Families for Reform of CAMHS

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

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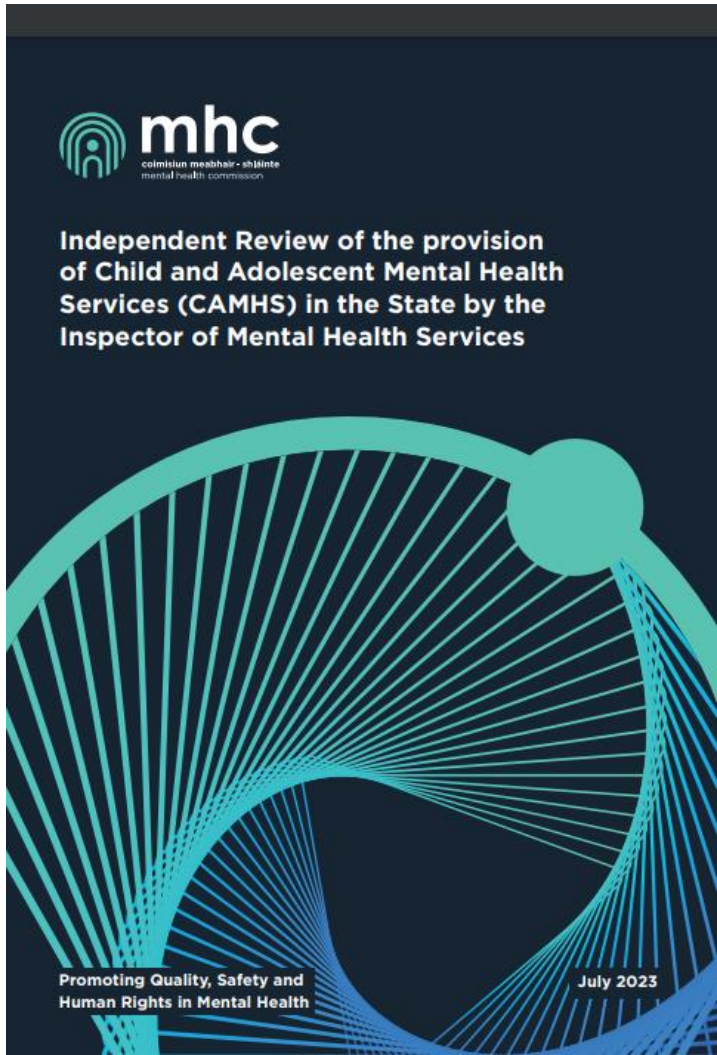
Background

- Group set up at the beginning of Summer 2023
- 380 families across Ireland
- 10 key reforms we are calling for
  (with 31 sub measures)
- Mental Health Commission Report and
  49 recommendations

  (not new concerns – 2017 Report; no Government commitment given so far to new 49 recommendations)



Key figures

- 22,000 children being referred to CAMHS every year

- 16,000 children awaiting appointments for primary care psychology (for mild to moderate mental health issues)

- Over 4,400 children waiting for first-time CAMHS appointments (for moderate to severe mental health issues); 735 children waiting more than a year.

  [NB. This figure only accounts only for the children who have not been turned away from the service]

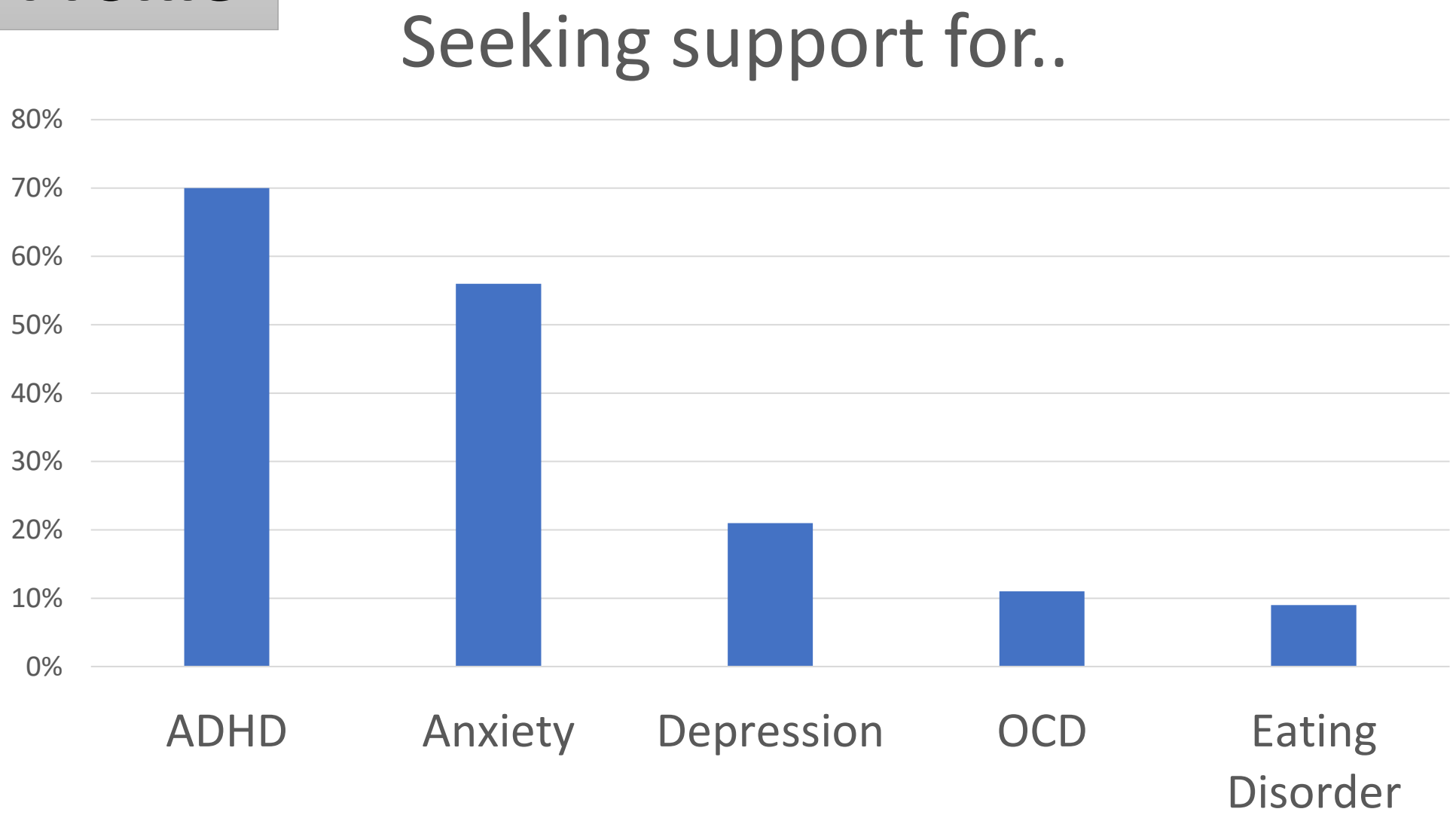
- The number of children with medical referrals to CAMHS being refused by the Service has jumped by 12% since 2020

- 6,471 children have presented to emergency departments in 4 Dublin hospitals since 2019 for mental health supports

How we compare at European Level

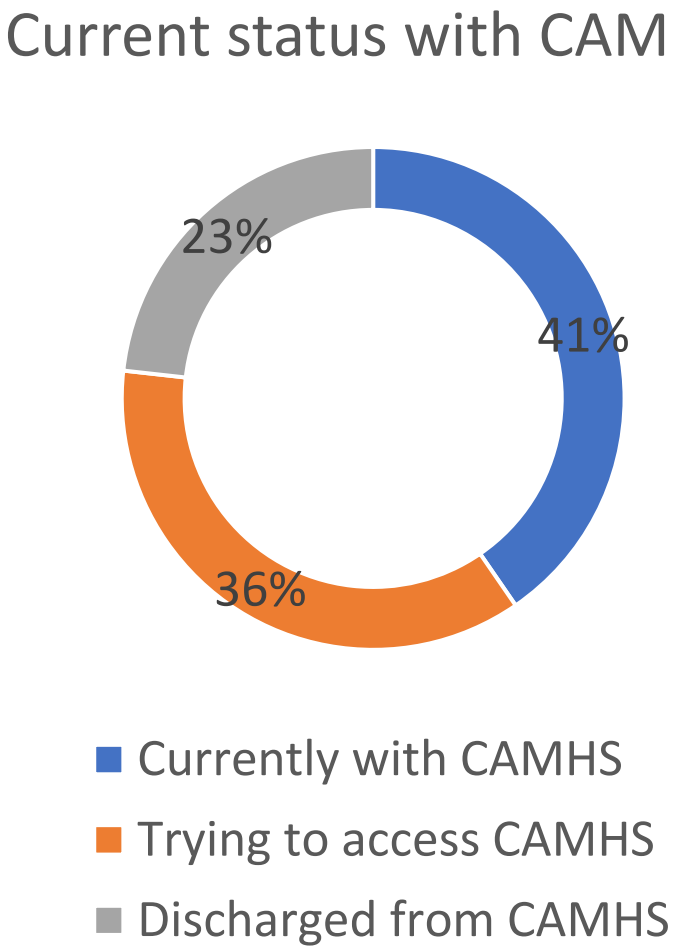
- Highest level of difficulty in accessing mental health services among citizens of the 27 EU member states; 44% of Irish people had a difficulty in receiving treatment for a mental health issue compared to the EU average of 25% *[EU Eurobarometer 2023]*
- In 2021, Ireland ranked in the bottom one-third of 41 countries in the EU/OECD for child mental health. *[UNICEF Report Card 16]*
- In 2020, the number of children aged 10-14 years who are self-harming increased indicating that the age of onset of self-harm is decreasing *[National Self Harm Registry Ireland 2020]*
- In 2020, One in every 128 girls, and one in every 233 boys, between the ages of 15-19 presented to hospital due to self-harm. *[National Self Harm Registry Ireland 2020]*
- In 2017, Ireland ranked the highest for girls dying by suicide in Europe. *[UNICEF Report Card 14]*

Group Profile



24% of members chose 'other' and mentioned suicidal ideation, self-harming, hallucinations, ODD, and general mental health deterioration.

Group Profile



- 41% of our members have a child currently with CAMHS
- 36% of our members have a child who they are trying to access CAMHS for
- 23% of our members have a child or young adult discharged from CAMHS

Reform 1

Annual ring-fenced funding for CAMHS which takes into account the commitments made by Government and the HSE over the last decade and the funding required to ensure a safe, effective and child-centred service going forward.

UNCRC recommendations in February:

child rights-based approach into the State budgeting process and define specific budget lines for all children

- Funding allocated to mental health has stalled between 5 and 6% of Ireland's total health budget in recent years.
- Compares unfavourably with other countries (France spends 14.5% and the UK spends 14%) and approx half of what the recommended spend is internationally.
- Many milestones from *Sharing the Vision* are categorised as having 'major delivery issues due to funding constraints'.

Budget 2024: Minister Mary Butler disappointed with amount allocated to mental health. Why is mental health not being prioritised?

Previous Commitments made

10% of the health budget to be spent on mental health

[Sláintecare Report 2017]

Reform 2

Address the clinical and administrative staffing shortage in CAMHS

Mental Health Commission Report 2023

- Not one CAMHS team is fully staffed and some teams operate at below 50% of what they should be
- Great variations in staffing levels and different disciplines leading to inequalities across CHOs
- No Practice Managers and low number of Team Coordinators
- Teams are operating at about 50% of their recommended administrative staff.

- Recruitment process is **slow and bureaucratic,** taking approximately 18 months from advertising post to appointing someone.

College of Psychiatrists Ireland - urgent need to train, recruit and retain more child psychiatrists

"That means wide-ranging reform of our mental health services – including investment, capacity and doctor numbers. Furthermore, we need to attract the doctors of tomorrow into our health system, and that doesn't happen by accident."

Reform 2

Address the clinical and administrative staffing shortage in CAMHS

Reforms sought:

2 (i) Adequate funding & greater **streamlining/decentralisation of the approval system to fill vacant clinical posts**;

2(ii) Identification and implementation of **other models** to deliver a mental health service for children based on international best practice;

2(iii) Increase the availability and quality of **Primary Care and Social Care services**;

2(iv) Set benchmarks for CAMHS staffing nationally and develop **clear action plans** on how these targets will be met and maintained;

2(v) Ensure a **practice manager and team coordinator for each CAMHS team**; and

2(vi) Ensure CAMHS teams are **fully staffed from an administrative perspective** so that clinical staff can focus fully on their clinical duties.

Previous commitments made

- A minimum of 647 consultant psychiatrist approved posts filled on a permanent basis by this year. Currently only 400. *[HSE NDTP workforce planning document p.26]*

- 129 CAMHS teams due for implementation in 2016. There are currently 74/75 teams. *[A Vision for Change]*

***A Vision for Change*, 2006**

Two child and adolescent CMHTs should be established for each sector of 100,000 population. Individual teams should comprise the following:

- one consultant psychiatrist
- one doctor in training
- two psychiatric nurses
- two clinical psychologists
- two social workers
- one occupational therapist
- one speech and language therapist
- one child care worker
- two administrative staff.

Reform 3

Remedy issues preventing access to CAMH Services

Waiting lists:

- Postcode lottery: worst affect areas - Area 4 (Cork, Kerry), Area 6 (Wicklow, Dublin South East), Area 8 (Laois, Offaly, Longford, Westmeath, Louth, Meath)
- Resorting to A&E (increasing issue with this)
- Resorting to going abroad or using online psychiatrists

Inconsistency in acceptance of referral rates:

- Acceptance of medical referrals varied hugely between 38% and 81% *[Mental Health Commission Report]*

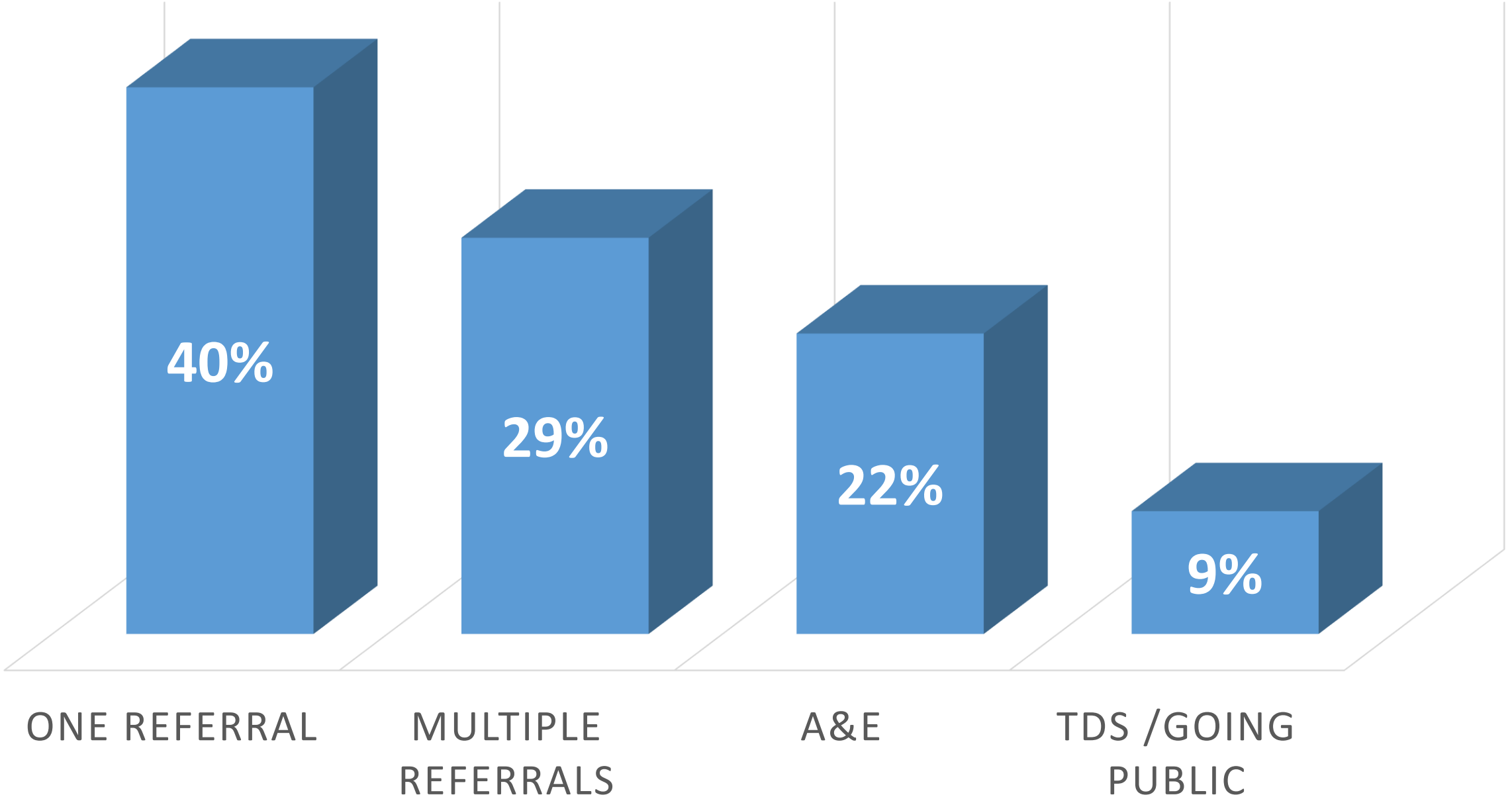
Reforms sought:

3 (i) The **increase of staffing and resources**, in line with those recommended in *A Vision for Change* to tackle lengthy waitlists and provide timely support to children experiencing mental health issues;

3 (ii) **Early consultation with families** on the impact that centralising CAMHS supports would result in for them; and

3 (iii) Greater transparency around the CAMHS **criteria for acceptance of referrals** to the service and **consistent application nationally.**

ACCESSING CAMHS: OUR MEMBERS



Illustrator: Missing the Mark

Personal experiences:

- **Parent 1:** The reality of not being able to access support from CAMHS and using an online psychiatrist

- **Parent 2:** The impact on her child of waiting for support when they needed it most

Reform 4

Integrate the children's mental health services with other children's services

Reforms sought:

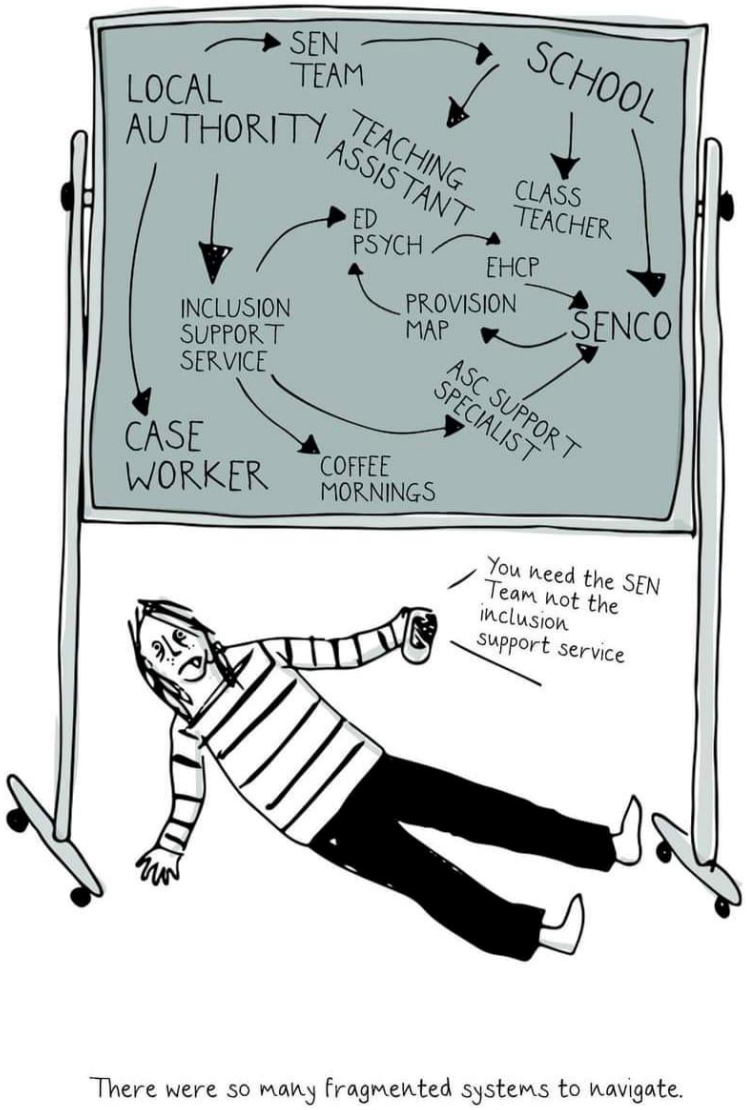
4 (i) Proper links and **joined up working between services** with a clear move away from the current 'pass the buck' approach.

4 (ii) Allocation of a **key worker** who acts as a single point of contact for each child and family to help them navigate the system and coordinate across services.

Prior Commitments

Joint working or shared care with other agencies, including HSE Primary Care, Children's Disability Network Teams and other agencies supporting children and adolescents.

[CAMHS Operational Guidelines 2019]



Illustrator: Missing the Mark

Personal experiences:

Parent 3: Integrated services…not our experience!

Reform 5

End the practice of discrimination against autistic children in the provision of mental health services

- **59% of our members have an autistic child and 85% of those members feel that having a diagnosis of autism has negatively impacted the service and support received by their child**
- Some members mentioned support being withdrawn once a diagnosis of autism was disclosed and others raised concerns that turning away autistic children is being used as a way of reducing waiting lists and refusing referrals.
- Some members felt that CAMHS explained away anxiety/depression as just being part of ‘ASD’ rather than acknowledging and offering support for the mental health issues being experienced.

- Autistic children, are 28 times more likely to consider suicide *[Committee on Autism]*

- Approx 70% of autistic children are estimated to have a dual diagnosis of a mental health disorder *[Autism Innovation Strategy, National Disability Authority]*

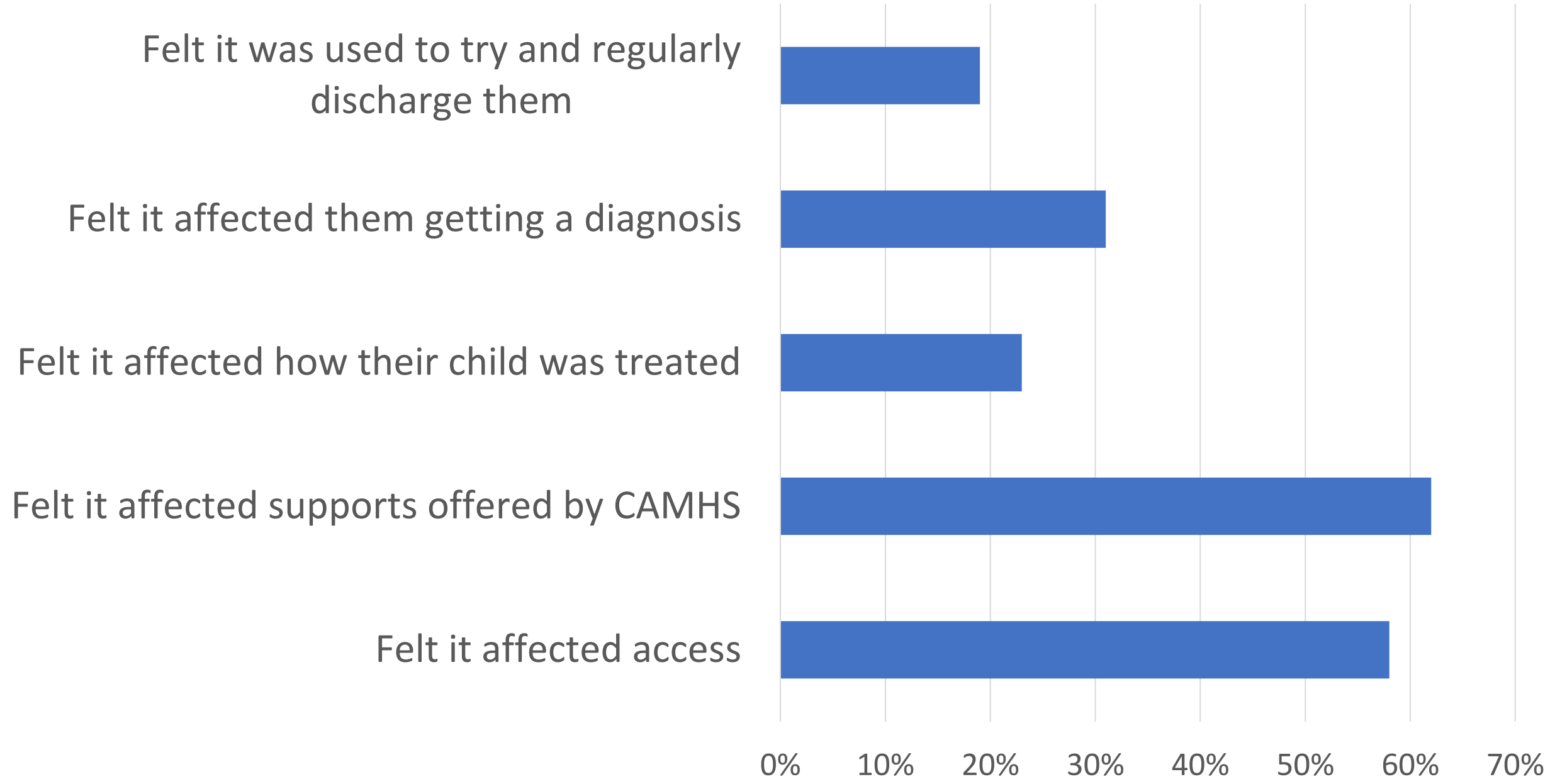
- The South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry, Psychology & Neuroscience estimates that 35% of women they treat for anorexia nervosa have autism. They are developing accessible and tailored treatments for these patients.

- UK has autistic people as a high priority group in the UK Suicide Prevention Strategy 2023-28

CAMHS:
provides specialised support and services to children experiencing moderate to severe mental health difficulties

CAMHS Operational Guidelines set out that admission can be refused to autistic children **“where there is an absence of a moderate to severe mental health disorder”**

Autism diagnosis: Our experience



- *“After being on a waiting list for over a year we were given 1 appointment and discharged as they decided my daughter is autistic. Emetophobia deteriorated over the following 6 months resulting in a trip to A&E because my daughter had stopped eating. A&E department concluded she needed to be under CAMHS care and contacted them to get an urgent appointment. We were given an appointment 2 months later but still no services as they want to wait on AON results before they offer any treatment. CDNT have said that even if there is an Autism diagnosis, it is CAMHs who would have to treat the emetophobia anyway.”*

- *“Referred to CAMHS after my daughter was in A&E for attempted suicide. Eventually CAMHS agreed to see our child, but it was a fight all the way. When they diagnosed her with ASD the help became speech and language support, which wasn’t all that was needed. They refused to hear me that my child was at risk of harming themselves..”*

- *“Was told that my child’s suicidal thoughts and plans were not really mental health issues and just their autism.”*

- *“Child refused support for severe anxiety, self-injurious behaviour and suicidal ideation as they kept saying it was due to autism and they do not deal with autistic children.”*

- *“they related all mental health issues back to ASD which they don’t treat. It’s an impossible situation”*

- *“the GP said we might want to keep quiet about ASD being a possibility if we are accepted.”*

- *They said my daughter's behaviour wasn't 'egodystonic' which I had to google and means they thought her behaviours were not out of character. I had to then repeatedly try and prove how nothing about her current behaviours were normal for her in the slightest. That she was in severe distress which was not at all normal”.*

- *they used ASD to dispense with looking at the child’s actual issues in my opinion”.*

- *"Appointments were about how everything was down to the fact that she is autistic. She denied that our daughter has an anxiety disorder - she now has complete agoraphobia."*

- *"Child treated as a burden. Outdated negative language re autism being used constantly in front of child."*

- *"His diagnosis of Autism was used to avoid providing him with mental healthcare services."*

- *"Once CAMHS found out that my son had autism all his issues were put down to autism."*

CAMHS Hubs

- Autistic children in CAMHS with **“a primary diagnosis of Autism”** have been excluded from accessing supports from the pilot phase of the launch of the CAMHS Hub.
- **But** Autistic children in CAMHS have already been deemed to reach the threshold of moderate/severe mental health issues..discrimination?

Instead of access to a CAMHS Hub…

“where an autistic child presents with a moderate to severe mental disorder the role of CAMHS may include in-reach consultation where the child or adolescent remains with the referrer or the child/adolescent is accepted for multidisciplinary case management for mental health condition; with autism supports if required remaining in the remit of Primary Care or Disability services.”

Our position: Autism

- A **burden of proof** is placed on families of autistic kids over and above that placed on families of neurotypical children to prove there is a 'mental health disorder' despite the fact that autistic children disproportionately experience greater mental health issues in comparison with their neurotypical peers

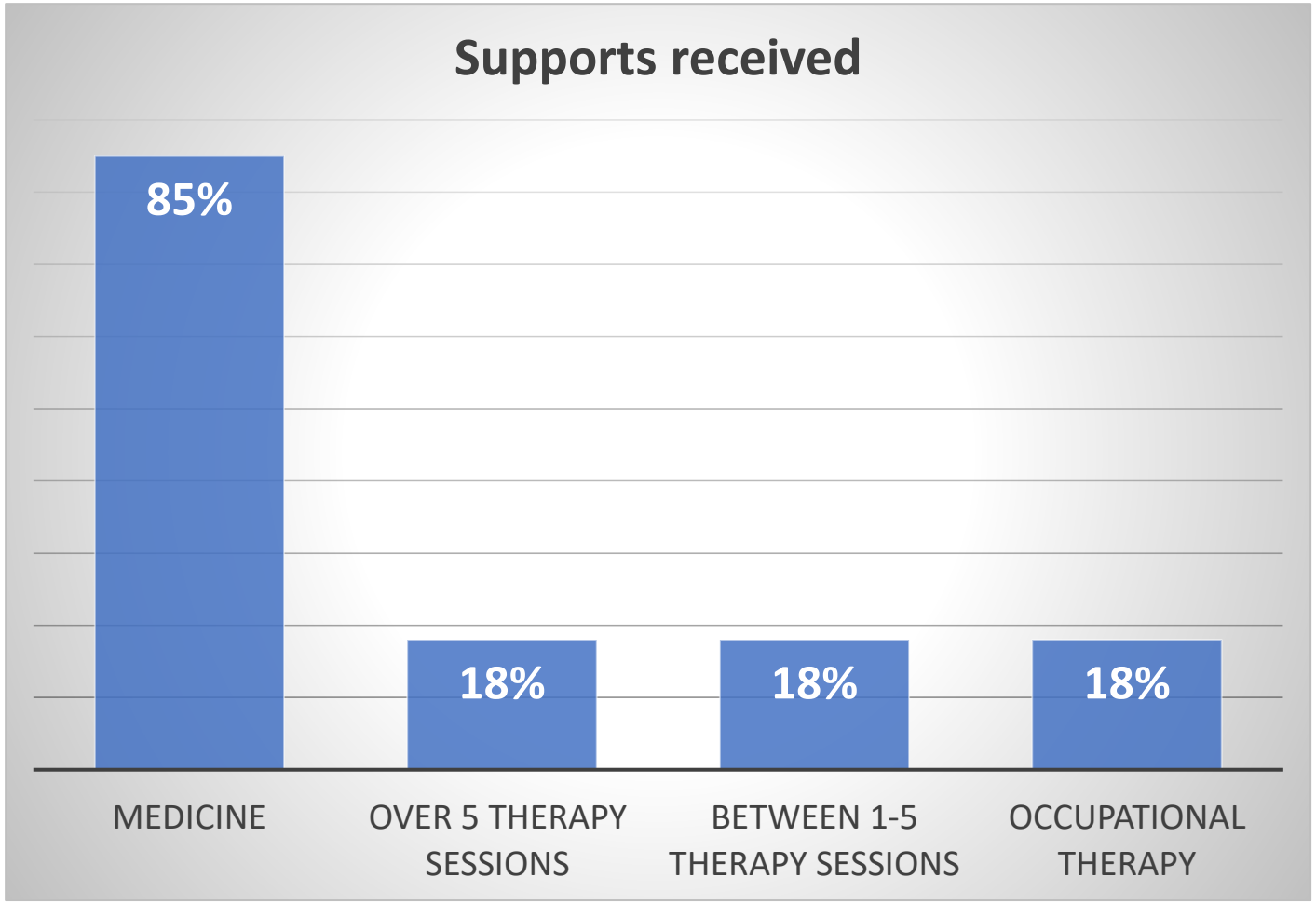
- **We would like narrative around and reality of autistic children to be changed so it is on a par with their neurotypical peers.**

i) CAMHS *is* the appropriate service for autistic children with moderate to severe mental health issues (on a par with neurotypical children); and

ii) where there is not a moderate to severe mental health issue the child will not fall within the remit of CAMHS (again on a par with neurotypical children).

Reform 6

Increase availability of supports and the types of supports offered to promote a child-centred approach to recovery



Reforms sought:

6 (i) **Therapeutic supports and proactive intervention** for our children based on their individual needs available consistently across the country;

6 (ii) **An end of the practice of discharging (or threatening to discharge**) children whose families decide not to use medication or take part in a parenting course;

6 (iii) Proper provision of **eating disorder services and gender & sexuality se**rvices

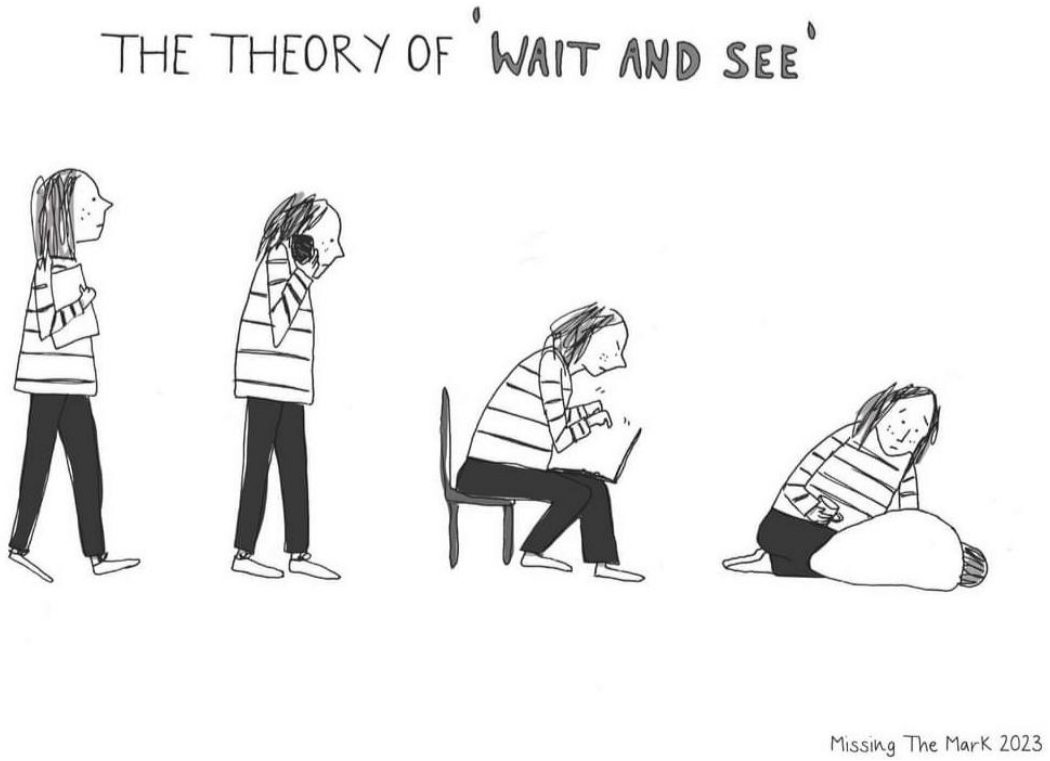
6 (iv) Delivery of the commitment to provide **out-of-hours mental health treatment for children**

Prior Commitments

Out of hours and 7 day a week CAMHS service

[HSE Executive Service Plan 2019]

Personal experiences:



- **Parent 4:**

Family's experience of CAMHS appointments.

Illustrator: Missing the Mark

Reform 7

Increase the number of CAMHS-ID teams and ensure a clear referral path to access them

- **31% of our members have a child with an intellectual disability who requires access to a CAMHS-ID service and of that group 81% have no access to mental health services.**

Policy	Reality
There should be 16 teams	4/5 partial teams
Each team should have 11 fulltime staff	10 consultant psychiatrists with no staff or one or two team members

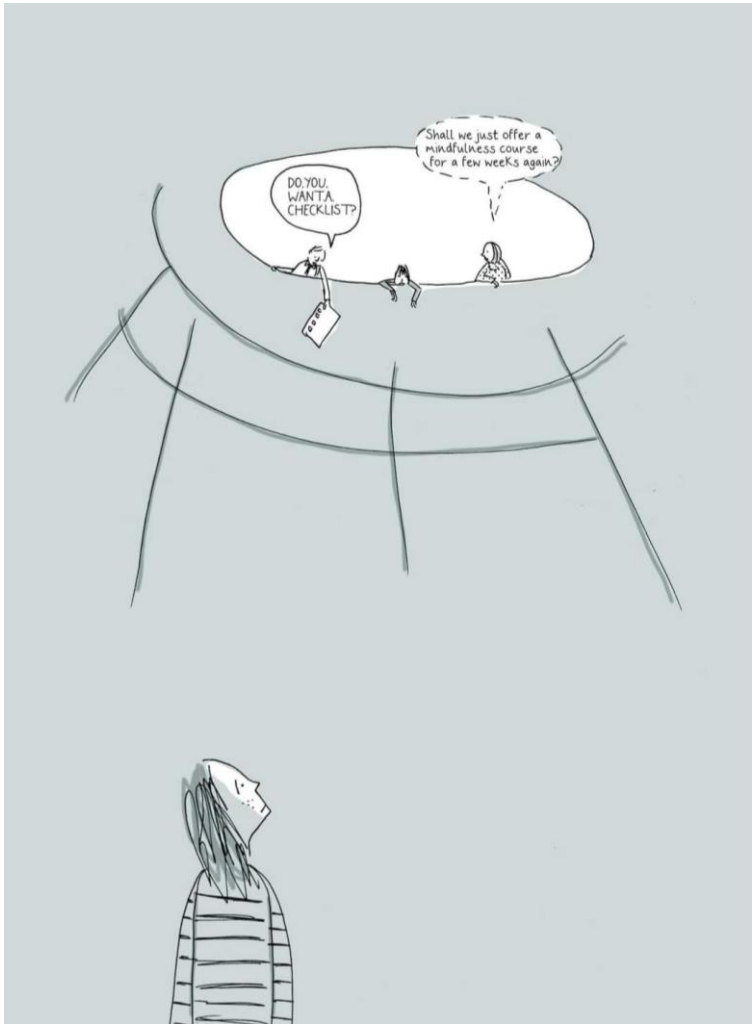
HSE*: 'There are some areas where difficulties in staff recruitment have contributed to areas not fully developing CAMHS MHID team. In those areas, local arrangements are in place such as consultant psychiatrists providing a consultative service'* **Not our experience!**

Prior Commitments

One CAMHS-ID team per 300,000 for children with intellectual disability. [*A Vision for Change – due for implementation in 2016]*

***A Vision for Change,* 2006. CAMHS-ID teams should include:**

- one consultant psychiatrist
- one doctor in training
- two psychologists
- two clinical nurse specialists (CNS) and registered nurses with specialist training
- two social workers
- one occupational therapist
- administration support staff



Personal experiences:

- **Parent 5:**

No mental health services available for her daughter

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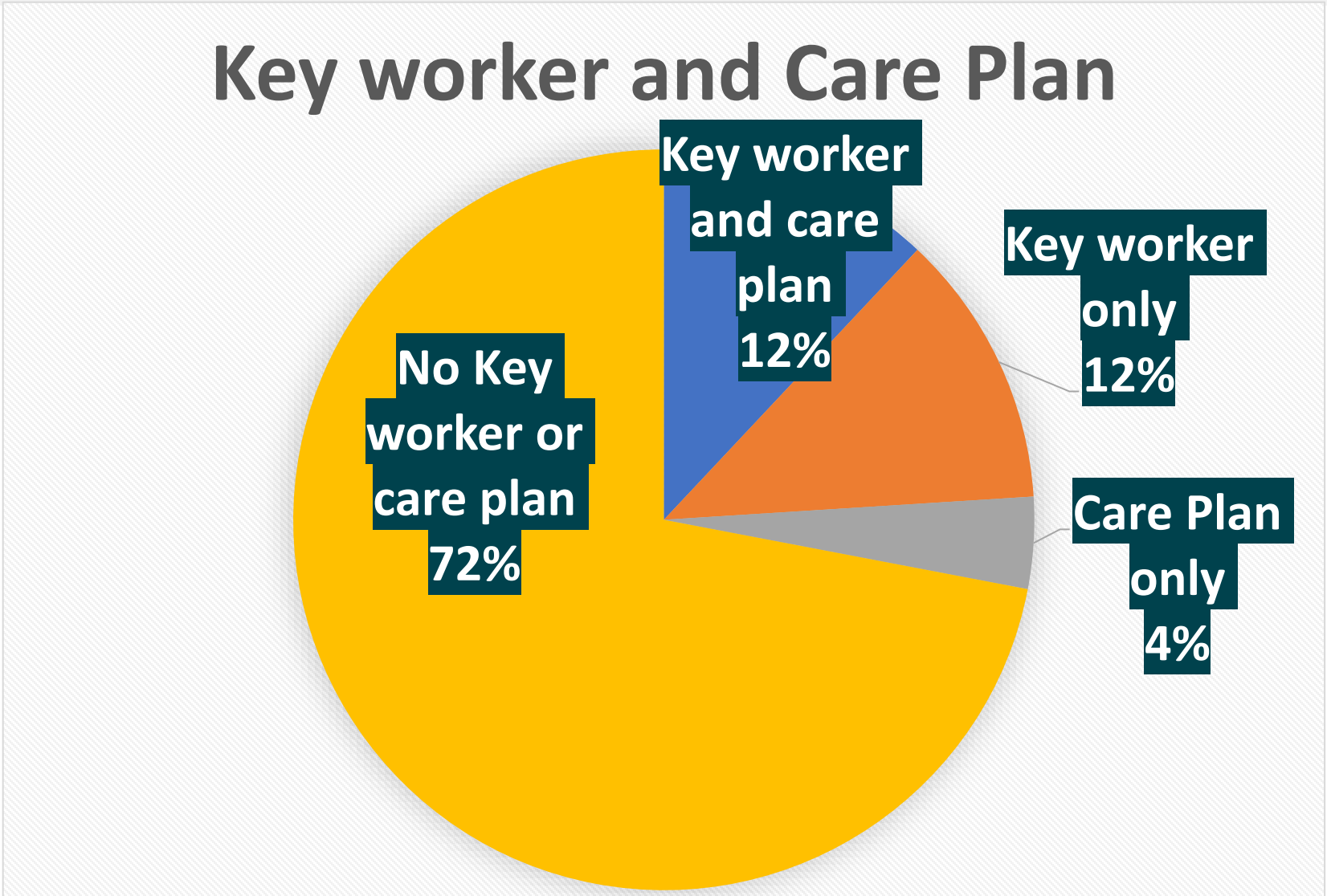
Reform 8

Appoint a key worker and provide a clear Care Plan to every child under the remit of CAMHS



Prior Commitments

Each child should be allocated a key worker who takes responsibility for remaining actively in contact with the family and coordinate care provided by all team members.

[CAMHS Operational Guidelines 2019]

Each child should have an Individual Care Plan which describes the levels of care and treatment needed to meet the assessed needs, is outcomes focused and is developed in collaboration with the child and their parent(s)

[CAMHS Operational Guidelines 2019]

Reform 9

Substantially improve the communication and provision of information between CAMHS and families under their remit

Reforms sought:

9 (i) **Proactive and responsive communication** between CAMHS and families about the care of their child;

9 (ii) The provision to families of a **list of services** offered by their local CAMHS team and **a "Whose Who"** of the team looking after their child;

9 (iii) The provision of a **short booklet or a copy of the CAMHS Operational Guidelines** to each family to ensure that they are aware of the structures of CAMHS and the services that they should expect; and

9 (iv) The provision of information to families in relation to **relevant supports** that might be of help to that family

Prior Commitments

CAMHS *"will aim to provide comprehensive information to families and other referrers and by communicating with all relevant parties effectively and efficiently".*

[Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services]

Reform 10

Ensure the introduction of a transparent, accessible and safe review and complaints process

- 74% of our members who submitted a complaint were not happy with how it was handled.
- 35% of our members would like to submit a complaint but are worried about how it would impact their child's care.
- 2023 survey held by the Ombudsman for Children, only 11% of children believed that the CAMHS staff listened to them and 27% believed the staff were dismissive.

What we are calling for

Implementation of our 10 key reforms and sub reforms

Commitment to the Mental Health Commission's 49 recommendations: including the **Regulation of CAMHS**

Government engagement and prioritisation of reform

How you can help

- Support legislation to regulate CAMHS
- 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:
  (i) Policy does not reflect the reality
  (ii) Impenetrable responses provided by Department of Health/HSE which don't reflect the reality of families

Suggestions?

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