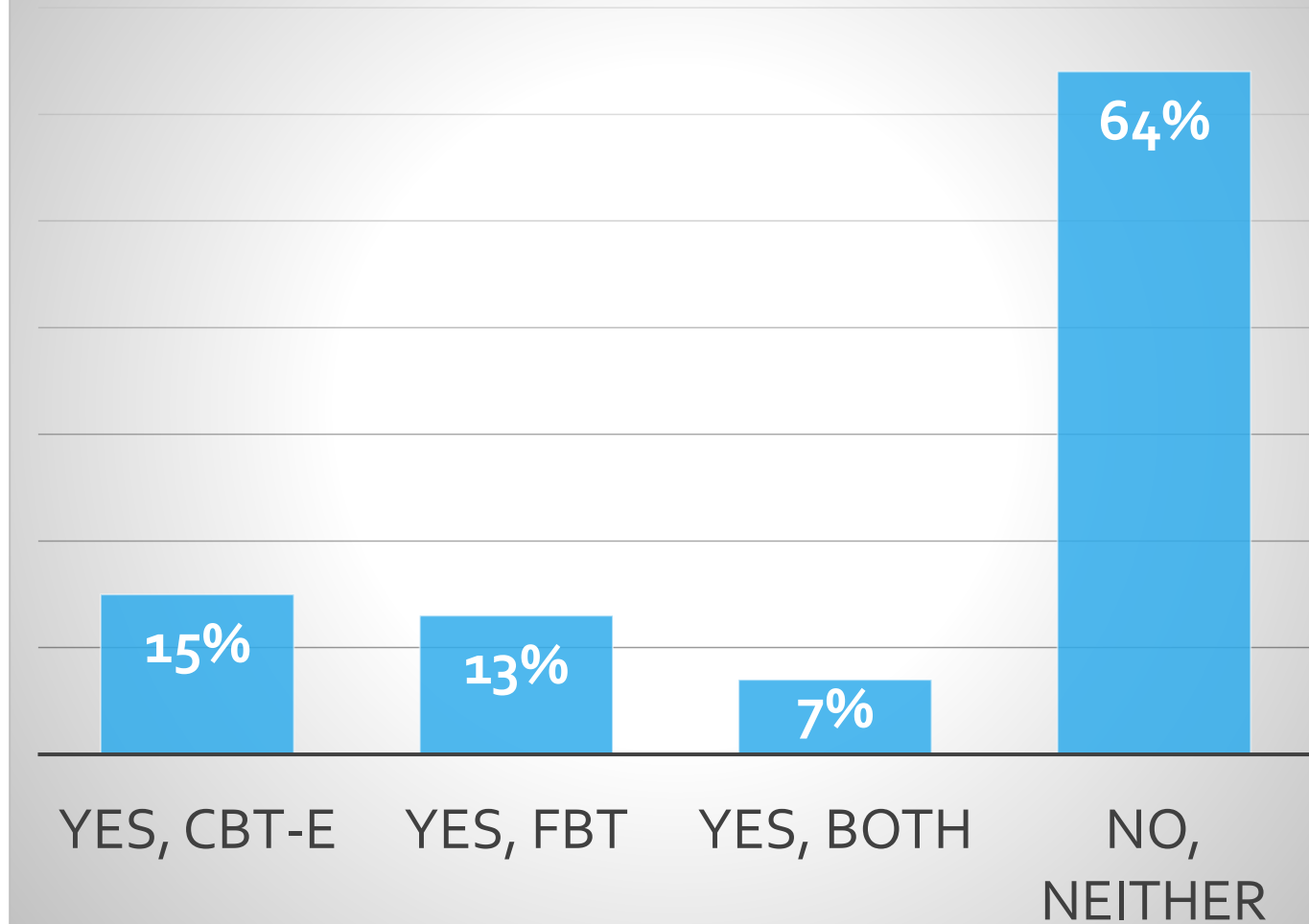


Experience of children with an eating disorder

Access to an eating disorder team or specialist staff member

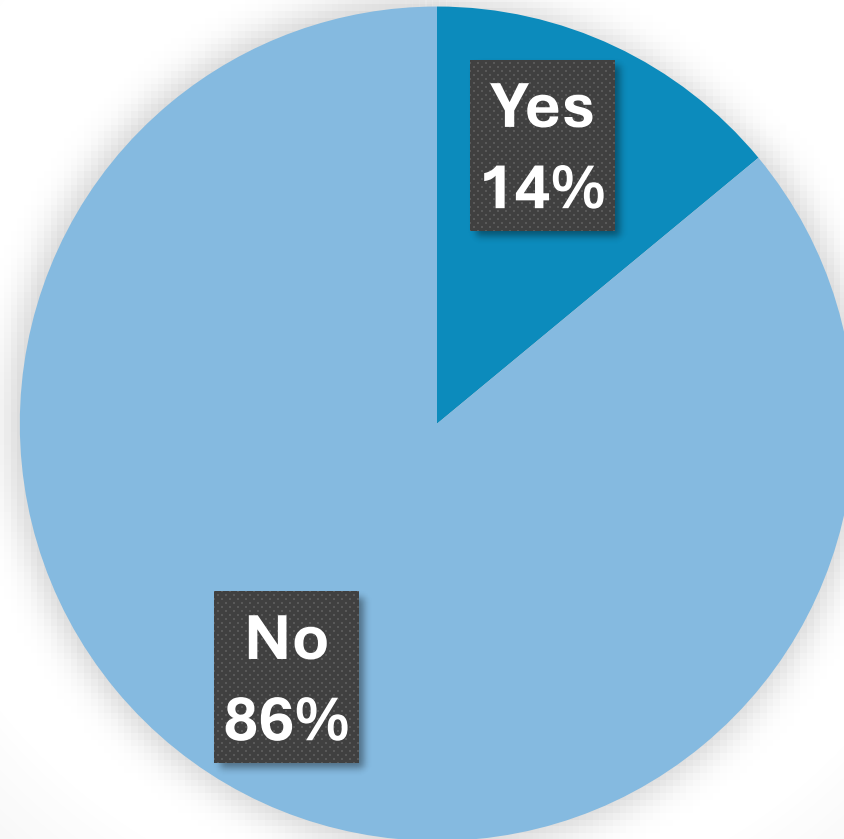


Offered CBT-E or FBT



Experience of children with an eating disorder

Adequate support for eating disorder



Families Voices: Experience of children with an eating disorder

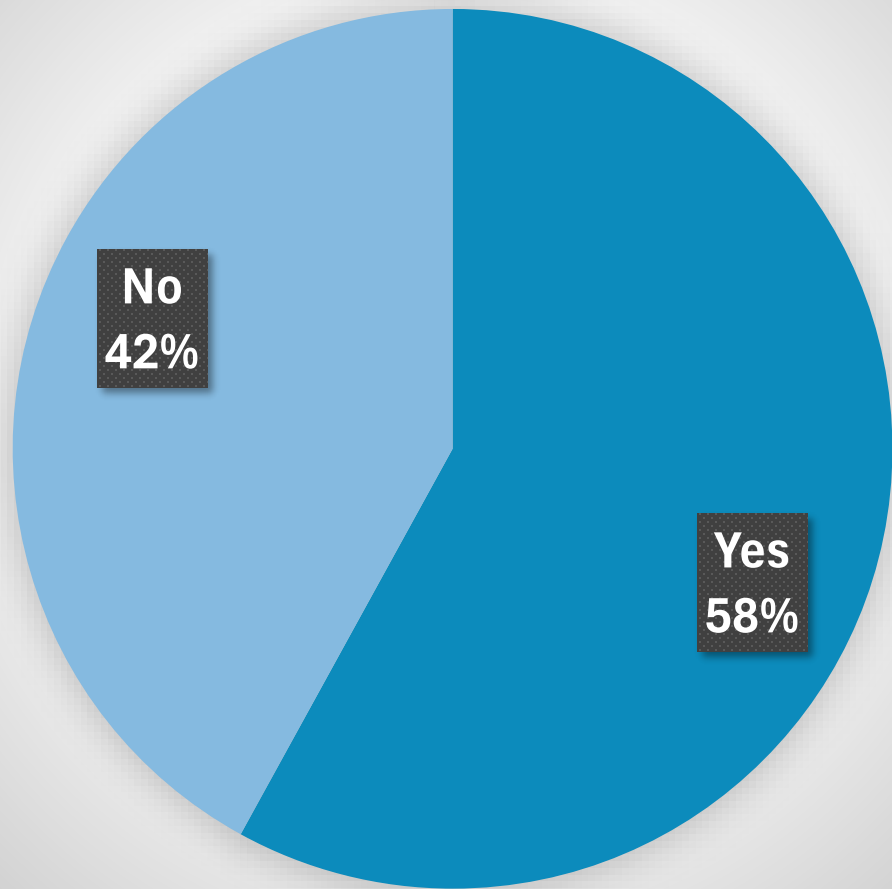
- *We went private, couldn't wait for CAMHS, she would be dead.*
- *This is escalating and I am left to manage it alone. Again, because of my background I have more knowledge than a lot of parents but I'm still mom. I am exhausted and it is impacting all of us.*
- *CAMHS told us that they wouldn't see her until she started eating again. It was a very difficult meeting and left us all confused.*



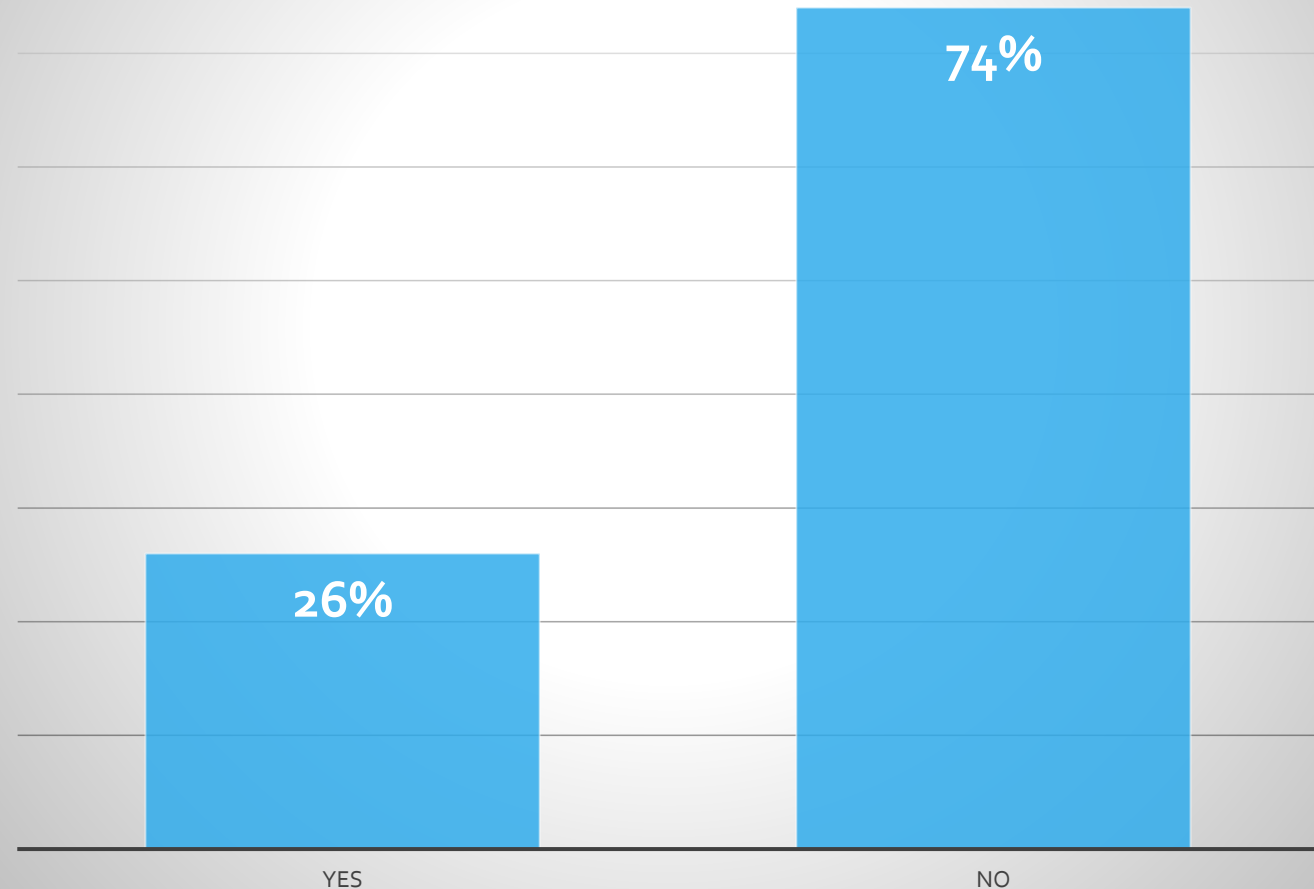
**Children
with
suicidal
ideation/
intent**

Experience of children who have experienced suicidal ideation or intent

Experienced suicidal ideation/intent



Adequate support received for suicidal ideation/intent



Families Voices: Suicidal ideation or suicidal intent

- *Was told to hide sharp objects and go to A&E if required.*
- *Still had to wait over 1 month to be seen after A&E referral.*
- *They say she is not going to do anything even though she threatens to hurt herself/says she wants to die on a regular basis. I hope they are right as I'm extremely worried.*
- *When he was actively trying to kill himself CAMHS would not refer him to a children's unit to keep him safe. We got our GP with referral from Pieta to refer him to John of Gods privately.*
- *My child took their own life, CAMHS did everything they could to discharge her and didn't believe.*

What we are calling for

Commitment to the Mental Health Commission's Recommendations:
including the Regulation of CAMHS

Commitment to the Oireachtas
Committee for Children's
Recommendations - May 2024

Government engagement and
prioritisation of reform

How you can help

- Keep raising the issue of CAMHS. Call on colleagues/government to prioritise the better provision of mental health services and a whole of government response.
- Call out the language used: Policy and responses provided do not reflect the reality



Report will be available online
from Thursday afternoon at:

<https://www.families-for-reform-of-camhs.com/>

Please promote findings:

@Reform_of_Camhs
#CAMHS

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