DGH NEURODIVERGENT CONSULTANCY

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Report on Qualitative Findings of a Survey of Autistic experiences of Child and Adolescent Mental Health Services

AIM

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Contents

Aims and Scope of This Report

This report contains the responses of 544 Individuals regarding their experiences with CAMHS. This report in particular will focus on the qualitative data pulled from the survey; quantitative data was examined in the previous report.

The survey was self-reported and as such has some limitations, none-the-less it is necessary to note that even just the quantitative data of the first report demonstrates some significant issues within CAMHS management of Autistic service users.

The overall aim of this report is to highlight the experiences of CAMHS by the people who responded to the survey. It is hoped that this qualitative data will help to contextualise the statistics in the previous report.

Due to the sheer number of responses this received, responses have been selected at random to be quoted in this report.

Details of The Survey

The survey was delivered through google forms for 10 days during March 2024. Below are the details of the questions asked (for the qualitative section of the survey) and how the data was managed. The survey was shared via social media and mailing lists.

Questions Asked

The following questions were asked in the qualitative section of the survey:

Section 2-

This section aimed to gather the lived experiences of Autistic people and their families regarding CAMHS.

Please note that it was the view of the author that due to the

privileged nature of formal identification of one's autism, self-identification should be accepted.

Respondents were asked to answer the following questions in as much detail as they were comfortable to.

1. What was your personal experience of CAMHS?
2. What (if anything) would you change about CAMHS?
3. Were there any parts of your CAMHS experience that were better than others?
4. What advice would you give to families of Autistic people trying to access CAMHS?

I will dedicate a section of this report to each question, exploring themes and responses and contextualising them within current knowledge.

Data Management and Processing

The survey received a total of 609 responses. 75 of these responses did not qualify for inclusion in the final data, leaving a total of 544 responses.

Some of the “Unsure” data in section 1 of the questions also had to be discounted due to the small sample size.

Findings of Qualitative Section of Survey

What was your personal experience of CAMHS?

Themes

The following themes were identified on this question:

- Rejected referrals
- Failure to identify and manage Autistic burnout
- Denial of suicide and self-harm risk
- Breaking trust
- Lack of clarity in decision making

Findings

Rejected Referrals

The first and most significant theme was one of CAMHS repeatedly rejecting referrals and making vulnerable families fight to be seen by services.

> **"A load of rubbish he's still suffering now but they don't want to know."**

Anecdotal reports from the Autistic community have (for a long time) highlighted that CAMHS refuse to accept referrals of Autistic children and young people. This is concerning given that more than half of patients referred to CAMHS present with Autistic traits with almost 10% having a family history of autism (Setlhare & Rafi, 2022). It is interesting to note that in 2010 1 in 10 CAMHS patients were diagnosed Autistic (Read & Schofield, 2010). Given that diagnosis rates of autism have increased over the past 14 years, it's reasonable to estimate that the 1 in 10 figure may now be a little conservative.

It is telling that there is a lack of academic literature on the prevalence of autism in CAMHS populations, with much of the data being provided by charities such as National Autistic Society rather than research by educational institutions.

> **“My granddaughter is suffering on a daily basis and CAHMS have refused to engage with emotional wellbeing.”**

Autistic children and young people are being referred to CAMHS during a vulnerable time in their lives. Despite this, CAMHS are turning them away on the basis that they are not equipped to support Autistic people. This highlights not only a lack of adequate resources within CAMHS systems, but also diagnostic overshadowing.

Diagnostic overshadowing is a term referring to the misuse of an existing diagnosis to explain away new or unrelated traits or symptoms (Gupta & Gupta, 2023). Anxiety is commonly stated to be an Autistic issue when it is actually a co-occurring condition. Anxiety is common amongst Autistic children and young people. Not only is it not a part of autism diagnostic criteria, but it is also a predictor of negative outcomes such as increased self-harming behaviour (Kerns *et al*, 2015).

Failure to identify and manage Autistic burnout

Another issue that has been highlighted in responses is the lack of knowledge around Autistic burnout and a failure to identify this debilitating state. Autistic burnout can best be understood as a state of total exhaustion of resources that can lead to skill loss and regression as well as suicidality (Raymaker *et al*, 2020).

> **“My 9 year old's level of Autistic Burnout, masking and distress went unrecognised by her CAMHS worker”**

Failure to understand and identify Autistic burnout is a significant issue that needs to be addressed. Autistic people in burnout may struggle to engage with interventions for mental health. It should also be noted that while burnout and mental health conditions

can and often do occur together, burnout is anecdotally reported by Autistic people to be unresponsive to traditional treatments for mental health problems such as medication.

> **“Lack of understanding of Autistic experience and no empathy or understanding why my child was not attending school, they could see no reason for her not to attend.”**

This highlights a broader issue of a lack of competency in understanding Autistic experience. To create a safe space for vulnerable Autistic young people, professionals need a good level of cultural competency from within the Autistic experience (Gray-Hammond & Adkin, 2023). Despite this, global populations of healthcare professionals appear to have limited knowledge of even basic autism features, and their self-reported efficacy working with Autistic patients was related to that knowledge (Corden *et al*, 2022).

Denial of suicide and self-harm risk

> **“failed to write self risk on care plan asked if she tied knots when self harming as if to give ideas”**

This issue is not unique to children’s mental health services, but unfortunately endemic to the mental health sector in general. Common reports are of people being stated not to be a suicide risk, even when they have active plans. It is also understandable that parents and carers would be concerned by professionals introducing their child to specific methods of self-injurious or suicidal behaviour at a time when a child is actively expressing a wish to end their own life.

> **“Repeatedly told her whilst she had ligatured and stated she wanted to die that she was not suicidal”**

Autistic children are 28 times more likely to think about or attempt suicide. 25% of young people who died by suicide in the lead up and short time after the first COVID lockdown were Autistic or ADHD (Willgoss, accessed 24/04/2024). There are currently over 2,000 Autistic and/or learning-disabled people in inpatient psychiatric units in the UK (Tudor, 2023).

Suicidality prior to admission to an inpatient unit has been suggested to be a predictor of suicidality in the three months after admission (Giacco & Priebe, 2016) and yet CAMHS are still failing to take it seriously in Autistic people.

Breaking trust

Trust is an essential element to the therapeutic relationship. It underlies our ability to take on and enact new information (Fonagy & Allison, 2023). Part of trust is knowing how to initiate and end therapeutic relationships in a safe and positive manner.

> **"Having seen the same lady for a year and finally feeling like she was building a rapport. She was told she was being discharged out of the blue. My daughter was left feeling rejected..."**

Rejection is an all-too-common experience for Autistic people and can be especially harmful during the formative years. Rejection Sensitive Dysphoria can play a significant role in negative outcomes for Autistic young people and has even been related to the emergence of eating disorders in Autistic populations (Kelly & Kelly, 2021).

> **"I put in a complaint and then dealt with a manager who lied over the phone to myself and to social workers confirming that we could access much needed services and then sent letters weeks later of disengaging."**

It's important to note that it is not only children and young people who experience the breaking of trust. Staff providing bad information and rejecting young people also impacts upon the family unit (Gray-Hammond & Munday, 2023). It is essential that trust is developed for both the young person and their family.

Lack of clarity in decision making

Families report confusion over the decisions made within the CAMHS service. It appears that a greater deal of transparency is required in order for families and their young people to engage with CAMHS in a way that feels appropriate to CAMHS professionals.

> **"It felt like a box ticking exercise. Unhelpful unsupportive and a lack of understanding of Autistics and ADHD clients."**

Lack of clarity can result in services taking a one-size-fits-all approach that could be seen as the aforementioned tick box exercise. This also feeds into the lack of trust between professionals and service users. If families feel that they are just another number to the professional, how can we expect them to trust professionals?

> **"Stopped offering any support before building any sort of connection when distress was too high to attend in person, no adjustments made, closing letter stated child "wouldn't engage" as though it was a choice"**

The other side to this lack of transparency is that discontinuation of services can feel sudden and unfair. Because CAMHS staff are not understanding the nuances of working with Autistic service users they are discontinuing their services because they find young people difficult to work with. It should again be noted that

this impacts upon the trust of families and their young people, making them less likely to seek support in the future.

Issues Identified

A significant issue that this question highlighted was the lack of transparency and trust between professionals and their service users. Seemingly unfair or even cruel decision-making processes coupled with a distinct lack of understanding of Autistic people has combined to create a situation where even if an Autistic person has their referral accepted, they are at risk of having the relationship breakdown.

On the matter of understanding and identifying Autistic burnout, this is an issue that needs to be immediately addressed. Professionals denying the impact of Autistic burnout or even failing to know of it as a concept are at risk of gaslighting the young person and their family (Raymaker *et al*, 2020). It should also be noted that unsupported Autistic burnout is associated with increased suicidality and risk of inpatient admission (Raymaker *et al*, 2020).

It is also necessary to highlight how healthcare inequality feeds into Minority Stress models. Minority Stress highlights the cumulative effect of social barriers to self-actualisation with greater levels of minority stress being associated with increased levels of mental health concerns (Botha & Frost, 2020). I would also note that there was no mention of signposting to Autistic peer support spaces. Such signposting could be helpful in reducing the effect of minority stress through community connectedness (Botha, 2020).

What (if anything) would you change about CAMHS?

Themes

The Following themes were identified on this question:

- Need for better trained staff
- Need for neurodiversity affirming practice
- Need to stop infantilising of children and young people, and parents
- Service needs a total overhaul

Findings

Need for better trained staff

One of the most common statements in this survey was that CAMHS staff need to have a greater amount of training on working with Autistic service users.

> **"Better trained/more staff, less waiting."**

Increasing the numbers of appropriately trained staff could make a significant difference to CAMHS as a service. It should be noted that there are two big barriers to this. As a service there has been a significant issue of lack of resources which impacts on ability to provide appropriate training (England & Mughal, 2019), this is an issues of government funding that will requite political action to address.

> **"Neurodivergent staff. Neurodivergence training"**

Another issue to highlight is that training is likely to come from sources that do not have lived experience of being neurodivergent. If Autistic people are not involved in staffing and training these services, the outcome will likely still be largely negative (Dillenberger *et al*, 2016).

> **"Actual up-to-date understanding of autism and how it affects young people, their mental health, and their family life."**

One of the most significant barriers to having an understanding of contemporary knowledge within the Autistic community is the lack of research into concepts that are widely discussed in Autistic spaces. Theories such as monotropism, double empathy, and burnout are still in their infancy with regards to academic research meaning that they are often not taken seriously by professionals who seek "evidence-based" approaches.

Need for neurodiversity affirming practice

> **"For them to be neuroaffirming. Not medical deficit based. Change the settings to be more ND friendly."**

Neuroaffirming practice has become somewhat of a buzzword in many circles with no clear definition of what is meant by it. At it's basis, it asks professionals to stop pathologising Autistic people and instead look at them as neurologically different. One of the issues with this has been the rise of "neurodiversity lite" models wherein only the traits of autism seen as useful to society are handled in a neuroaffirming manner.

> **"It needs scrapping and a specific service for neurodivergent young people. CAMHS are not fit for purpose"**

It has been argued that not only does neurodiversity affirming practice lack concrete methodologies, but it may also be fundamentally incompatible with "gold standard" interventions for mental health such as cognitive behavioural therapy (Pantazakos & Vanaken, 2023). This suggests to us that calls for an overhaul of mental health services is not only a desire of those in the system, but a potentially necessary part of improving service accessibility.

Need to stop infantilising of children and young people, and parents

The infantilising of Autistic people has been a large feature of community discussions for many years, it can be viewed as one of the significant barriers Autistic people face to equitable treatment.

> **"My son (who was 8 and very articulate) was treated like a toddler. He felt embarrassed by the way they spoke to him and could not understand the point of the meetings."**

When working with Autistic young people one should always assume competence. However, there is a wider issue within society of mainstream representation of Autistic people being one of child-like and incompetent people (Ahktar *et al*, 2022). Autistic children need to feel respected in order for trust to be established.

> **"...don't treat ND parents like they are children."**

The infantilisation of neurodivergent parents is part of a broader issue of parent carer blame. Disabled parents are significantly more likely to fall victim to institutional practices of parent carer blame, and neurodivergent parents are not an exception to that rule (Clements & Aiello, 2021). Treating neurodivergent parents as children is just one of the multitude of ways that professionals position them as incompetent parents.

Service needs a total overhaul

The most frequent response to the question of what could be changed was "everything". A huge majority of people felt that the entire system was unfit for purpose and should be scrapped in favour of something new.

> **“Absolutely everything actually offer [support] for young people who are struggling mentally regardless of their autistic or not”**

Respondents overwhelmingly felt that CAMHS in its current form was unfit for purpose. This indicated systemic issues that are making this service inaccessible and unsupportive. Let us not forger that children and young people’s lives may very well depend on the provision of this service.

> **“It needs a complete overhaul”**

Overhauling a system like CAMHS would take many years. Families know this, and it is the authors opinion that they would not make such a large demand if the need was not proportionate. CAMHS as a service need to consider why families of Autistic people are making this call and consider how they can best serve Autistic people and their families rather than defend their own position.

> **“its a completely failing struggling system as far as i can tell…”**

Issues Identified

Families of Autistic children and young people overwhelmingly feel that CAMHS in its current form is not serving them well. The overarching theme throughout these responses is that CAMHS as a service need to completely change how they work.

Neurodiversity affirming practice could be a helpful starting point if a concrete methodology can be identified, but as mentioned, traditional psychotherapeutic approaches tend not to be compatible with neurodiversity affirming practice (Pantazakos & Vanaken, 2019). Commonly used therapeutic modalities also often only have limited efficacy in Autistic populations for both

Autistic traits (Weston *et al*, 2016). It could be inferred that due to diagnostic overshadowing, CAMHS interventions target both Autistic traits and mental health issues.

We also can not excuse or ignore a culture of parent blame which was prevalent in responses from this question, particularly those rooted in the infantilisation of parents, particularly mothers. Such institutional practices do direct harm to the therapeutic relationship and are ultimately doomed to provide negative outcomes for all involved.

Were there any parts of your CAMHS experience that were better than others?

Themes

There was one single overarching theme among the responses. Almost every response was the same. There were no positive parts of the CAMHS experience for Autistic children and young people and their families.

Findings

> **“No every contact with [CAMHS] has been Poor. Two counties and two children requiring help support and diagnosis.”**

It would seem that no matter where in the country respondents were answering from, they all had the same response. The system is broken and unfit for purpose, or even overtly harmful.

> **“We did not get to have an experience.”**

We can not forget that many families don’t even get through the door at CAMHS meaning that they can not comment on what the system is like from the inside.

> **“No it was all truly awful. From being told that a kid that young can’t want to die to ‘he’ll eat when he’s hungry’ the whole thing was shocking from start to finish.”**

This goes further than service user satisfaction. It gets into the realms of overt harm.

Issues Identified

It is clear from the survey responses that satisfaction with CAMHS over all is far too low. Some have expressed concern for the harm that this system is doing. It is a sad indictment of CAMHS that

nearly all of the responses said that everything needed to be changed. This highlights systemic failings on a grand scale.

Mareva *et al* (2024) has also indicated that staff satisfaction within the service is falling, with increasing levels of personal burnout among staff. CAMHS is overwhelmed, under-resourced, and distinctly lacking in the appropriate skills to support Autistic children and young people.

Further academic research has also indicated that issues with CAMHS are systemic rather than isolated with many Autistic people and their families falling foul of the things identified so far by this report (Ashworth *et al*, 2024).

What advice would you give to families of Autistic people trying to access CAMHS?

Themes

This question again had a single almost unanimous response. That response was “don’t bother”. There were also people saying to go private.

Findings

> **“Go private, a charity, anyone else”**
>
> **“Don't bother.”**
>
> **“Don’t do it. If you do, don’t be afraid to complain”**
>
> **“If you can afford to go private then do. The wait is not worth it nor is the input you actually get.”**

It is difficult to expand on this any further than responses do. It is clear that significant changes need to be made to the service.

Issues Identified

I feel it necessary to highlight the call to go private in these responses. Private mental health care is an expensive thing to access for a demographic that is already likely to be experiencing financial hardship.

Families of Autistic children and young people are significantly more likely to experience financial stress (Anderson *et al*, 2024). Financial hardship has also been linked in literature to increases in behaviours that may be considered challenging by some (Trentacosta *et al*, 2018)

We can then see a self-perpetuating cycle of need for support, financial hardship, and expenditure on private services leading to further hardship and a greater need for support. This should not be happening in a country with universal healthcare.

Conclusions

CAMHS exists as a service to support children and young people during a deeply vulnerable time in their life. Mental health crises can be life threatening, and people deserve to know that CAMHS is there to help them when they need it.

Despite this, CAMHS as an institution is consistently failing to provide the support that Autistic people are entitled to, with many being denied support altogether. The issues start at the governmental level and filter down into the understanding and attitudes of staff working within the system.

Parents and carers clearly are not happy with the system, and many are being forced to pay out of pocket to access private care in the absence of support from CAMHS. This needs to be changed immediately.

How the system can be changed will be addressed in a further report, but until such time that systemic issues are challenged, CAMHS staff need to take immediate action to mitigate the harms being perpetuated by systemic failings.

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