Families for Reform of CAMHS, written submission to the Committee on Children, Equality, Disability, Integration and Youth:

Access to CAMHS for children with a dual diagnosis

7th November 2023

Introduction

Families for Reform of CAMHS welcomes the opportunity to make a submission on the difficulties faced by families of a child with a dual diagnosis when trying to access the Child and Adolescent Mental Health Services (CAMHS). As a new group who are sharing experiences and collecting data through surveys and polls, we are beginning to gain a clear picture of systemic discrimination against our neurodivergent children in the provision of mental health services and a complete lack of a functioning service for children with intellectual disabilities.

Families are being turned away from CAMHS and denied supports when they and their child need it most and we are calling on the Government and the HSE to address this situation urgently and as a matter of priority.

While our submission presents a stark picture of the experiences of families trying to access support from a broken and under resourced system, we would like to underline that we have found the staff working in CAMHS to be dedicated professionals who are trying to help our children despite the system and often at a cost to their own wellbeing[1].

Background

Families for Reform of CAMHS is a family representative and support group for families who are trying to access CAMHS, currently with CAMHS or who have been discharged from CAMHS.

The group was set up in May 2023 and is currently made up of over 640 members from across the country. According to a survey carried out in August 2023, 70% of our members are seeking support for their child for ADHD; 56% for anxiety; 21% for depression; 11% for OCD and 9% for an eating disorder. 24% of members chose the option of 'other' in the survey and specified that they were seeking support for suicidal ideation, self-harm, emotional dysregulation, hallucinations, oppositional defiance disorder and general mental health deterioration.

59% of members have an autistic child and 31% of members have a child with an intellectual disability. Some members also have a child with a physical, neurological and/or genetic condition.

I. Access to mental health services for autistic children

Policy position

CAMHS Operational Guidelines 2019 set out that admission can be refused to autistic children *"where there is an absence of a moderate to severe mental disorder"* but that where there is such a disorder, *"it is the role of CAMHS to provide appropriate multi-disciplinary mental health assessment and treatment for the mental disorder. This may involve joint working or shared care with other*

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[1] https://irishpsychiatry.ie/cpsychi-press-statement-doctor-burnout-having-hugely-negative-impact-on-patient-care-021023/

agencies including HSE Primary Care, Children's Disability Network Teams, and other agencies supporting children and adolescents."

While the possibility of refusing services to autistic children is explicitly called out in the CAMHS Operational Guidelines, it is the threshold of having a moderate to severe mental health difficulty which is specified to be the deciding factor as to whether children can access CAMHS.

Experiences of members of *Families for Reform of CAMHS*

Discrimination against autistic kids

While the HSE denies that there is any discrimination against autistic children, we strongly believe based on our experience that the exclusionary clause in respect of autistic children is often being used against them to not offer supports or a differential diagnosis. That rather than diagnosing an anxiety disorder or acknowledging self-harm or suicidal ideation as part of a mental health issue, everything is linked back to autism so as not to have to offer supports.

According to our August survey, 59% of our members have an autistic child, and of those members 85% said that having a diagnosis of autism has negatively impacted the service and support received by their child from CAMHS.

This is deeply concerning to us, especially as 70% of autistic children will have at least one co-occuring psychiatric condition and 41% will have two or more[2]. One of the more common co-occuring conditions is ADHD and this is covered in more detail later in the submission.

Some of our 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. Many members said 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.

Many of our members have to make repeated referrals to CAMHS for their autistic child and some have to resort to attending the Emergency Department of a hospital to receive an appointment with CAMHS or to obtain an initial diagnosis which can then be used to access CAMHS.

Where an appointment is offered, families are oftentimes then met with an uphill struggle where all symptoms are linked back to the autism diagnosis and the family is told that the Child Disability Network Team – who does not specialise in moderate to severe mental health issues - should be providing the support. A burden is placed on families to repeatedly explain and set out how the issues being experienced are not typical of the child, inconsistent with their usual behaviour and causing severe distress.

Some experiences and views expressed as part of the August 2023 survey are set out below:

- *"CAMHS have withdrawn service once a diagnosis of ASD was mentioned."*

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[2] 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

- *"CAMHS genuinely believe children with autism should not be seen by them, and that there is no role for ADHD or anxiety medication in improving their quality of life. Absolute discrimination. Shame on them."*

- *"The second time, they tried to discharge us as soon as they found out that she is autistic. They would not add her to waiting lists (for the anxiety team) and constantly threatened to discharge us as our child being autistic meant that they were taking another child's spot."*

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

- *"It [autism diagnosis] has been used to prevent him from getting a service."*

- *"It [autism diagnosis] caused difficulty being accepted to the service, the service was slow to accept the diagnosis of OCD and is used as a reason to refuse therapeutic support."*

- *"Child is autistic. Serious anxiety. CAMHS keep referring back to disability services."*

In order to learn more about the challenges that families were experiencing in accessing mental health supports for their autistic children, we ran another survey in October 2023. The results showed that of our members with an autistic child:

- 62% felt that their child being autistic negatively affected the supports offered by CAMHS;
- 58% felt that their child being autistic negatively affected their ability to access CAMHS;
- 31% felt that their child being autistic negatively affected them getting a diagnosis;
- 23% felt that their child being autistic negatively affected how their child was treated; and
- 19% felt that their child being autistic was used to try and regularly discharge them.

Some of the experiences and views expressed as part of the October 2023 survey are set out below:

- *"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.”*
- *The home school liaison warned me strongly not to disclose that my daughter was waiting for an autism assessment when we first attended CAMHS. Her experience was that they would discharge her immediately to primary care services. The psychologist who carried out the assessment previously worked for CAMHS and also warned me they would try to discharge her when they found out she was having the assessment. Although she has been kept on there is no counselling service in spite of severe anxiety and suicidal ideation. We feel they don’t take her seriously. She feels invalidated, small, invisible, her words. We haven’t seen a doctor in 5 months after her overdose despite being on medication.”*

The experience of autistic children being turned away from CAMHS while experiencing suicidal ideation was also raised multiple times and is of particular concern to our group. A number of experiences are set out below:

Parent Experience (9 year old daughter):

Parent 1 shared the referral letter sent and refusal letter received at the time of their daughter’s mental health crisis. The referral letter – sent by the family’s GP asking for CAMHS engagement - sets out how this 9 year old girl was saying that *“she wished she was dead and that she didn’t want to be here”*. The letter of refusal from CAMHS stated, *“She does not appear to have a moderate to severe mental health illness and therefore we will not be accepting this referral. It is common for children with disabilities to have meltdowns and say they do not want to be here.”* The refusal letter was sent from CAMHS having never met the 9 year old.

Parent Experience (13 year old son):

“Our son – who is autistic – was turned away on his first referral to CAMHS even though he was self-harming and was experiencing suicidal ideation. We got a letter suggesting various autism supports on “enclosed sheet”. There was no enclosed sheet. Second time they only saw us because the GP insisted but CAMHS referred us on to family therapy at a local charity. Apparently we are not in the catchment for that charity though as we were turned away from them. CAMHS then refused two

referrals from a private consultant. Only got an appointment through A&E referral. But everything is attributed to autism."

Parent Experience (8 year old son):

"When X was suicidal CAMHS told us "well, he probably doesn't know what he is saying" and said that the ASD needed to be managed better. They never admitted him for his suicidal ideation only for an ADHD assessment. The meds caused increased suicidal ideation and weren't followed up on adequately (i.e. they didn't phone to see how it was going until a few weeks into it). When I mentioned his anxiety during the ADHD assessment and queried the effect of the stimulants on his anxiety (which I saw as the cause of the suicidal ideation at that time) the doctor said "what anxiety?" and then ushered us out. The part I found shocking was the complete minimisation, "he doesn't know what he's saying". X is fully verbal and very intelligent. He knows exactly what he's saying."

Parent Experience (13 year old son)

"My son is on the spectrum and was with CAMHS before he was diagnosed. He got his diagnosis through CAMHS in 2019 at the start of COVID and lockdowns etc. I firmly believe if he was diagnosed before that CAMHS wouldn't have seen him at all.

My son was struggling badly with OCD and anxiety. He begged his CAMHS doctor to send him to a residential hospital for help. The doctor refused. He was hitting himself and stopped all verbal communication for over 10 weeks. Not long afterwards my son took an overdose and I rushed him into hospital. I refused to take my child home from hospital. The CAMHS doctor rang me very upset with me for not taking my child home from the hospital. I told him I would if both himself and the hospital paediatrician signed a letter saying the child's life was safe. He told me that they couldn't do that so my reply was I can't take him home. The fighting went on for three days. I was then told my son was discharged without me being present. That he was homeless and TUSLA was going to be contacted to take my son from me. Eventually I got a Zoom meeting with the CAMHS residential hospital. It lasted 3 hours and they rang back after 15 minutes to say they were going to admit him immediately for a week to get him over the danger zone. He spent a month there and we had appointments with them every second day for a while afterwards."

Parent Experience (14 year old son)

"My son came to me during the first year of lockdown and told us he was struggling with being at home all the time and was missing his friends. As we spoke to him he admitted that he had been struggling for a while and not only wanted to end his life but had a plan and date to do it by. He told us that he planned to go to the bridge on the M3 and throw himself off it into the traffic. We praised him for being so honest with us and telling us before he hurt himself and promised that we would get help for him and keep him safe.

The GP advised us to present ourselves at A&E as it is the only way to access CAMHS in an emergency situation. We showed up at A&E at 8am where I explained that my autistic sone was suicidal and we urgently needed help. We were seen within an hour and the Doctor told us they had placed a call with psychiatry and CAMHS and that hopefully someone would be with us soon. By 6pm that day we still hadn't been seen. Another 2 hours went by before we were told that everyone from CAMHS had gone home and so had the psychiatric doctor.

I was told that CAMHS didn't deal with autistic children and that I should go back to the School Age Team for help. At this stage I broke down crying and said that my son's mental health was not an *issue the school age team were equipped to deal with and asked how was I meant to keep him safe. I was told not to leave him alone and lock up anything sharp.*

We eventually received an appointment for CAMHS after several weeks. The first appointment consisted of them saying my sons issues were down to his autism diagnosis. I became upset and said I wanted it in writing that they were refusing to treat a suicidal child because of his autism and that I would be contacting my solicitor. At this point they backtracked and said they would give my son a prescription for an antidepressant. I queried counselling and they said they were not equipped to deal with children with autism. We had 3 further appointments. At the final appointment they called my son the wrong name and told my I should take him off his Ritalin medication (that he has never taken nor been prescribed). My son asked not to go back. We sourced private counselling and have been left with zero faith in CAMHS."

Integrated services

The *CAMHS Operational Guidelines 2019* set out that "joint working or shared care" is envisaged between CAMHS and other agencies including HSE Primary Care, Children's Disability Network Teams, and other agencies supporting children and adolescents. This has not been the experience of our members.

> *"Does CAMHS ever work with another agency? Our experience is that CAMHS won't work with another agency. Our CDNT psychologist contacted CAMHS to get advice about our daughter's possible anorexia type behaviours (extreme restrictions on what she would eat and exercise). Our CDNT psychologist repeatedly said that it (eating disorders) was outside of her remit – but CAMHS had already discharged our daughter despite raising concerns."*
>
> *"I pushed and pushed for a meeting between CAMHS and CDNT. I was repeatedly promised one and when my daughter's file was audited I was told I would definitely get one. It never happened and I've given up fighting for one as it was so draining".*

CDNT is the service with responsibility to provide specialised support to disabled children, including autistic children, whereas CAMHS is the service with responsibility to support children (whether autistic or neurotypical) with moderate to severe mental health conditions. CAMHS is also the service that supports children with ADHD.

Research indicates that given the high rate of co-occurrence between ADHD and autism, both conditions should be considered when one of the conditions is present and young children with an initial diagnosis of autism should be monitored for ADHD[3]. Given that it is estimated that:

- 15-20% of the world's population is neurodivergent[4];
- 70% of autistic children will have at least one co-occurring psychiatric condition; and
- co-occurrence of autism and ADHD is very high[5]

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[3] 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

[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7732033/

[5] Rates of co-occurrence of autism and ADHD vary:- In children, clinical studies investigating ADHD symptoms in ASD report a co-occurrence ranging between 53 and 78%; whereas in community samples, it is lower at 28–31%. A meta-analysis of the co-occurrence of ASD symptoms in young people from both clinical and community ADHD samples found a comorbid rate of 21%. This suggests that ADHD symptoms may be more likely to be found in people with ASD than vice versa and a meta-analysis of rates of ASD in people with ADHD would be helpful to consolidate the available data. Extract from Young et al: *Guidance for identification and*

the rationale for the ongoing division of responsibilities between the two services should be questioned. At present it results in many families not accessing relevant supports as they are pushed between services neither of which can support the child holistically or in a manner which is integrated with the other services.

Position of *Families for Reform of CAMHS*

While the HSE website acknowledges that autistic people often have other conditions including mental health problems and ADHD[6], this acknowledgement does not appear to translate to acknowledgement and supports provided at service level. This is deeply concerning to us, especially as autistic children are 28 times more likely to consider suicide[7] and approximately 70% are estimated to have a dual diagnosis of a mental health disorder[8]. In addition, research shows autistic people are more likely to develop anorexia nervosa, with 23-37% of people with anorexia nervosa being autistic[9]. Anorexia nervosa has the highest mortality rate of any psychiatric disorder.

It is important to note that autism is a lifelong neurodevelopmental difference, whereas anxiety and other mental health disorders are separate treatable conditions. ***Denying mental health issues and denying mental health supports based on a child being autistic cannot be justified in our opinion***. We believe that diagnostic overshadowing is taking place.

This is particularly evident by the recent and concerning change in policy approach as part of the pilot phase of the new CAMHS Hubs. CAMHS hubs have been developed to offer short-term intensive support to children going through an acute mental health crisis, however autistic children have been excluded from accessing those supports.

The exclusion section of the CAMHS Hubs Model of Care document, sets out that autistic children in CAMHS *with "a primary diagnosis of Autism"* will not have access to a hub. Autistic children in CAMHS have already been deemed to reach the threshold of having a moderate or severe mental health issue so this new phrasing and emphasis on a "primary diagnosis of autism", rather than acknowledging a dual diagnosis is troubling to us and we hope not reflective of growing discrimination.

As a group we believe that at best, a burden of proof is placed on families of autistic children over and above that placed on families of neurotypical children to prove that there is a 'mental health disorder' despite the fact that autistic children disproportionately experience greater mental health issues in comparison with their neurotypical peers. And at worst, and as evident in a wide number of our members experiences, systemic discrimination is prevalent in the provision of mental health services to autistic children.

At policy level , we would like the narrative around autistic children to be changed so it is on a par with their neurotypical peers. We propose an approach which clarifies that:

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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

[6] www2.hse.ie/conditions/autism/

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

[8] Crow, B. and Salt, A. (2015) "Autism: the management and support of children and young people on the autism spectrum (NICE Clinical Guideline 170)", Archives of Disease in Childhood - Education and Practice.

[9] https://link.springer.com/article/10.1007/s11920-017-0791-9?fbclid=IwAR3d_lyNj6Y-2KNdgPLxpYq7-OoV2blSKCDFXk45gmTsbOmpv7Ze6UlJ5Y8#Sec11 Autism Spectrum Disorder in Anorexia Nervosa: An Updated Literature Review

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).

The UK has identified autistic people as a high priority group in the UK Suicide Prevention Strategy 2023-28 and we are calling for a similar approach – one which is not based on exclusion - is adopted in Ireland.

At service level, we would like a complete culture shift where the prevalence of mental health issues in autistic children is acknowledged and supports provided accordingly. We would also like an acknowledgement of the high rates of co-occuring autism and ADHD and for integrated services to be provided.

Questions currently with the Department of Health and HSE for response:

On the 28 September, 18 questions were submitted to the Department of Health and the HSE, including the 3 below relating to the treatment of autistic children within CAMHS. We are currently still waiting for a response:

> (viii) Is anything being done to address the current discrimination against autistic children in mental health services and if so what?
>
> (ix) Will consideration be given to changing the narrative to a more inclusive rather than exclusionary one around autistic children so it is more on a par with their neurotypical peers? The threshold of having a moderate to severe mental health issue will remain either way.
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> (x) Will the current approach to launching the CAMHS Hubs pilot be remedied so that autistic children with a moderate to severe mental health issue also have access on a par with their neurotypical peers?

II. Access to mental health services for children with intellectual disabilities

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 4-5 partial teams. *A Vision for Change* sets out that each of the 16 teams should have 11 fulltime staff. The reality is that there are 10 consultant psychiatrists and they either have no staff or only one/two team members.

The consequence of this is sorely felt by our members who are being discharged from or refused by CAMHS on the basis that their child should be seen by CAMHS-ID. Even when there is no CAMHS-ID service in their area and they are not allowed to be referred to an area where there is a CAMHS-ID team.

Based on our August 2023 survey:

- 31% of our members have a child who requires support from a CAMHS-ID service.
- Of that group, 81% have no access to a CAMHS-ID team.

- Of the 19% of members who do have access to a CAMHS-ID team, 80% said that they have not received adequate support.

The HSE has said that, "*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'.* Local arrangements being in place has not been the experience of our members who are left with no support or access to services at all.

The HSE has advised that they are considering looking into a supervisory model where appropriately qualified clinical psychiatrists advise clinicians in CHO areas where there is not a relevant psychiatrist. Minister of State for Mental Health Mary Butler advised that consideration would be given to the possibility of children from a CHO with no CAMHS-ID team to be referred to another CHO area. No timelines could be provided for either of these proposals. In addition, no timelines could be shared about when there will be a CAMHS-ID service in each CHO area.

Position of Families for Reform of CAMHS

At the moment the majority of children with intellectual disabilities - who have a moderate to severe mental health issue - cannot access any mental health services. They are discharged from CAMHS or refused by CAMHS because they should be seen by "the specialist service" (CAMHS-ID) which is largely non-existent. They are discharged to nothing and with no appropriate support.

A telehealth solution at some point in the future is not good enough. A whole cohort of children are currently being denied access to mental health services based on having an intellectual disability.

III. Access to mental health services for children with ADHD

Assessing for and diagnosing ADHD falls under the remit of CAMHS. As CAMHS is responsible for supporting children with ADHD *and* children with moderate to severe mental health issues, urgent referrals for children considered at risk with severe mental health concerns will always be seen before an ADHD referral. CAMHS waitlists are therefore largely populated by children waiting for an ADHD assessment.

ADHD Ireland has outlined how recent 'waitlist initiatives' only offer a short-term solution for reducing the numbers on the CAMHS waitlists but don't factor in capacity to offer supports to a child following diagnosis:

> *"To cope with rising waitlists for services, the HSE have recently been funding 'waitlist initiatives'. These are advertised as temporary contracts making suitable recruitment difficult, and retention of any gains difficult (with waitlists rising again once the initiative ends). There is no guidance for clinicians working in CAMHS on what a good ADHD assessment looks like, and what good intervention for ADHD looks like. Although children on the waitlist have benefited from speedier assessment as part of waitlist initiatives, the use of the waitlist as a key metric by the HSE for how CAMHS teams are functioning is an ongoing issue. Once these children have been assessed they now require supports, and demand for intervention within CAMHS far exceeds capacity.*[10]*"*

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[10] https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_sub_committee_on_mental_health/submissions/2023/2023-06-13_opening-statement-ken-kilbride-chief-executive-officer-adhd-ireland_en.pdf

A common experience of our members seeking support for a child with suspected ADHD is to have to make multiple referrals before being accepted by CAMHS. Many families in our group have resorted to obtaining a private diagnosis of ADHD between referrals to better the chances of their next referral being accepted. CAMHS generally does not accept a private diagnosis – and will carry out their own assessment once the child is accepted by the service – but it does appear to help families to initially get in the door.

Not providing early assessments and support is concerning as approximately one half on children with ADHD will have at least one psychiatric disorder comorbid to ADHD[11]. In addition, research funded by the National Office of Suicide Prevention and conducted in partnership with UCD, the HSE and ADHD Ireland showed that in terms of suicide risk: 20% of all ADHD adults have attempted suicide in their lifetime; 50% of all ADHD adults have self-harmed in the past; and 10% consider suicide an option for the future.

As highlighted earlier in this submission, co-occurrence of ADHD with autism is common but the service provision, if any, is very fragmented with families often being passed between services. Parents within our group have highlighted how their child's mental health has deteriorated while on the waiting list for ADHD support from CAMHS and outlined how disagreements arose between services about whether the child was presenting as autistic or with ADHD.

Parent Experience (son aged 12)

"We were told that children who were looking for only an ADHD diagnosis were often not treated as a priority despite overwhelming proof that medication made massive differences to the majority of those with ADHD. Obviously that should be the case with other issues such as suicidal idealisations etc. but they admitted that this often led to those children/young adults mental health deteriorating to the point of 'crisis' and then needing emergency help. Options were waiting list 2years or reach a crisis, deteriorate to suicidal thoughts and actions and be seen quicker.

We definitely saw a decline in our sons mental health and behaviours escalated as we waited 2 years to be seen! By then he was the 'bold boy' 2 preschools and 2 national schools by senior infants due to behaviours. After a serious incident we were given an appointment but then discharged in the next one due to them thinking he was autistic. We were sent pillar to post with CAMHS and CDNT both saying he didn't fit their remit. In the end we had to get a private ASD diagnosis to access school supports. He was later diagnosed with severe combined ADHD by CAMHS."

Parent Experience (daughter aged 12)

"My daughter was always an anxious child. At age 5 I had her privately assessed for ADHD and it was confirmed at age 7 that she had ADHD and a query of PDD-NOS.

Around this age my daughter began to be bullied and found it very difficult to deal with. She began skin picking and would often have open cuts and wounds on her face, arms and hands. She began talking to us about how she felt she didn't fit in, was an outsider and didn't want to wake up anymore.

I contacted our GP who put in referral to CAMHS. After several months we finally had an appointment, however, they tried to discharge her by saying she was autistic and they didn't deal with autistic children.

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[11] 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

I pointed out several times that she had not been diagnosed with autism and had in fact been discharged by early intervention as they felt she did not present with autism. After arguing with them, in front of my very upset 7 year old, they agreed to schedule a session with their OT and offered a block of sessions with their speech and language therapist.

A year later she still had not received any counselling or psychiatric help and they tried to discharge my daughter. I said as soon as I left the room I would be contacting my solicitor and every media outlet I could.

I was asked to wait and come into a further meeting with one of the doctors in CAMHS. A month later they agreed to put my daughter on antidepressants and would monitor her. I queried the use of antidepressants on a child with ADHD and cited several studies that showed that the use of ADHD meds helped anxiety in young children with ADHD far more. I was told that she didn't have ADHD, that she was autistic and this was all they would offer.

We then had four appointments with a different doctor whom my daughter clicked with and began to actually talk to. Whilst this doctor believed my daughter was on the autism spectrum, she admitted that she did see strong traits of ADHD in her. She also apologised and said that she would no longer be able to see us as she was being moved to another area as her six months were up (this would be the fifth doctor my daughter would have seen under CAMHS.)

The new doctor asked us had we considered having her tested for ADHD. My daughter was now 11 so this was 3 years later. The doctor expressed surprise that she had already been diagnosed privately as this was no-where in her file. The doctor and CAMHS now accepted that she did in fact have ADHD and agreed to trial ADHD medication for her. He explained that before this could happen, a blood test, ECG and heart rate/pulse would need to be recorded before any medication could be prescribed. He said that unfortunately he would no longer be at CAMHS as his six months were up but his replacement would follow up with us.

I contacted our GP every week in July and August to find that no request for bloodwork etc had been received. I placed several calls into CAMHS and sent several emails asking for someone to get back to me. Eventually a secretary told me that there was no record of what tests had been ordered and no one available to re-order them. At this point I started a formal complaint procedure with the HSE .

Following the complaint, they agreed to bring my daughter in to begin medication and arrange for a full OT assessment to help with her sensory issues. When I asked about counselling for her I was informed that they simply don't have the staff for that service and are unable to offer it".

Position of Families for Reform of CAMHS

Research shows that ADHD is extremely treatable through a mixture of medication and behavioural treatments. It is imperative that children presenting with possible ADHD are assessed and offered supports as early as possible. It is also important that they are supported in a holistic manner where there are indications of any co-occuring conditions like autism or a psychiatric disorder.

Conclusion

As concerns have been repeatedly reported about CAMHS[12] with no truly effective action or prioritisation being taken to reform the system, *Families for Reform of CAMHS* is calling on the Government, as a matter of urgency, to legislate for the regulation of the service, to publicly commit to the implementation of the Mental Health Commission's 49 recommendations and to take concrete

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[12] See for example the Mental Health Commission's 2017 Report in addition to its report earlier this year. And the 2016 Observations from the United Nations Committee on the Rights of the Child in addition to their recommendations earlier this year.

action to address the discrimination against neurodivergent children and lack of service for children with intellectual disabilities.

Families for Reform of CAMHS
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