



DGH NEURODIVERGENT  
CONSULTANCY

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



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## Acknowledgements

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There were so many people who supported the data acquisition stage of this project that I can not list them all. Many of you have shared the survey and amplified the importance of this endeavour.

I would particularly like to thank the Autistic community and associates who dedicated time to giving their experiences of CAMHS a voice that I could use for the betterment of society. Our children deserve equal and appropriate access to mental health care, and the whole way through this, my aim has been to represent the plight that is currently ongoing in UK children's mental health services.

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## 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 quantitative data pulled from the survey, with qualitative findings coming at a later date.

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 this first report demonstrates some significant issues within CAMHS management of Autistic service users.

The overall aim of this report is to highlight the findings of the CAMHS survey showing the statistics it created. This will then be followed by a qualitative report noting peoples personal experiences, and both will then ultimately be pulled together in order to write a third report giving recommendations to improve services.

## 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 quantitative 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 quantitative section of the survey:

#### **Section 1-**

**This section aimed to gather data on qualification to submit to the survey.**

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.

Responses answering "No" to both questions 1 & 2 were removed from the data pool.

Responses Answering "No" to question 3 were removed from the data pool.

1. Are you Autistic? (Self-ID accepted)
  - a. Yes
  - b. No
  - c. Unsure
2. Do you have Autistic children? (Self-ID Accepted)
  - a. Yes
  - b. No
  - c. Unsure

3. Do you have personal Experience of CAMHS either as a patient yourself, or your family member is/was a patient, or you have worked for CAMHS? (This includes having a referral refused)
  - a. Yes
  - b. No

## **Section 2-**

**This section formed the main body of quantitative data regarding CAMHS.**

The following description was given to this section:

“Please rate the following statements from 1-5 with 1 = Strongly Disagree through to 5=Strongly Agree

The questions apply to either yourself, your loved one, or your service users if you are a professional.”

1. Accessing CAMHS is easy and understandable
2. CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)
3. CAMHS treated my child with dignity and respect (or your service user if you are a professional)
4. CAMHS understand Autistic experiences
5. CAMHS adjust their approach to suit Autistic needs

This concludes the quantitative section of the survey.

## 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

The data was then broken down into the following categories:

1. Overall results (Including all qualifying data)
2. Autistic respondent regarding Autistic children
3. Autistic respondent regarding non-Autistic children
4. Non-Autistic respondent regarding Autistic children
5. Unsure respondent regarding Autistic children

## Findings of Quantitative Section of Survey

### Overall Results

#### Respondent Identity

Notable to the results of this survey is that most respondents were confident that they were not Autistic.

#### Are you Autistic?

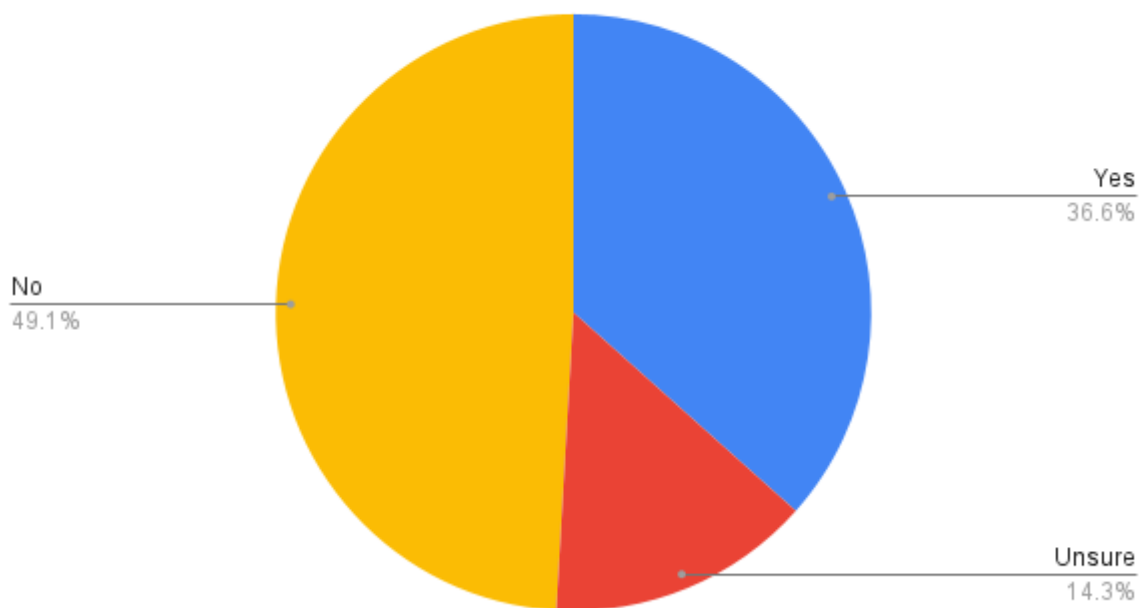


Figure 1- Results of Section 1- Question 1: Are You Autistic?

In total, 49.1% of included respondents did not identify as Autistic themselves. This is comparable to 50.9% who identified as Autistic or unsure of the Autistic identity. You will see in figure one that 36.6% of respondents were Autistic and 14.3% unsure.

Question 2 provided unsurprising results given the aims of the survey. It was found that the majority of respondents had Autistic children with 88.4% responding that they did have Autistic children.

Converse to this, 5.3% were unsure of their child's Autistic identity and 6.3% stated that their child was not Autistic. It was necessary to keep data from Autistic people regarding non-



Autistic children as Autistic parents, carers, and professionals often report having a different experience of CAMHS to non-Autistic people.

### Do you have Autistic Children?

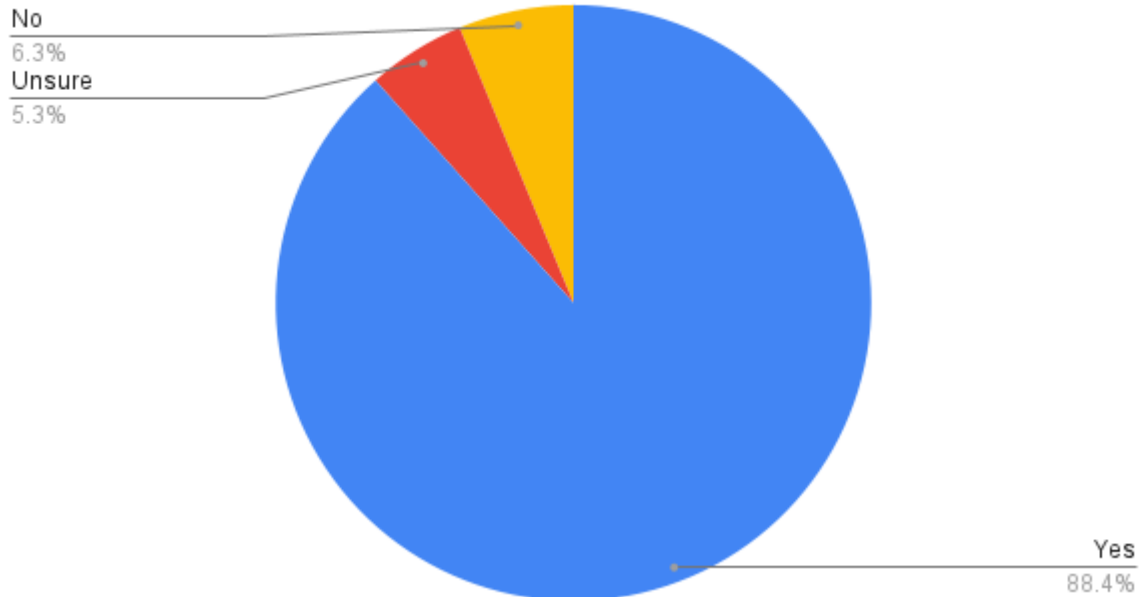


Figure 2- Section 1- Question 2: Do You Have Autistic Children?

## Quantitative Findings

All Statements were rated as follows (Rated 1-5: 1= Strongly Disagree, 5= Strongly Agree)

### *Accessing CAMHS is easy and understandable*

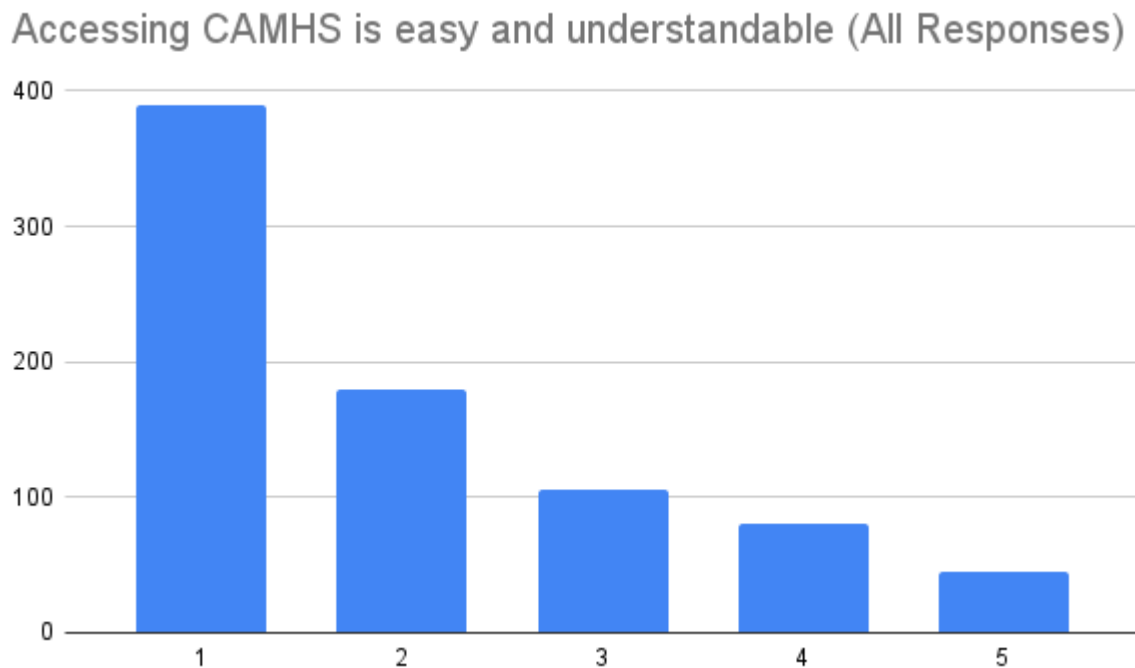


Figure 3- Data from Section 2- Question 1 (Bar Chart)

Respondents overwhelmingly disagreed that CAMHS is easy and understandable to access. 48.8% of all included respondents strongly disagreed with this statement with 71.3% disagreeing to some extent. This immediately highlights the issue that CAMHS is not an accessible service and raises questions around how it can improve its accessibility for this particular demographic of service users. Only 15.6% of respondents felt any sort of agreement that

CAMHS was easy and understandable to access.

Accessing CAMHS is easy and understandable (All Responses)

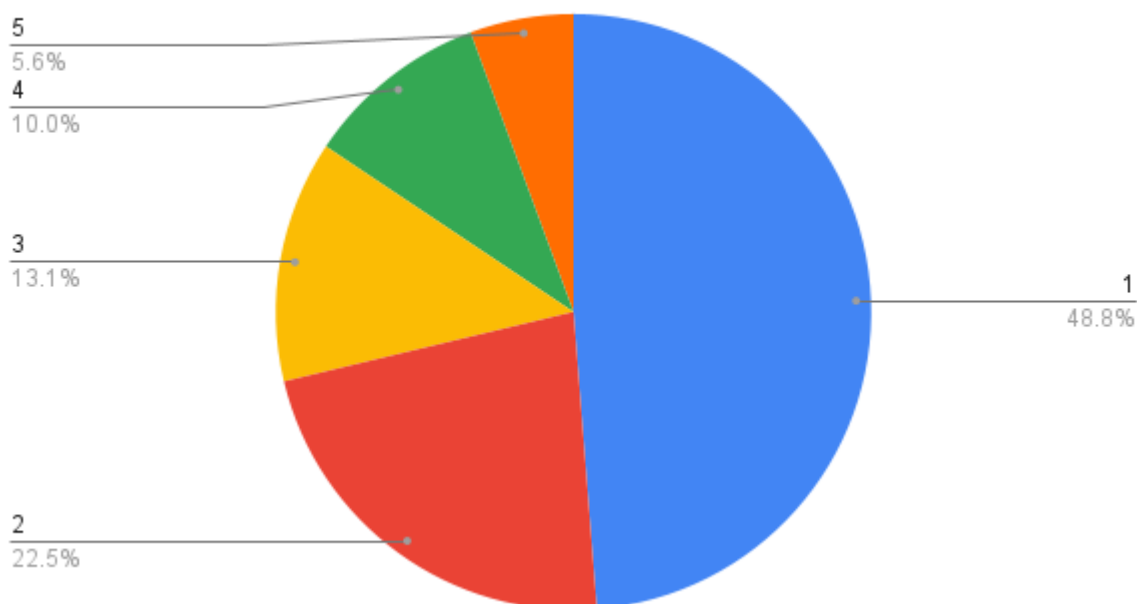


Figure 4- Section 2- Question 1 Percentages

In the 2018-19 period approximately one quarter of referrals of all children and young people were rejected by specialist mental health services (Crenna-Jennings & Hutchinson, 2020). It is reasonable to infer that Autistic children and young people may be over-represented in this group. The most common reason for rejection by CAMHS was the belief that a condition could not be appropriately supported by them (Crenna-Jennings & Hutchinson, 2020). Anecdotally, we hear this reasoning used frequently to reject Autistic children and young people from CAMHS.

*CAMHS were attentive and supportive of mine or my loved ones needs (or your service users needs if you are a professional)*

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

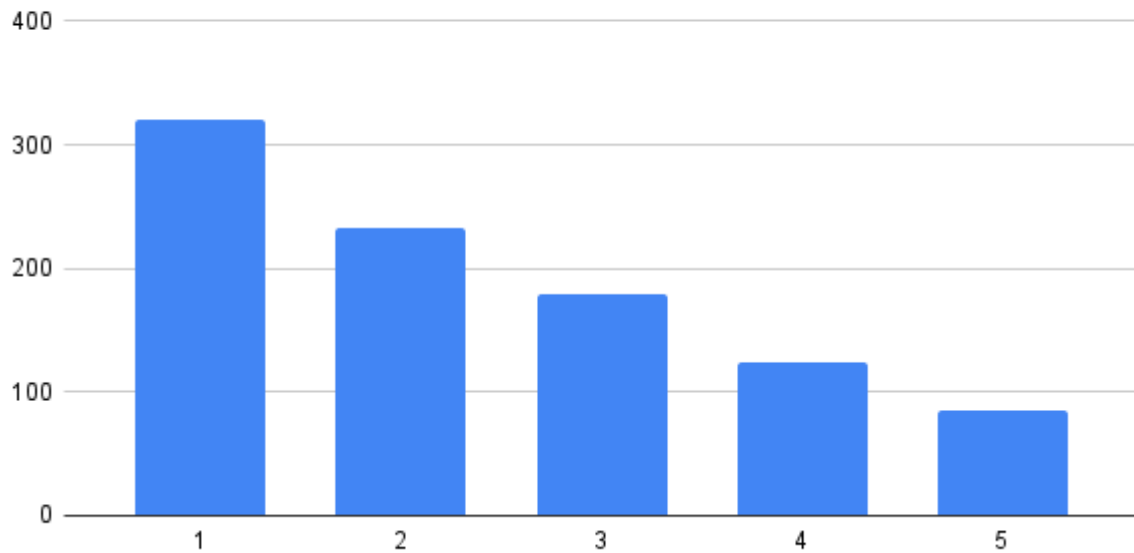


Figure 5- Section 2- Question 2: Results

While the responses to this question followed a similar trend to the previous, the differences were less pronounced. The more even distribution gives the impression that levels of attentiveness and support may be a more balanced experience for those whose experiences are addressed by this report. Despite this, the majority still disagreed to some extent.

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

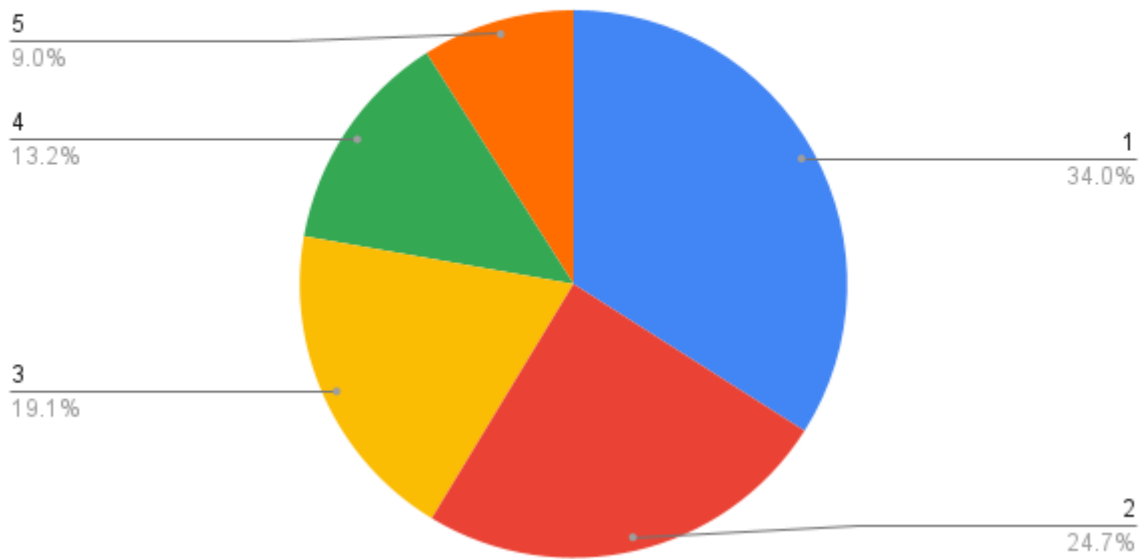


Figure 6- Section 2- Question 2- Percentages

You will see from figure five that over half (58.7%) of respondents disagreed that CAMHS was attentive and supportive. Interestingly, the number of people who neither agreed or disagreed was slightly larger than in the previous question at 19.1%. Only 22.2% of respondents felt that they agreed that CAMHS was attentive and supportive.

This is deeply troubling. CAMHS will be most likely to encounter people during incredibly vulnerable points in their lives. Effectiveness is going to be contingent (in part) on the trust between professionals and service users. If service users do not feel the service is attentive and supportive, this will undermine the relationship.

*CAMHS treated my child with dignity and respect (or your service user if you are a professional)*

This question gave some really interesting results. People were actually trending more towards agreeing with this statement than disagreeing.

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [All Responses]

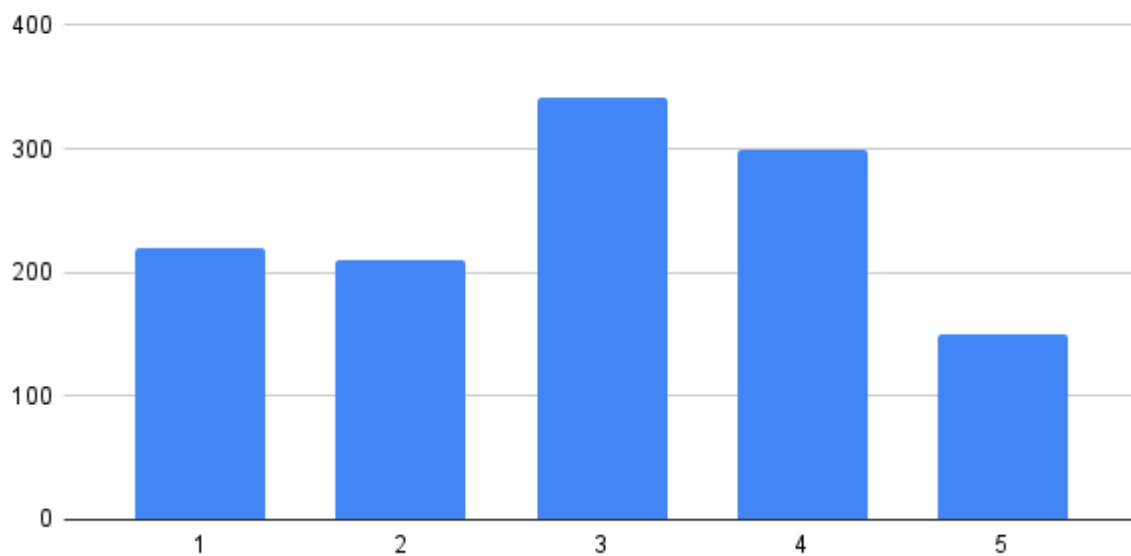


Figure 7- Section 2- Question 3- Results

As you can see in figure 7, the most popular response was to neither agree nor disagree with a surprisingly high number showing some overall agreement.

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [All Responses]

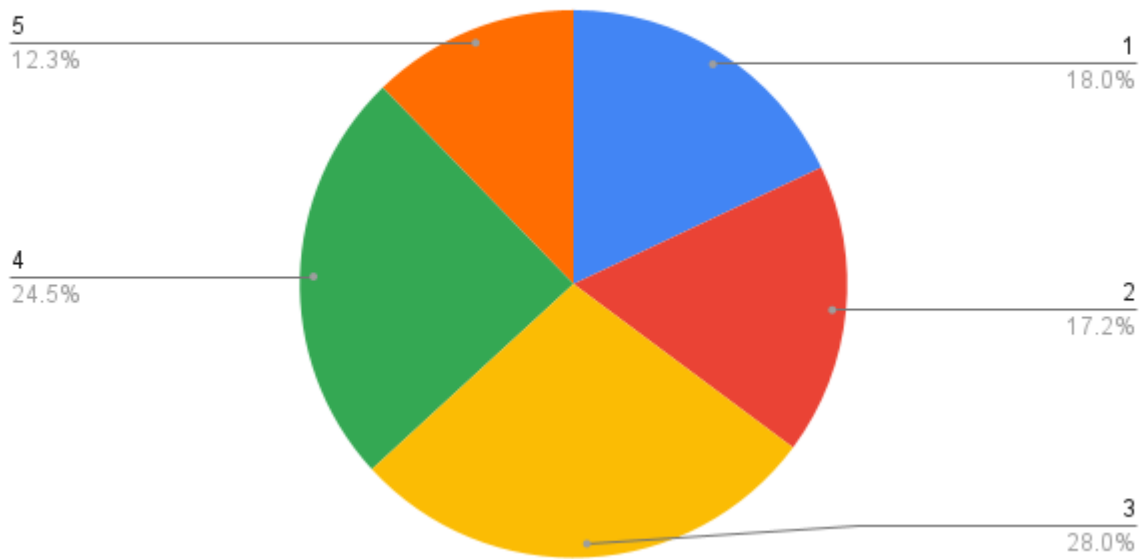


Figure 8- Section 2- Question 3 Percentages

28% of respondents neither agreed nor disagreed, but the overall difference between those who agreed or disagreed with this statement was surprisingly even. 35.2% disagreed that CAMHS treated their child with dignity and respect versus 36.2% who agreed.

I find this interesting as this indicates that for perceptions of respect in CAMHS approaches most people felt that there was a reasonable level of dignity and respect. This stands in contrast to anecdotal reports of CAMHS mistreatment which suggest a much more significant leaning towards disagreement on this statement.

Despite this apparent balancing of results on this question, it's important to note that over a third of respondents feel that CAMHS did not treat their child or service user with dignity and respect, and a further 28% having an experience that gave them neutral opinions of this measure.

It is not acceptable that so many people have had this experience, and it is something that needs to be addressed with urgency.

Gardner *et al* (2016) found that 79% of nurses surveyed around their attitudes towards Autistic people reported Autistic people to be “difficult” or “very difficult”. This seems to be indicative of a culture wherein having needs outside of normative standards is seen as a nuisance rather than being well accommodated which may explain why only around a third of respondents felt that CAMHS acted with dignity and respect.



### *CAMHS understand Autistic experiences*

The results of this statement leaned again quite heavily back towards strong disagreement. This is reflective of anecdotal reports and attitudes with Autistic community spaces.

#### CAMHS understand Autistic experiences (All Responses)

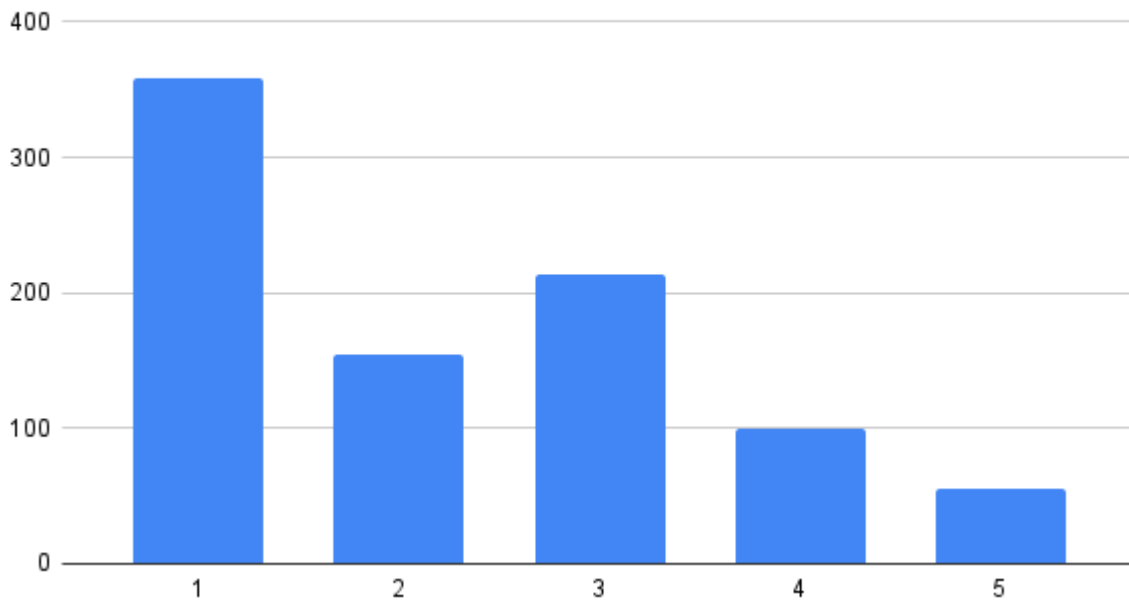


Figure 9- Section 2- Question 4- Results

#### CAMHS understand Autistic experiences (All Responses)

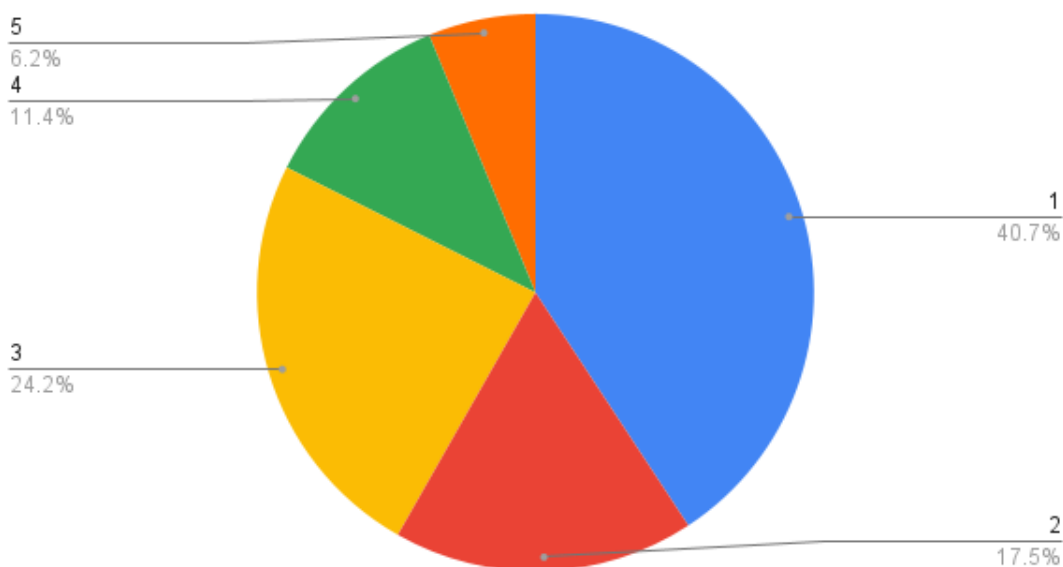


Figure 10- Section 2- Question 4- Percentages

Only 17.6% of respondents felt that CAMHS understand Autistic experience to some degree. 24.2% had no strong feelings either way, with 58.2% disagreeing (of whom, 40.7% strongly disagreed that CAMHS understand Autistic experience).

Not only does this reflect attitudes of the Autistic community, it also reflects research in the attitudes and competency of healthcare professionals working with Autistic people.

When tested on knowledge of autism diagnostic criteria healthcare professionals achieved between 47.37% and 71.05% correct answers (Corden *et al*, 2022). Given that many in the Autistic community feel that the diagnostic criteria needs significant revision, I do not feel this disparity in knowledge reflects an environment in which Autistic experiences are well understood by professionals.

### *CAMHS adjust their approach to suit Autistic needs*

This was the last statement to be rated by respondents, and in line with most of the other statements, was quite oriented towards disagreement with 51% of respondents disagreeing that CAMHS adjust their approach to suit Autistic needs.

CAMHS adjust their approach to suit Autistic needs (All Responses)

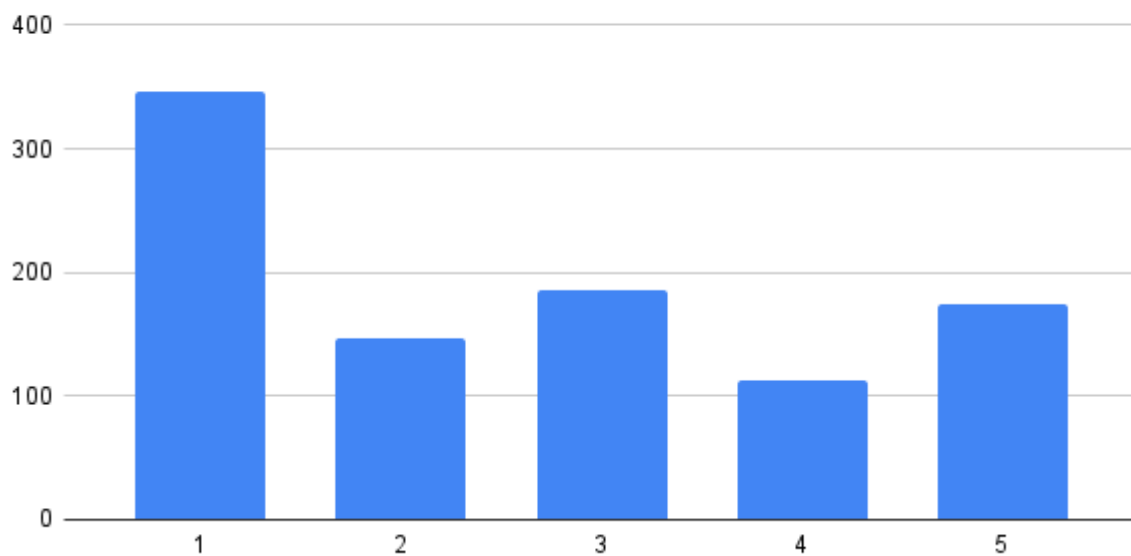


Figure 11- Section 2- Question 5 Results

CAMHS adjust their approach to suit Autistic needs (All Responses)

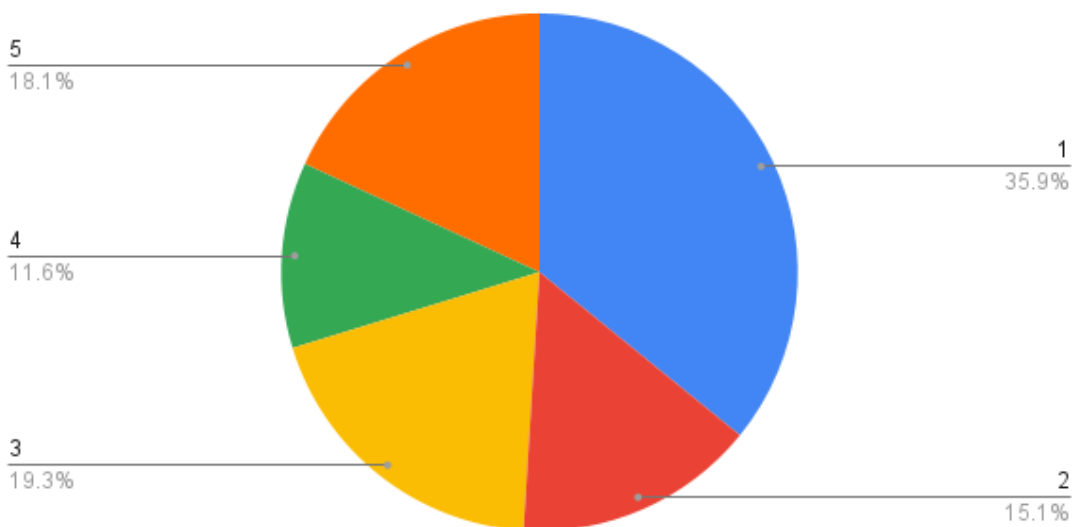


Figure 12- Section 2- Question 5 percentages

This seems to be reflective of the previous statement. If CAMHS do not have a good grasp of Autistic experience, it is unsurprising that only 29.7% of respondents agreed that they adjust their approach to suit Autistic needs.

NICE guidelines state that professionals treating mental health issues in Autistic people should “consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for autistic people.” (NICE Guidance, 2012).

The results of this statement indicate a failing to follow the NICE guidance that is considered necessary to be effective in this area of professional practice.

## Autistic Respondent Regarding Autistic Children

### Respondent Identity

All respondents in this set of data identified as being Autistic themselves, and responding regarding Autistic children and young people. This was considered an important data set as it was likely to be an extremely vulnerable group.

### Quantitative Findings

All Statements were rated as follows (Rated 1-5: 1= Strongly Disagree, 5= Strongly Agree)

#### *Accessing CAMHS is easy and understandable*

The results to this statement for this particular group of respondents was relatively similar to the overall results of the entire data pool.

#### Accessing CAMHS is easy and accessible (Autistic with Autistic Children)

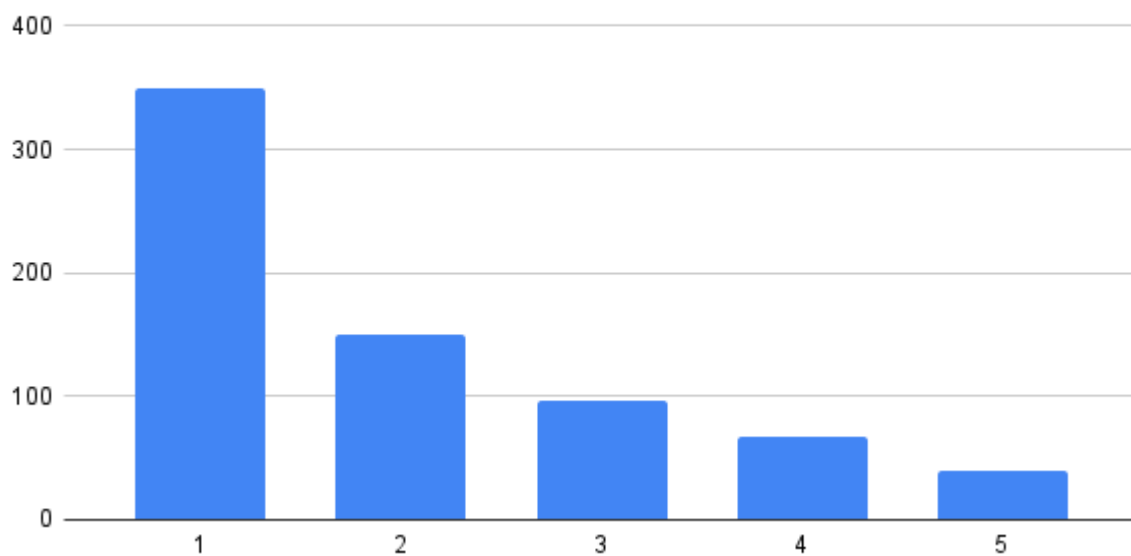


Figure 13- Section 2- Question 1 results

Results to this question were incredibly reflective of the ratings given in the overall results. This could be indicative of

accessibility issues that specifically impact on Autistic children and young people, and their families.

I would note that for Autistic people accessing services there exists the “Double Empathy Problem” which posits an empathy divide caused by non-Autistic people not having a point of reference within the Autistic experience (Milton, 2012). In this case, that gap means that service providers are likely not even aware of accessibility issues for this group of respondents. This highlights the need for services to engage with the diverse communities they are supposed to serve.

Accessing CAMHS is easy and accessible (Autistic with Autistic Children)

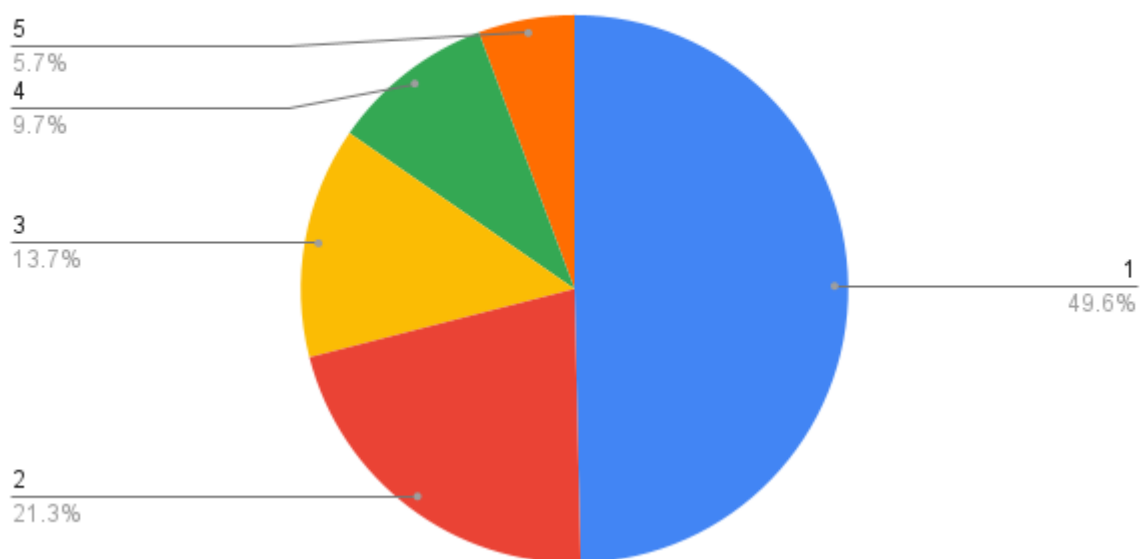


Figure 14- Section 2- Question 1 percentage

Only 15.4% of respondents gave any kind of agreement with the statement. Almost 50% strongly disagreed that CAMHS was accessible with a total of 70.9% disagreeing to some extent that CAMHS was easily accessible.

I would note the 13.7% who had no strong feelings either way. A service like CAMHS should be rated very highly on this measure,

and having so many people rate it at 3 or below indicates a very inaccessible system.

*CAMHS were attentive and supportive of mine or my loved ones needs (or your service users needs if you are a professional)*

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

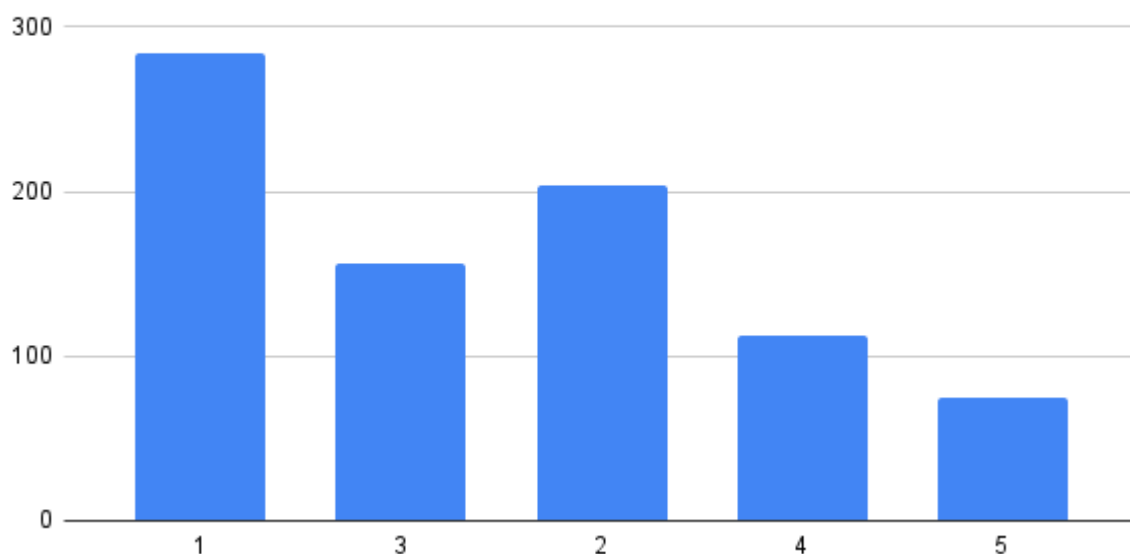


Figure 15- Section 2- Question 2 results

Interestingly, this statement showed different results to the overall data in this particular group. It is interesting that more people indicated no strong feelings towards either agreeing or disagreeing. The author would suggest that this could be indicative of inconsistency in experiences between individual communications and professionals, with some perhaps going better than others.

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

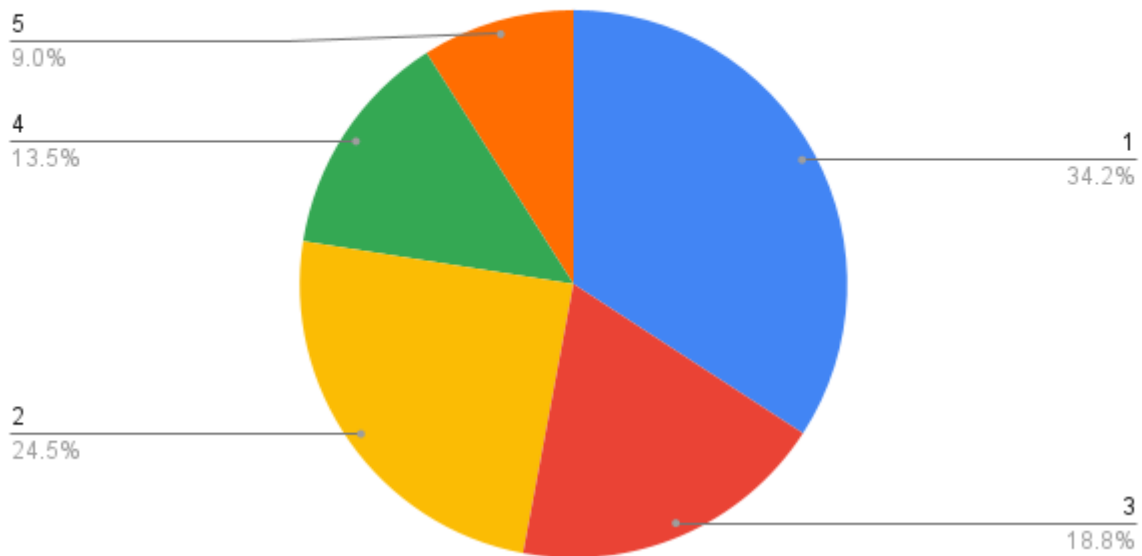


Figure 16- Section 2 -Question 2 percentage

Almost a quarter of this respondent group had no strong feelings either way. Despite this, 53% of respondents indicated that they do not feel CAMHS were attentive or supportive. It should be noted that services working with vulnerable populations should not be failing in their duty to attend to and support the needs of their service users. This fundamentally undermines the professional relationship and reflects anecdotal reports from Autistic community spaces.



*CAMHS treated my child with dignity and respect (or your service user if you are a professional)*

This statement returned some surprising results. Overall distribution was fairly even across all ratings with agreement being much higher than expected.



Figure 17- Section 2- Question 3 results

We can see that the greatest number were seen where people did not feel strongly either way, close followed by some degree of agreement.

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [Au with Au children]

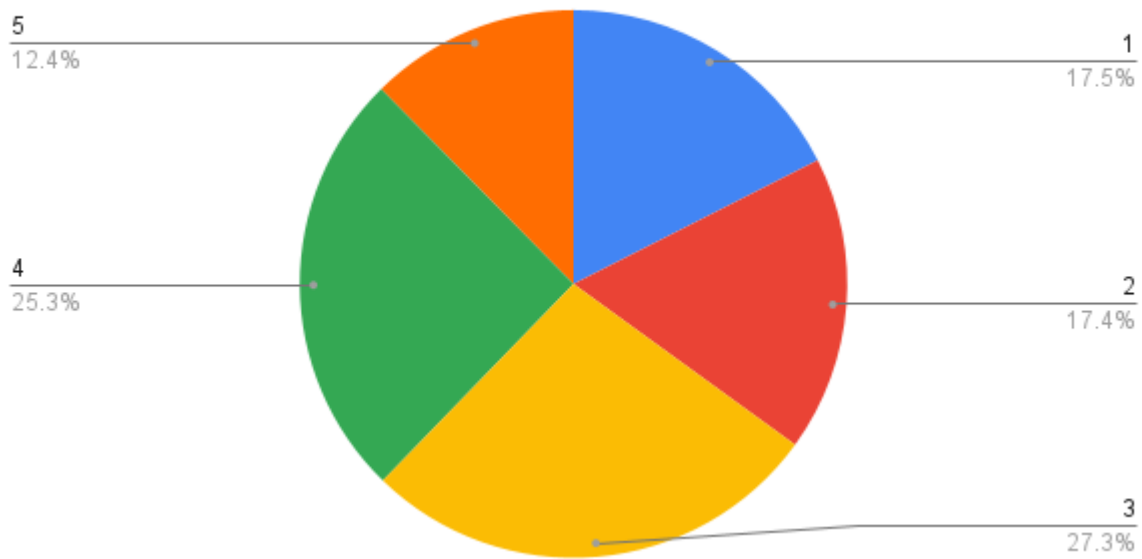


Figure 18- Section 2- Question 3 percentage

While evenly balanced, it is important to note that only 34.9% disagreed with the statement, with 37.7% agreeing overall that CAMHS acted with dignity and respect.

This suggests that something is being done better in this domain, which can be explored further in qualitative findings. It is important to note however that it is unacceptable that only around a third of respondents felt that CAMHS acted with dignity and respect. While these results are less overtly troubling than others, they do not mitigate the harm being done by systemic issues.

## CAMHS understand Autistic experiences

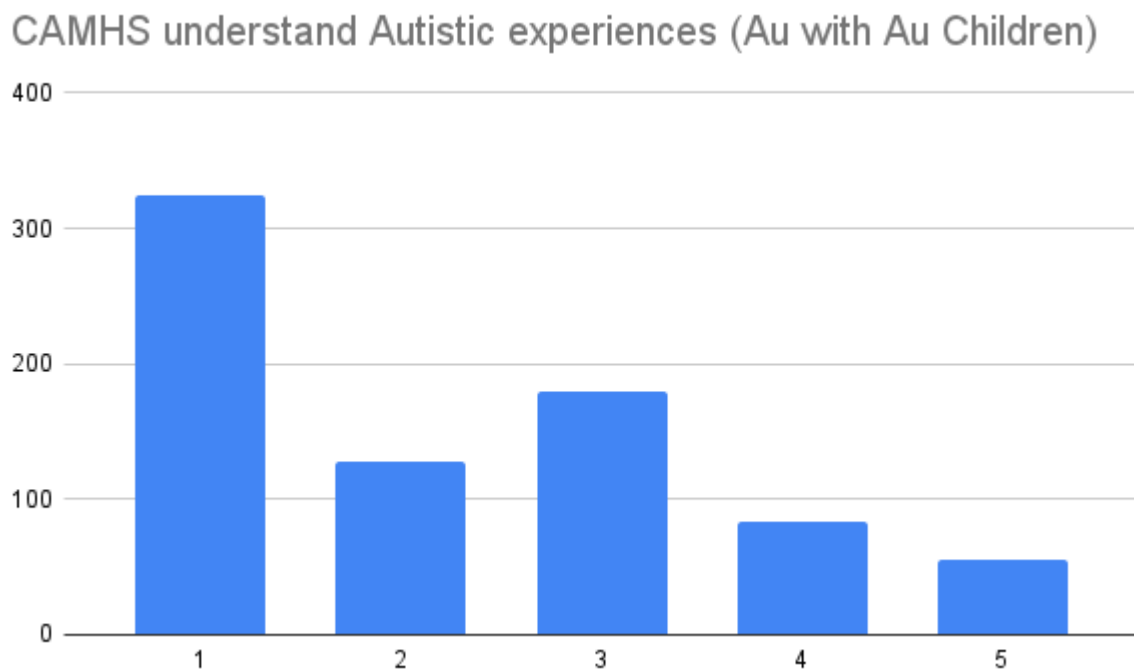


Figure 19- Section 2- Question 4 Results

The overwhelming consensus was that CAMHS do not understand Autistic experiences. This is unsurprising for anyone who has supported families through CAMHS processes or is active in UK Autistic community spaces.

CAMHS professionals carry an element of notoriety for having very restricted and biased knowledge of Autistic experience, with most knowing little beyond the DSM V criteria for autism.

It is also interesting that a sizeable number had no strong feelings of agreement or disagreement highlighting that overall, this is a significant area for improvement.

## CAMHS understand Autistic experiences (Au with Au Children)

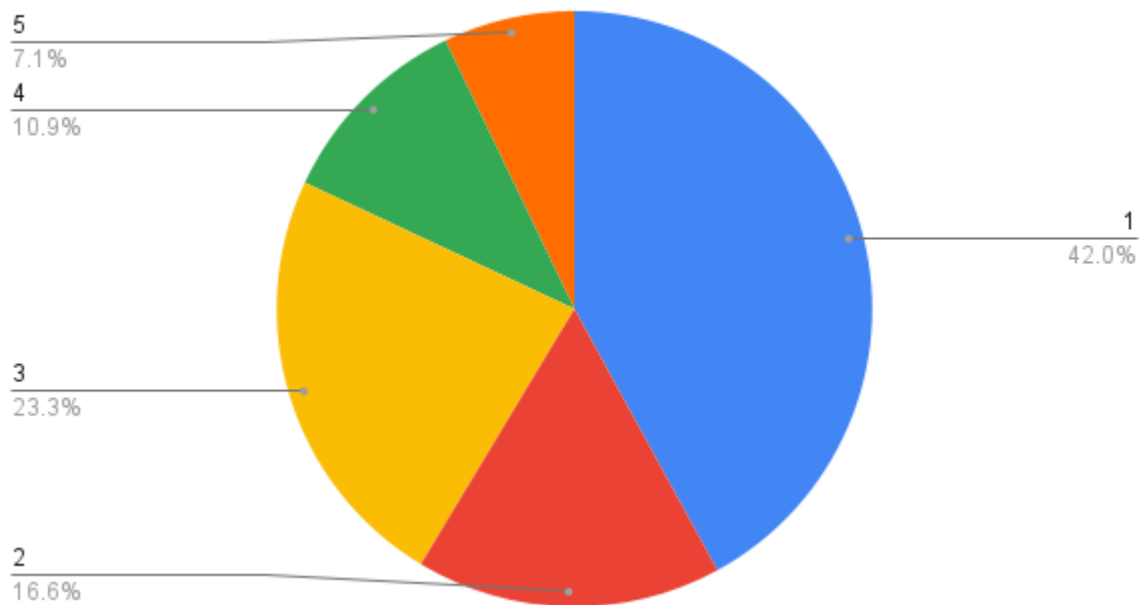


Figure 20- Section 2- Question 4 percentage

58.6% of respondents disagreed to some extent that CAMHS understand Autistic experiences, with almost a further quarter of them having no strong feelings either way. Only 18% felt that CAMHS understand Autistic experiences indicating that there is a potential for harm in this area.

This is reflected in Ashworth *et al* (2024) who found report on young people failing to engage with CAMHS due to an approach that used inappropriate or even non-existent accommodations for Autistic children and young people.

It would seem that despite the introduction of mandatory learning around autism, professionals are struggling to cross context and apply their learning in the real world. It may also suggest that the current learning on offer needs to be reviewed for accuracy and practicality.

### *CAMHS adjust their approach to suit Autistic needs*

This statement had a more balanced response despite the majority still rating it in disagreement. I believe that this area may be impacted by disparities in available skillsets between different NHS trust areas.

CAMHS adjust their approach to suit Autistic needs (Au with Au Children)

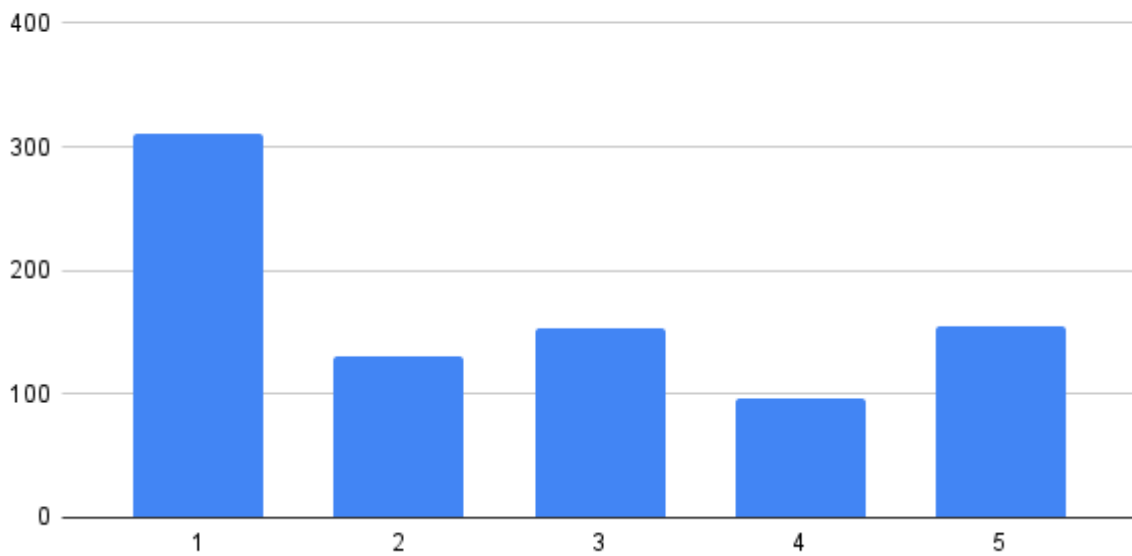


Figure 21- Section 2- Question 5 percentage

CAMHS adjust their approach to suit Autistic needs (Au with Au Children)

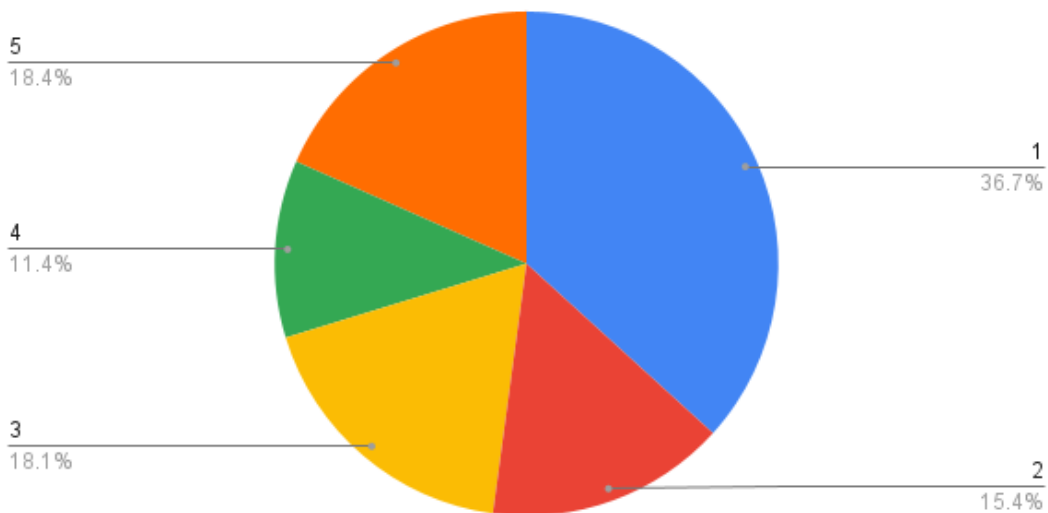


Figure 22- Section 2- Question 5 percentage

A greater number of people indicated that CAMHS do change their approach to suit Autistic people at 29.8%, however, it should be noted that 52.1% of people disagreed on this statement.

This again is suggestive of a systemic failure, starting with the knowledge imparted to CAMHS staff when they are entering the role. In simple terms, a lot of this starts with lack on Autistic-led training.

## Autistic people regarding non-Autistic Children

### Respondent Identity

All respondents in this data pool identified as being Autistic but are supporting a non-Autistic child or young person. It should be noted that this section only represents 34 respondents and therefore the results may be difficult to generalise.

### Quantitative Findings

All Statements were rated as follows (Rated 1-5: 1= Strongly Disagree, 5= Strongly Agree)

#### *Accessing CAMHS was easy and understandable*

This statement stands out because none of the respondents agreed with it. You will see in Figure 23 that all responses were either disagreement or no strong feelings either way.

Accessing CAMHS is easy and understandable (Autistic without Autistic Children)

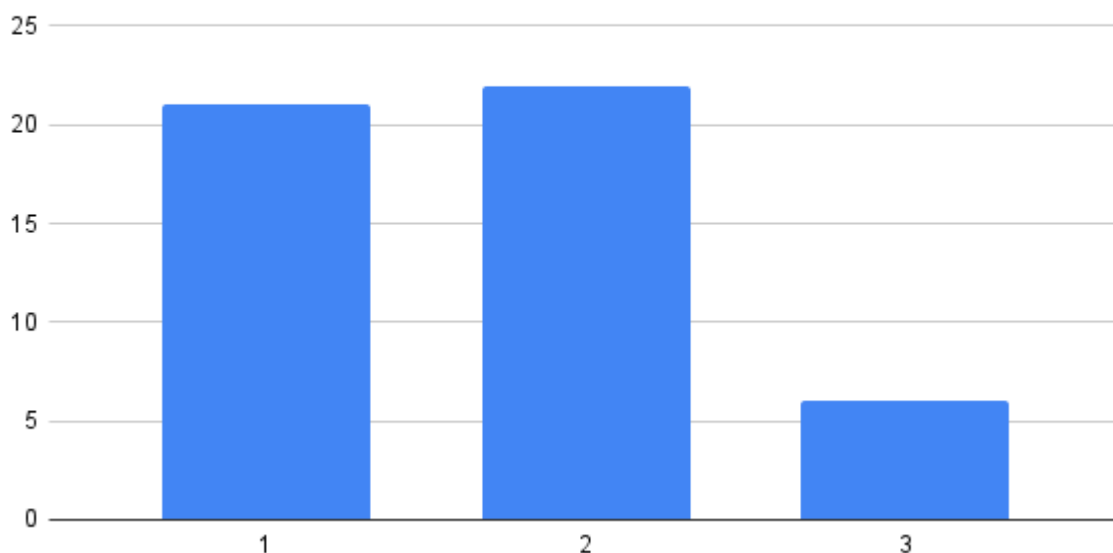


Figure 23- Section 2- Question 1 results

The data shows that the vast majority of respondents in this pool disagree that CAMHS was easy and understandable to access. While this may be because it was a small sample that did not

capture the full picture, the author would note that this could also indicate that Autistic people may have more negative experiences of accessing these systems for their young people. It is reasonable to infer that Autistic parent-carers and professionals are more prone to negative experiences when trying to utilise CAMHS services.

### Accessing CAMHS is easy and understandable (Autistic without Autistic Children)

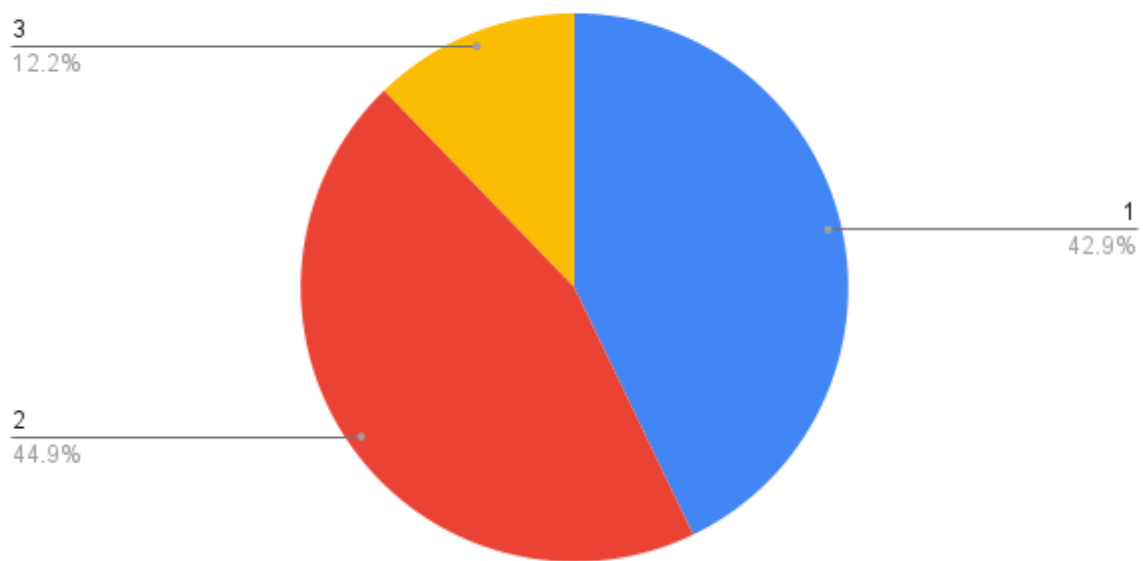


Figure 24- Section 2- Question 1 percentage

Over all, you will see that 87.8% disagreed with the statement, while only 12.2% had no strong feelings.



*CAMHS were attentive and supportive of mine or my loved ones needs (or your service users needs if you are a professional)*

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

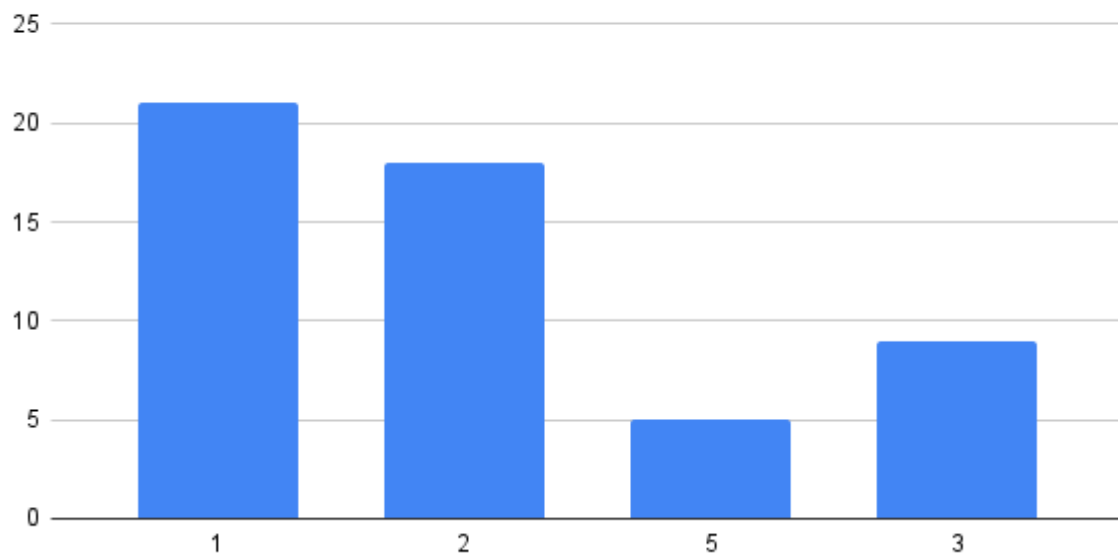


Figure 25- Section 2- Question 2 results

While there was some agreement with this statement, it should be noted that none of the respondents in this pool had any strong agreement with the statement. As per the first statement, respondents overwhelmingly voted in disagreement on this statement.

It was interesting that so many less people took a neutral position on this statement. This suggests that for this group, the statement had a polarising effect that it didn't have for the previous groups.

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

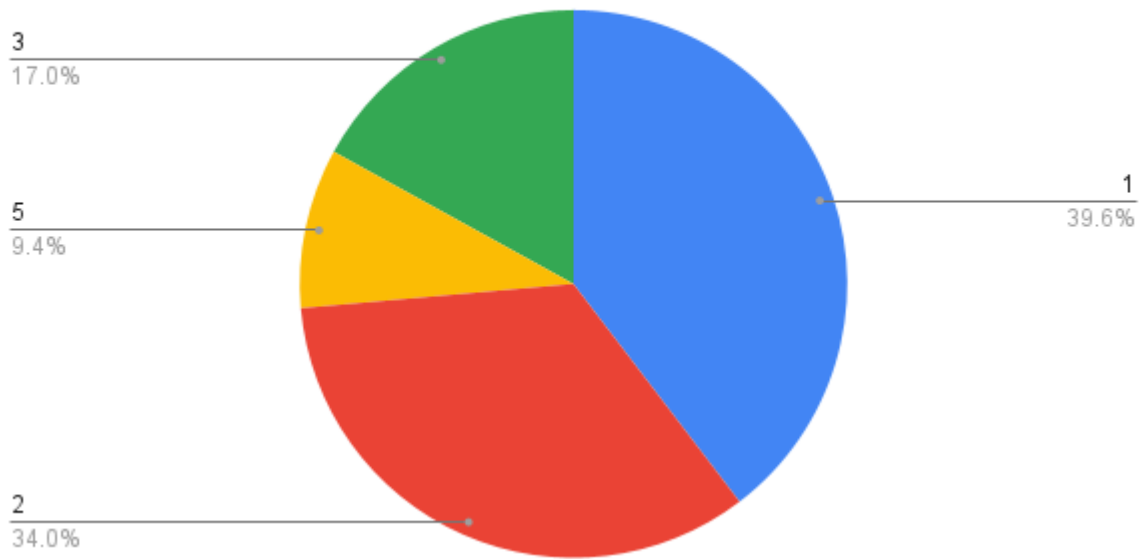


Figure 26- Section 2- Question 2 percentage

Almost three quarters disagreed with this statement at 73.6%. 17% had some agreement, with none strongly agreeing with the statement. As previously mentioned, only 9% took a neutral position.

This combined with the statements results for the Autistic supporting Autistic young people group suggest that there is a notable issue ongoing in this area for Autistic people helping children and young people access CAMHS.

*CAMHS treated my child with dignity and respect (or you service user if you are a professional)*

This group needs further data gathered on this statement in particular. The vast majority took a neutral stance rather than agreement or disagreement. Further data acquisition may provide deeper insight into this.

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [Au without Au Children]

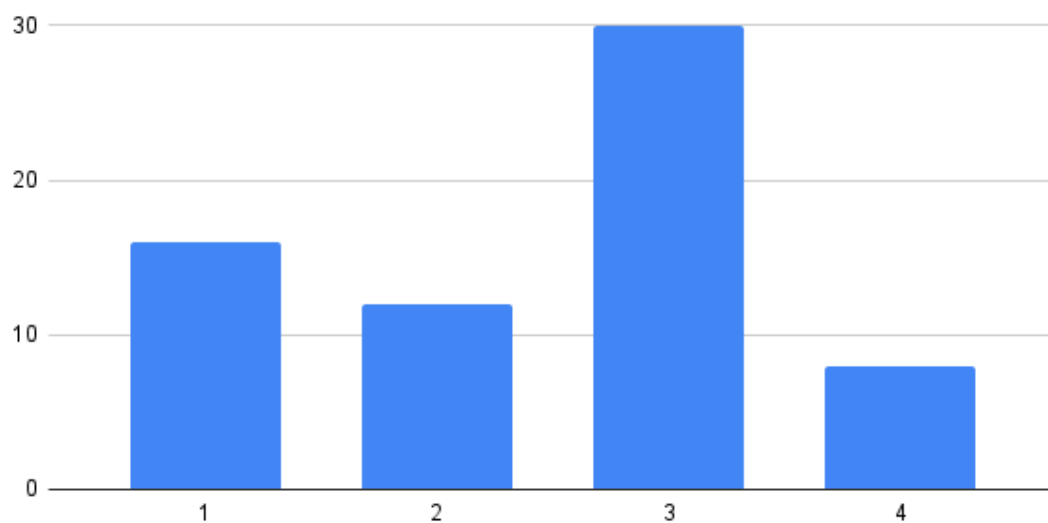


Figure 27- Section 2- Question 3 results

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [Au without Au Children]

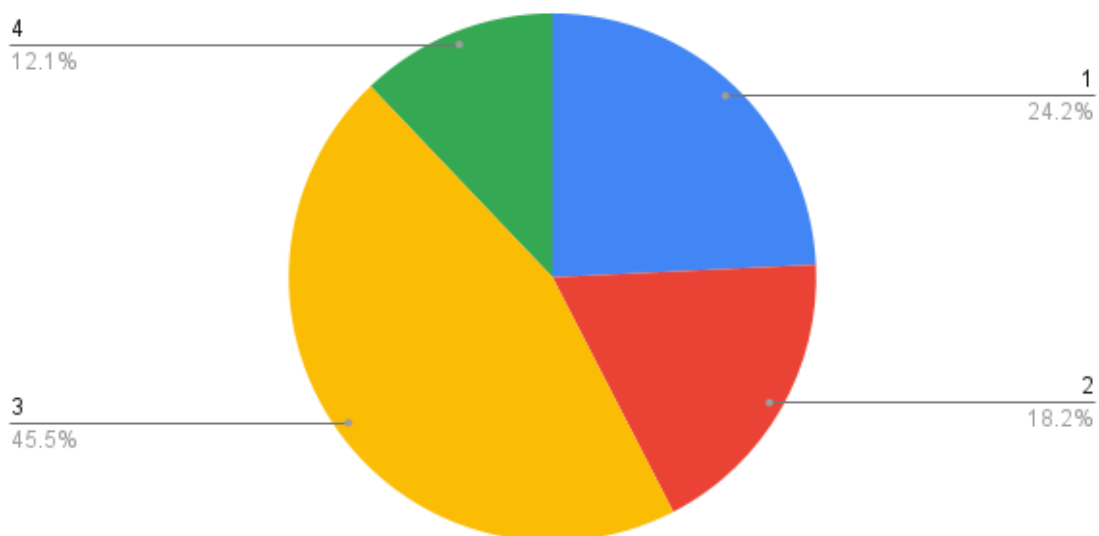


Figure 28- Section 2- Question 3- percentage

Almost half of respondents in this data pool took a neutral stance (45.5%). There was still a great deal of disagreement with 42.4% disagreeing that CAMHS treats children and young people with respect.

What has stood out to me in this area for all data pools is that further research into this is urgently required. Despite it being a common complaint, trying to find academic literature on this topic turns up incredibly limited findings.

### *CAMHS Understand Autistic experiences*

Exactly half of respondents disagreed with this statement. This is reflective of views within Autistic community spaces that suggest significant failings by CAMHS in most domains.

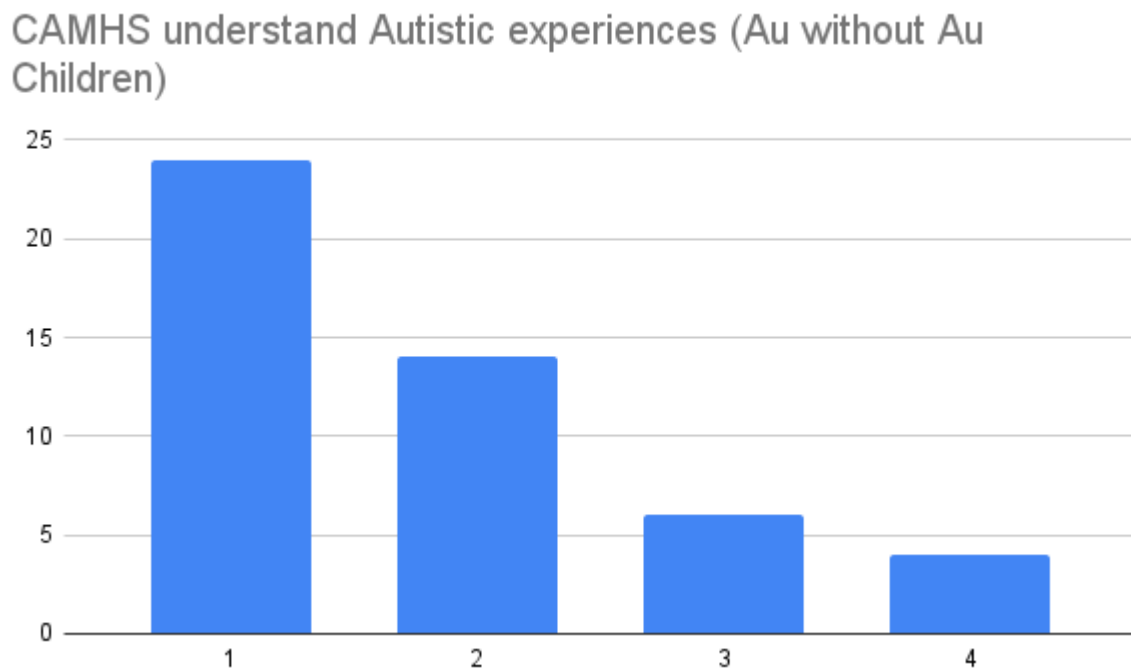


Figure 29- Section 2- Question 4 results

There was a negative trend with higher ratings of the statement representing increasingly smaller numbers of participants in this data pool.

The author would suggest that Autistic people, regardless of their child’s neurocognitive style, are more likely to have had negative experiences of CAMHS. It is also likely that some in this pool are referring to their own experiences of being a CAMHS patient.

Autistic children under CAMHS grow into Autistic adults. If the data in this report is to be believed, it is unsurprising that Autistic people experience mental health issues at a higher rate than non-Autistic people, particularly as they move into adulthood (Lai *et al*, 2019).

*CAMHS adjust their approach to suit Autistic needs*

It should be noted that a higher than expected number of people felt strong agreement with this statement, however the majority still disagreed.

CAMHS adjust their approach to suit Autistic needs (Au without Au Children)

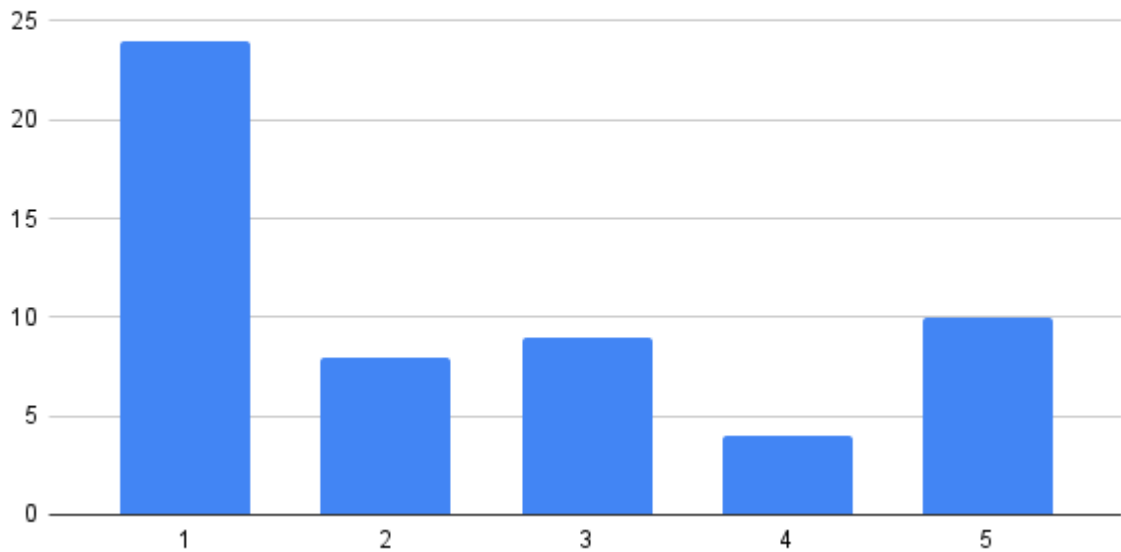


Figure 30- Section 2- Question 5 result

CAMHS adjust their approach to suit Autistic needs (Au without Au Children)

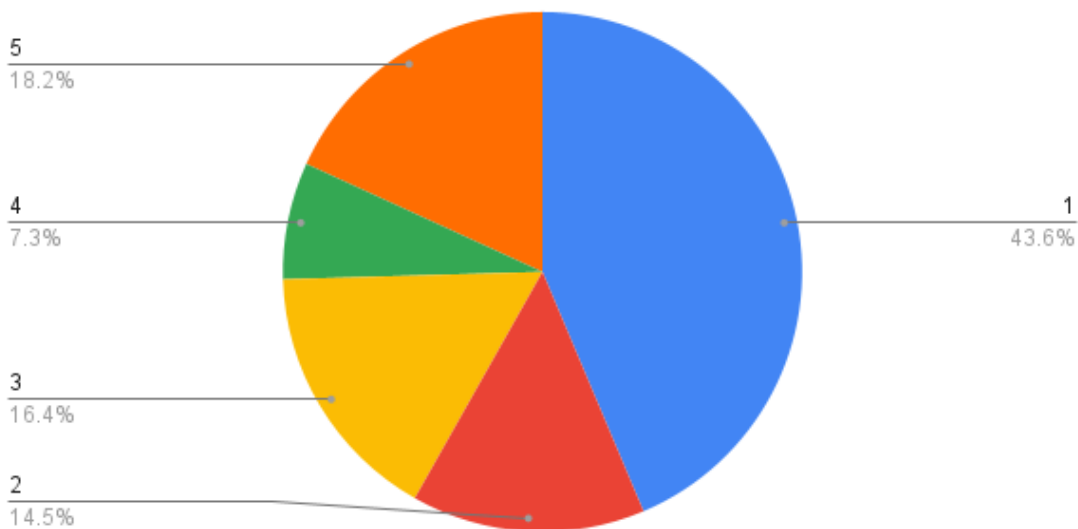


Figure 31- Section 2- Question 5

It is possible that the reason a quarter (25.8%) agreed with this statement is because respondents in this pool were formerly patients themselves, potentially experiencing CAMHS before the current resource crisis in the NHS. It should still be highlighted though that 58.1% of people disagree with the statement which is unacceptable.

## Non-Autistic respondents regarding Autistic Children

### Respondent Identity

This data pool consisted of 246 responses all of whom identified as not being Autistic but supporting an Autistic child or young person.

### Quantitative Findings

All Statements were rated as follows (Rated 1-5: 1= Strongly Disagree, 5= Strongly Agree)

#### *Accessing CAMHS was easy and understandable*

Accessing CAMHS is easy and understandable (Not Autistic with Autistic Children)

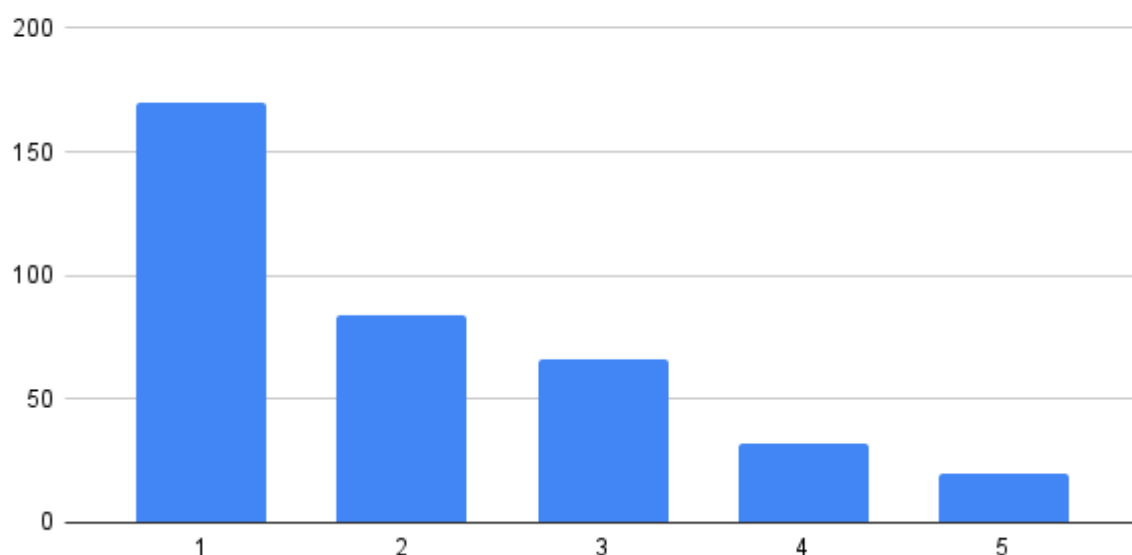


Figure 32- Section 2- Question 1 results

Results for this data pool are remarkably similar to those for other groups. From this we can posit that accessibility issues within CAMHS are not unique to Autistic adults. It would appear that regardless of neurocognitive style, adults trying to use the system on behalf of a child are encountering significant issues.

This highlights the reports within community spaces of the bureaucratic nature of CAMHS and the wider NHS, with



thresholds for support often acting as confusing and dangerous gatekeepers to accessing support.

### Accessing CAMHS is easy and understandable (Not Autistic with Autistic Children)

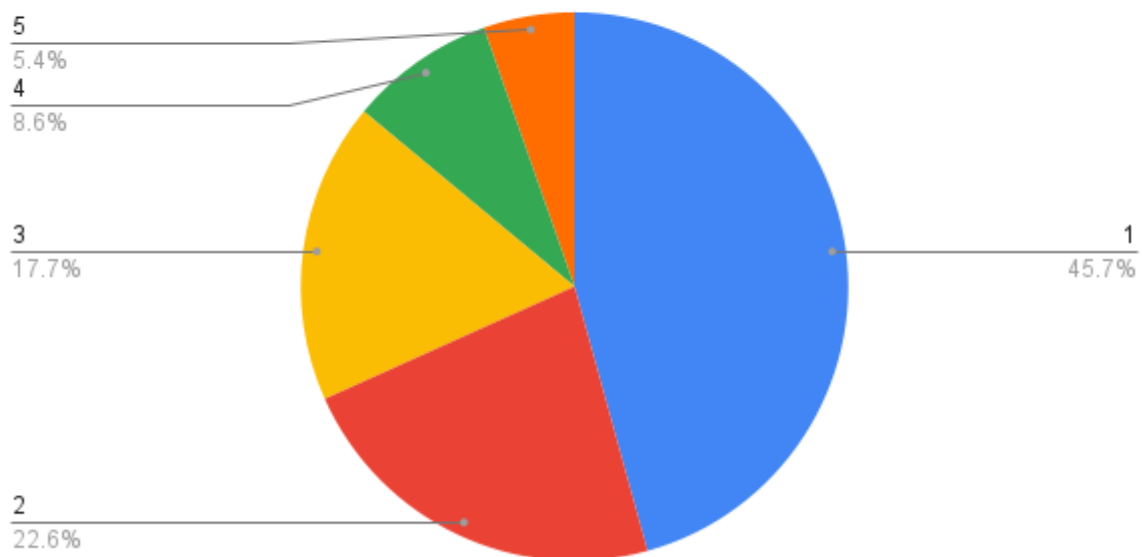


Figure 33- Section 2- Question 1 percentage

Over two thirds (68.3%) of respondents in this pool disagreed that CAMHS was easy and understandable to access. By comparison, only 14% had the opposing opinion. The overarching consensus appears to be that CAMHS is neither easy or understandable to access.

It has been suggest that a lack of personalisation of treatment may play a role in difficulties with accessibility in CAMHS (Kirk *et al*, 2023). This is reflective of community reports that one-size-fits-all approaches are impeding the ability of community members to access CAMHS.

*CAMHS were attentive and supportive of mine or my lived ones needs (or your service user if you are a professional)*

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

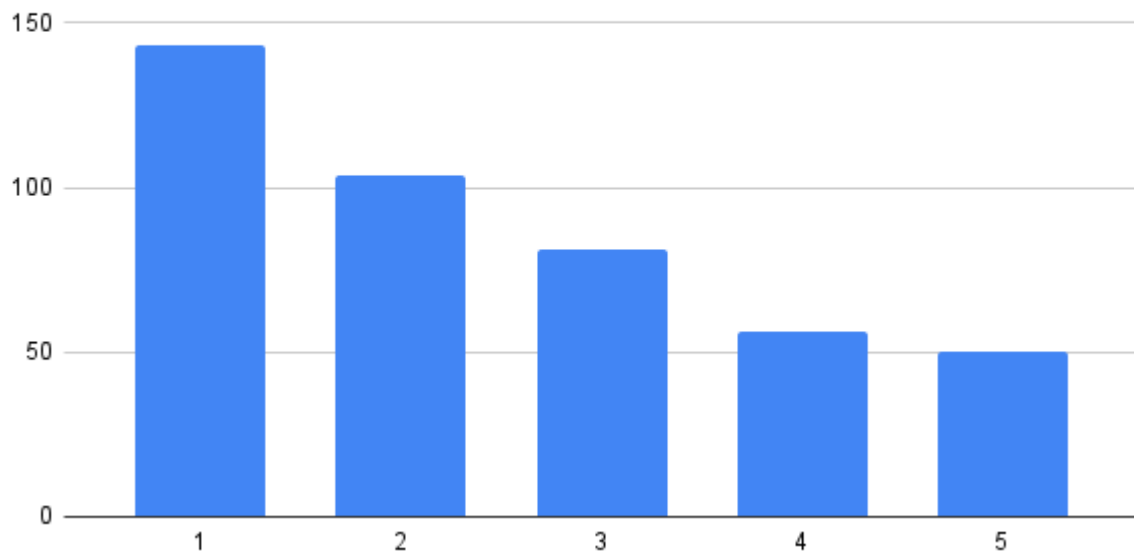


Figure 34- Section 2- Question 2 results

Distribution of ratings showed a declining trend towards agreement with the majority again rating CAMHS as not being attentive and supportive.

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

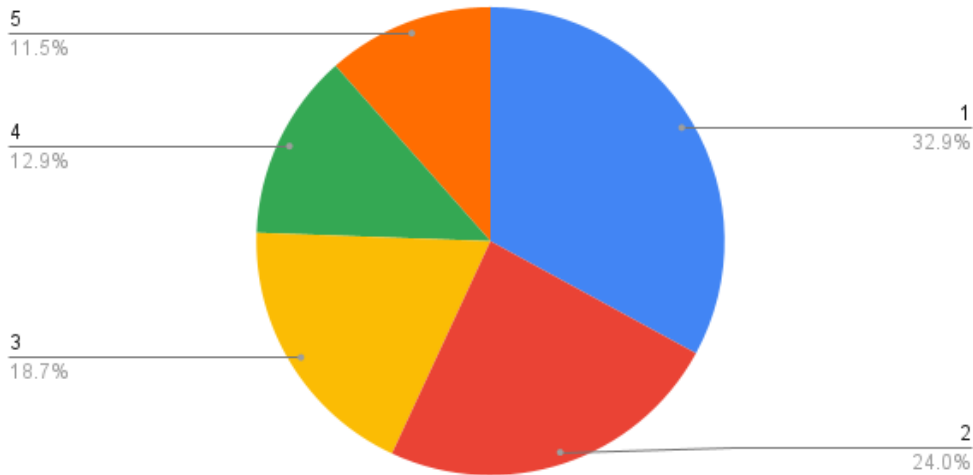


Figure 35- Section 2- Question 2 percentage

56.9% disagrees with the statement compared to just under one quarter (24.4%) who agreed. It is also notable that almost 20% had no strong feelings on this statement. The author would again note that results like this indicate a need for a great deal more effort to be put into developing this area.

*CAMHS treated my child with dignity and respect (or your service user if you are a professional)*

This was perhaps the most surprising of all the results. The majority of respondents agreed with this statement.

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [Not Au with Au Children]

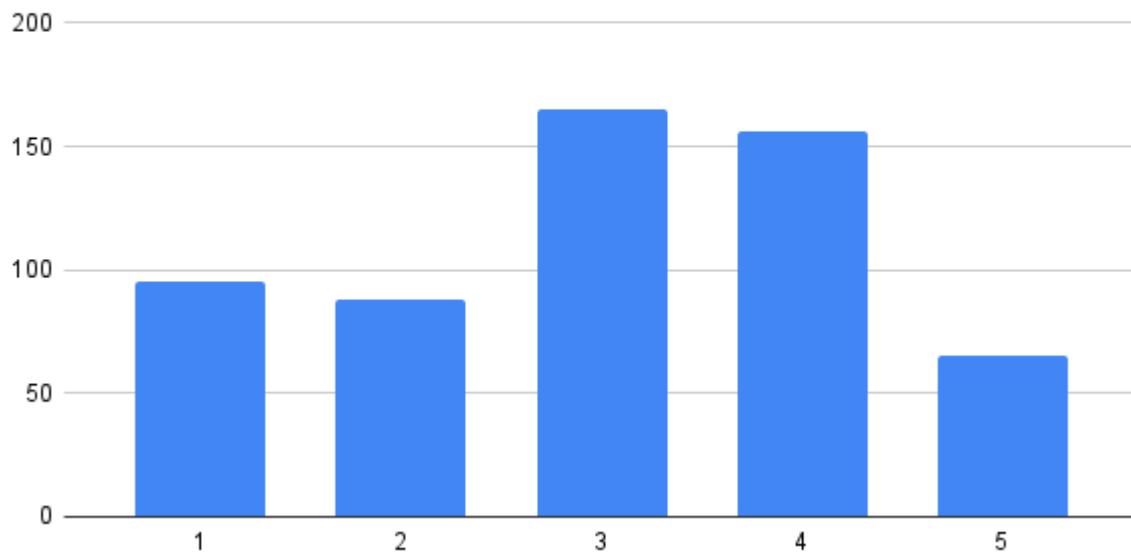


Figure 36- Section 2- Question 3 results

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [Not Au with Au Children]

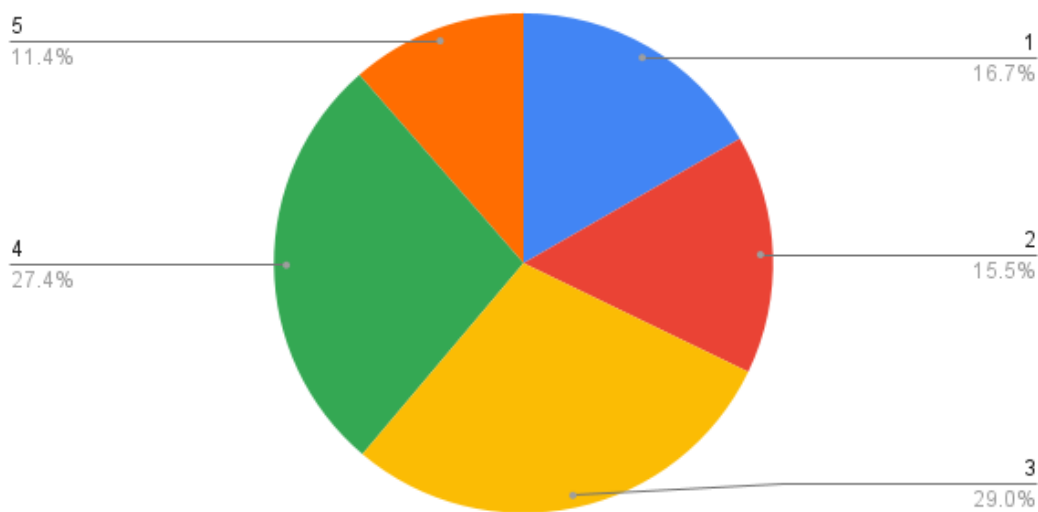


Figure 37- Section 2- Question 3 percentage

38.8% agreed with the statement compared with 32.2% who disagreed. One might suggest that a factor in this is a difference in what this group considers “dignity and respect” compared to others and might be related to the double empathy problem (Milton, 2012), with non-Autistic respondents feeling differently due to cultural differences between themselves and Autistic respondents.

It should still be noted that 61.2% of respondents either had no strong feelings or disagreed, highlighting that dignity and respect of patients is a significant issue for CAMHS.

## CAMHS Understand Autistic Experiences

CAMHS understand Autistic experiences (Not Au with Au Children)

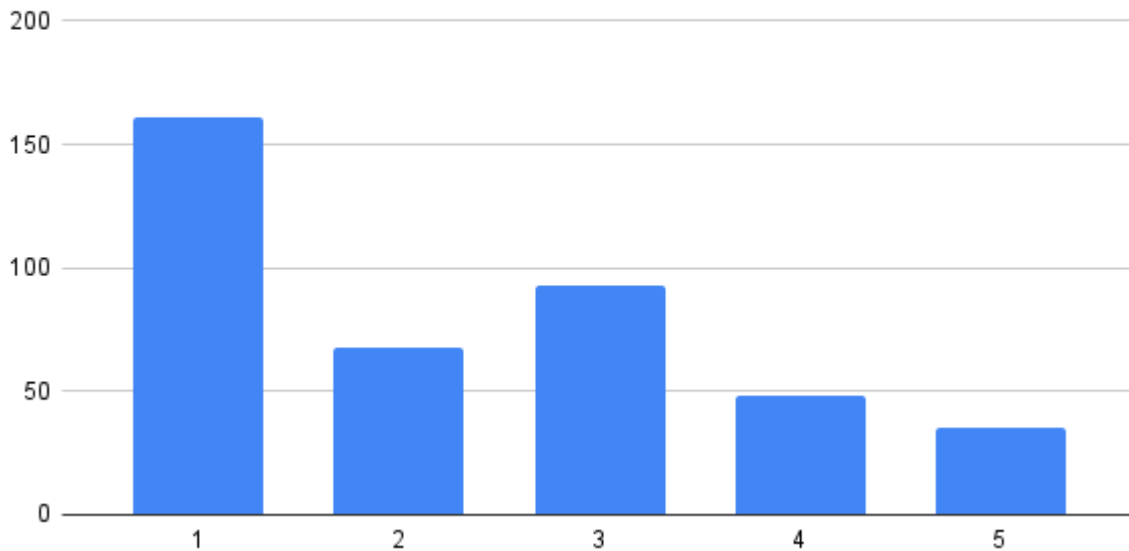


Figure 38- Section 2- Question 4 results

Again, the majority disagreed with the statement, but with a slightly higher proportion of this sample having no strong feelings either way. It would appear that the course of this report is to establish that despite mandatory training, CAMHS staff do not understand Autistic experience to a satisfactory level.

CAMHS understand Autistic experiences (Not Au with Au Children)

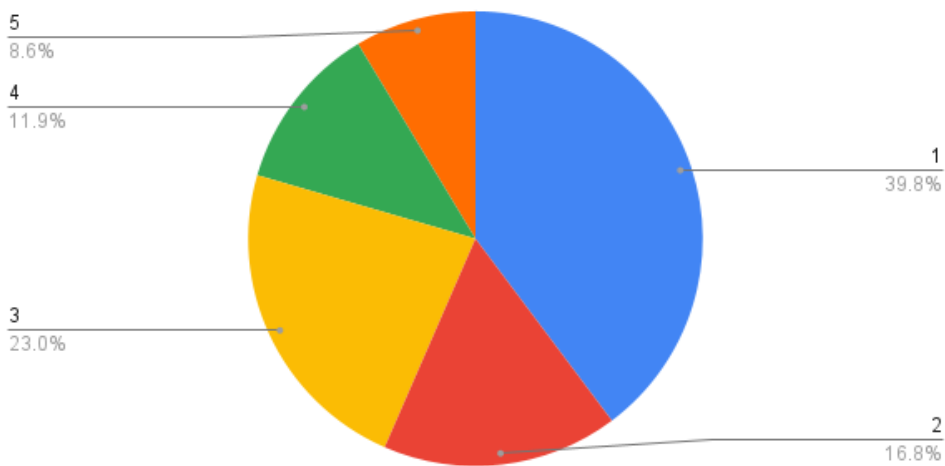


Figure 39- Section 2- Question 3 percentage

56.6% of respondents disagreed with the statement with a further 23% having no strong feelings either way. Given that Autistic people are more likely to have a mental health problem (Lai *et al*, 2019) and represent 93% of under-18s in psychiatric wards (NAS, 2023), understanding Autistic experience should be a basic prerequisite.

## *CAMHS adjust their approach to suit Autistic needs*

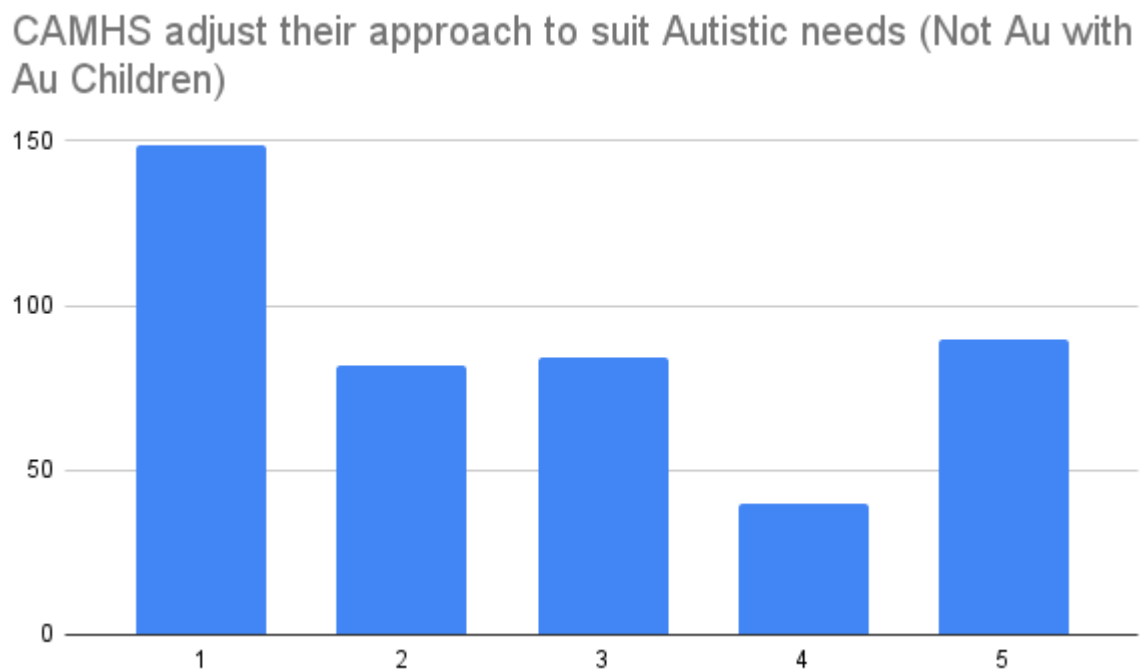


Figure 40- Section 2- Question 5 results

It was again interesting to see from the distribution of ratings that a greater number in this group strongly agreed that CAMHS adjust their approach to suit Autistic needs. While this may be promising, it could also be indicative of non-Autistic parent-carers and professionals having a different standard in mind to those which their Autistic counterparts would consider appropriate. Further research would be needed to establish this.

Despite this, it is again important to note that too many people are disagreeing or having no strong feelings either way. NICE guidelines are clear that therapies and treatments need to be adjusted to meet the needs of Autistic service users, and it would seem that on the whole, this is not being done.



### CAMHS adjust their approach to suit Autistic needs (Not Au with Au Children)

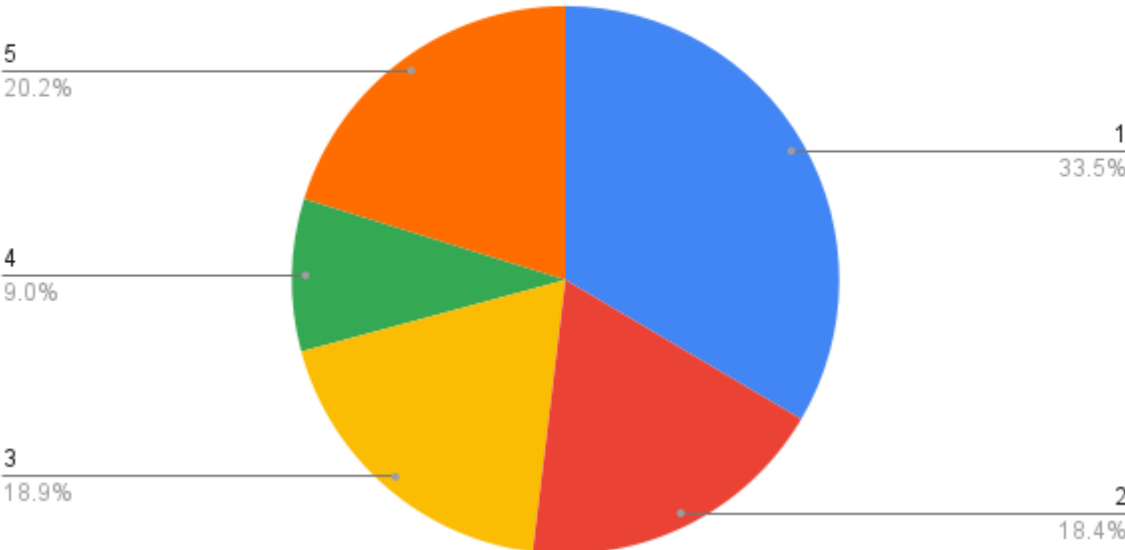


Figure 41- Section 2- Question 5 percentage

Overall, just 29.2% agree with this statement, with the rest either having no strong feelings or disagreeing to some extent (18.9% and 51.9% respectively). One-size-fits-all approaches are not helpful to anyone, especially not Autistic children and young people.

## Unsure Respondent Regarding Autistic Children

### Respondent Identity

This group comprised of respondents who were unsure of their Autistic identity but were supporting Autistic children or young people. There were 74 responses in this section.

### Quantitative Findings

All Statements were rated as follows (Rated 1-5: 1= Strongly Disagree, 5= Strongly Agree)

### *Accessing CAMHS was easy and understandable*

Accessing CAMHS is easy and understandable (Unsure with Autistic Children)

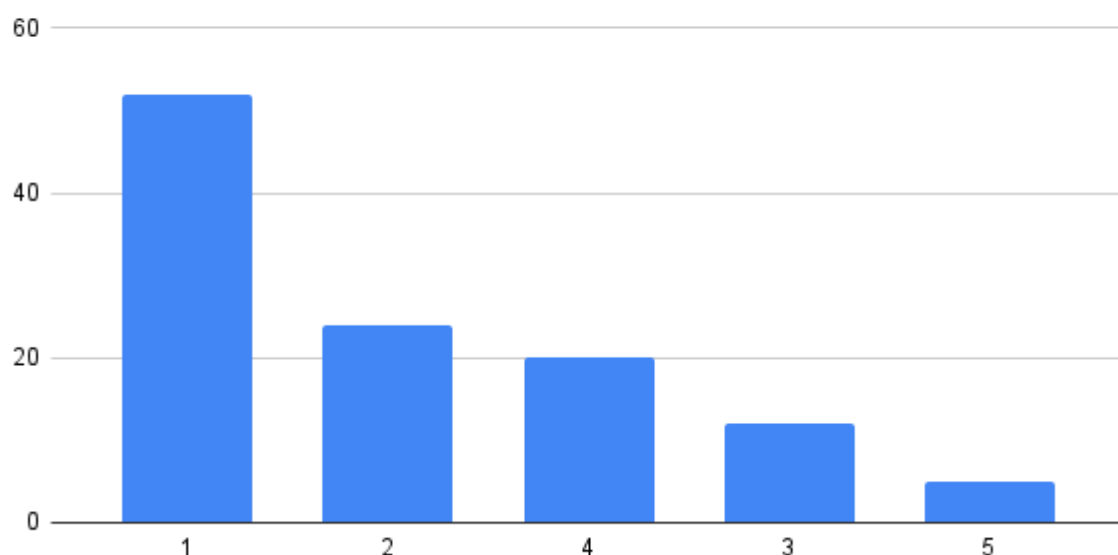


Figure 42- Section 2- Question 1 results

We have established in this report that there is a consensus among all demographics represented in this report that CAMHS is not easy or understandable to access. This particular group reflects a similar result to all of the others for this statement.

The overwhelming response is one of disagreement on this statement for this group of respondents.

### Accessing CAMHS is easy and understandable (Unsure with Autistic Children)

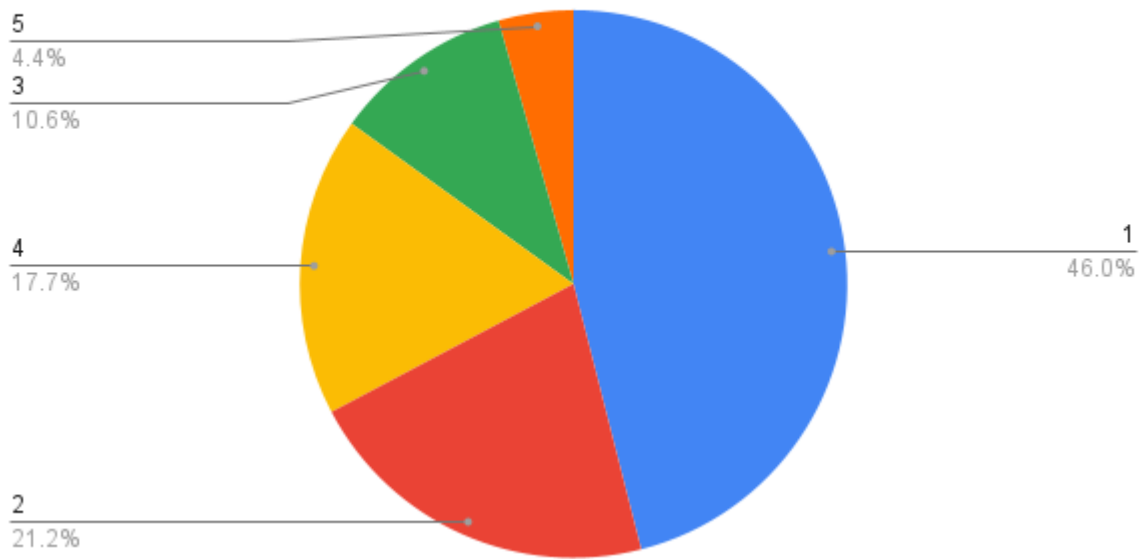


Figure 43- Section 2- Question 1 percentage

67.2% disagree with a further 17.7% having no strong feelings. Just 15% of respondents had any agreement with the statement.

This group is interesting because they are unsure of their identity, but sure of the child or young person's identity. Given that there are estimated to be 1.2 million undiagnosed Autistic people in the UK (O'Nions *et al*, 2023) and the high heritability of autism (Taylor *et al*, 2021), it seems reasonable to infer that many of these respondents are in fact Autistic themselves.

*CAMHS were attentive and supportive of mine or my loved ones needs (or your service user if you are a professional)*

An overwhelming majority of this group rated this statement from 1-3 indicating either disagreement or neutrality. This suggests that for those who are unsure of their Autistic identity, they were much more likely to have a negative view of CAMHS attentiveness and support.

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

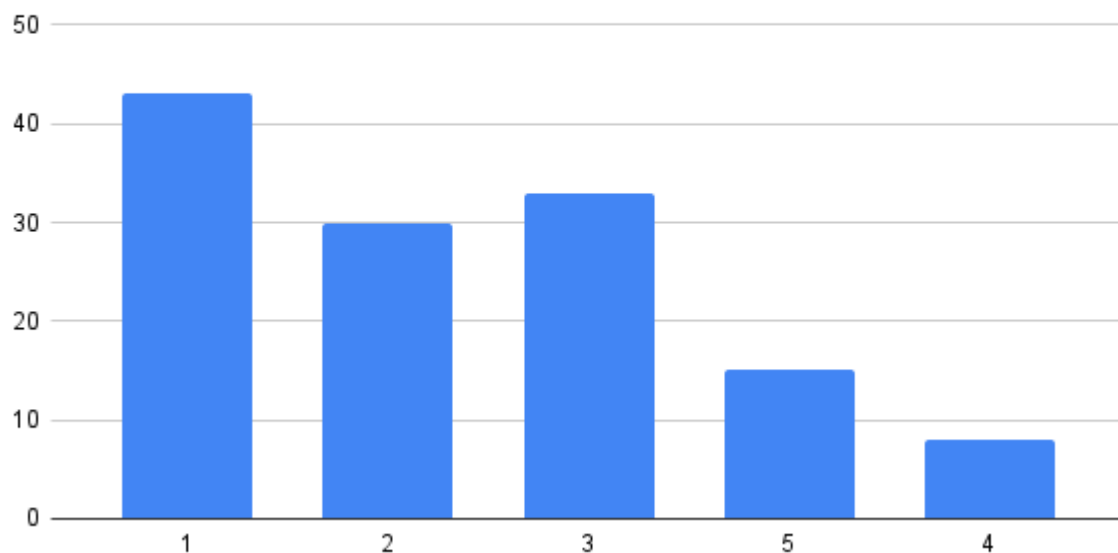


Figure 44- Section 2- Question 2 results

56.6% of respondents in this group disagree that CAMHS were attentive or supportive with a total of 82.2% having no explicit agreement with the statement (*Figure 45*).

While this may be a result of reductions in available resources and staff being over-worked, it is also reasonable to assume that staff training and attitudes will impact this as well.

CAMHS were attentive and supporting of mine or my loved ones needs (or your service users needs if you are a professional)

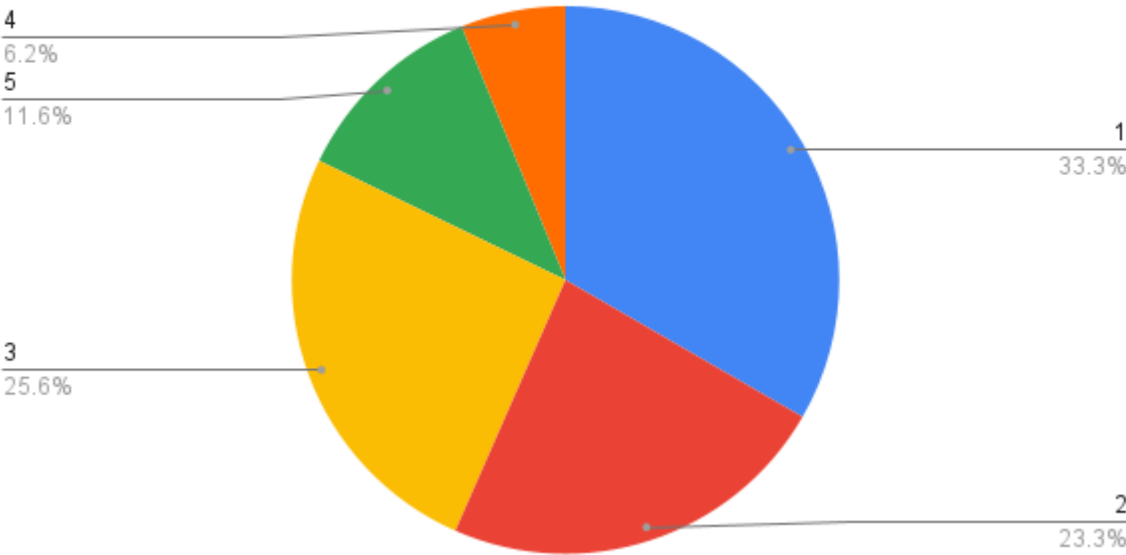


Figure 45- Section 2- Question 2 percentage

*CAMHS treated my child with dignity and respect (or your service user if you are a professional)*

Again, this statement generated surprising results, with most giving a neutral opinion, and limited difference between those who agree or disagree. It should still be noted however that more people disagreed than agreed that CAMHS treat children with dignity and respect.

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [U/S with Au Children]

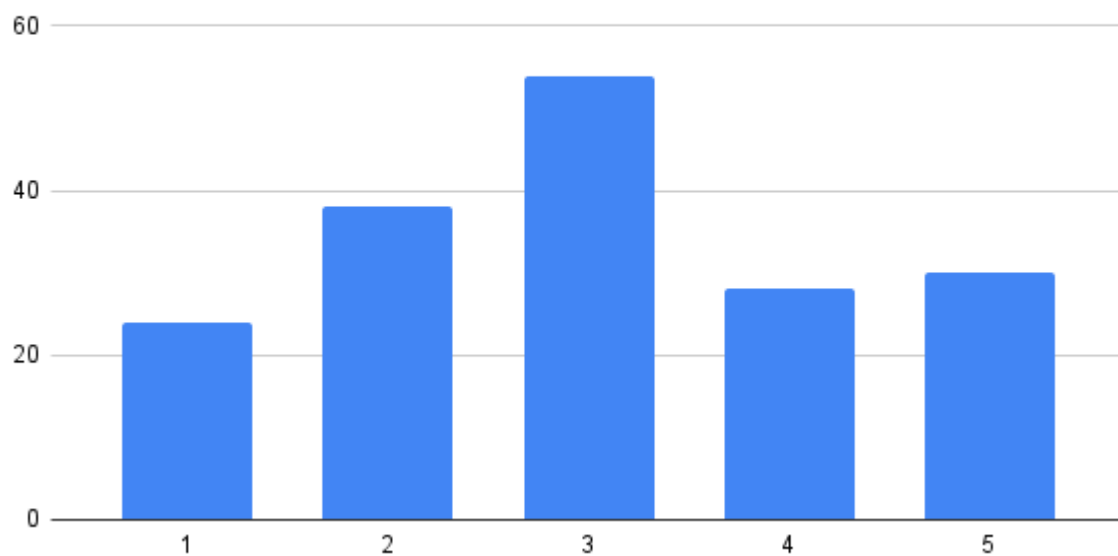


Figure 46- Section 2- Question 3 results

It should be noted that results from 1-3 should be considered unfavourable and indicate the need for significant intervention in the attitudes and methodologies of staff to mitigate the harm caused by approaching Autistic children and young people without the dignity and respect that they deserve. It seems that the results of this survey stand in opposition to the claim of neurodiversity affirmation by the NHS.

CAMHS treated my child with dignity and respect (or your service user if you are a professional) [U/S with Au Children]

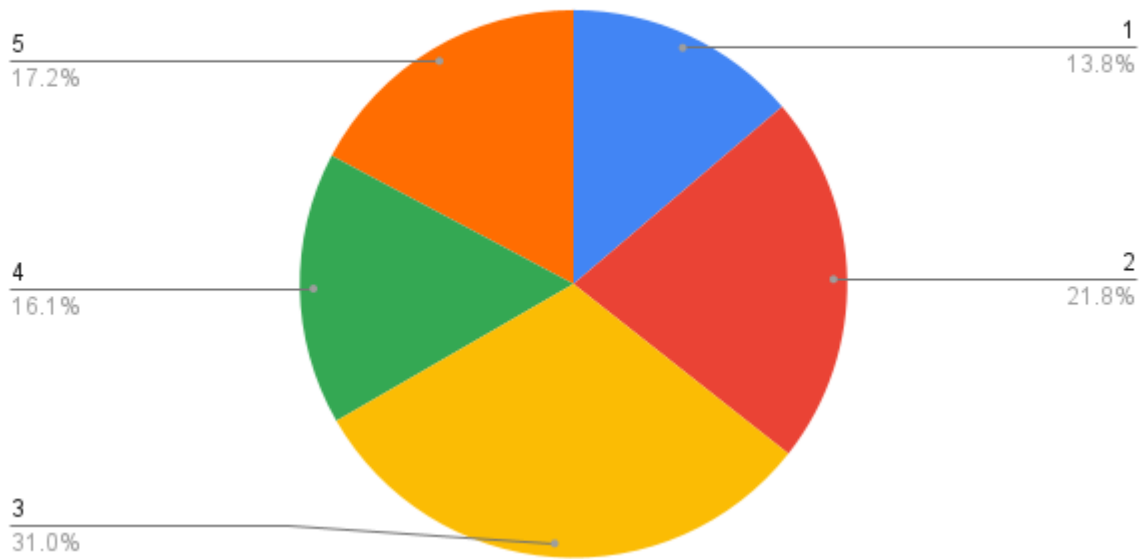


Figure 47- Section2- Question 3 percentages

35.6% disagreed with the statement compared to 33.3% who agreed. 31% had no strong feelings either way.

### CAMHS understand Autistic experiences

Around half of respondents in this group disagreed with this statement with a further third having no strong feelings.

CAMHS understand Autistic experiences (U/S with Au Children)

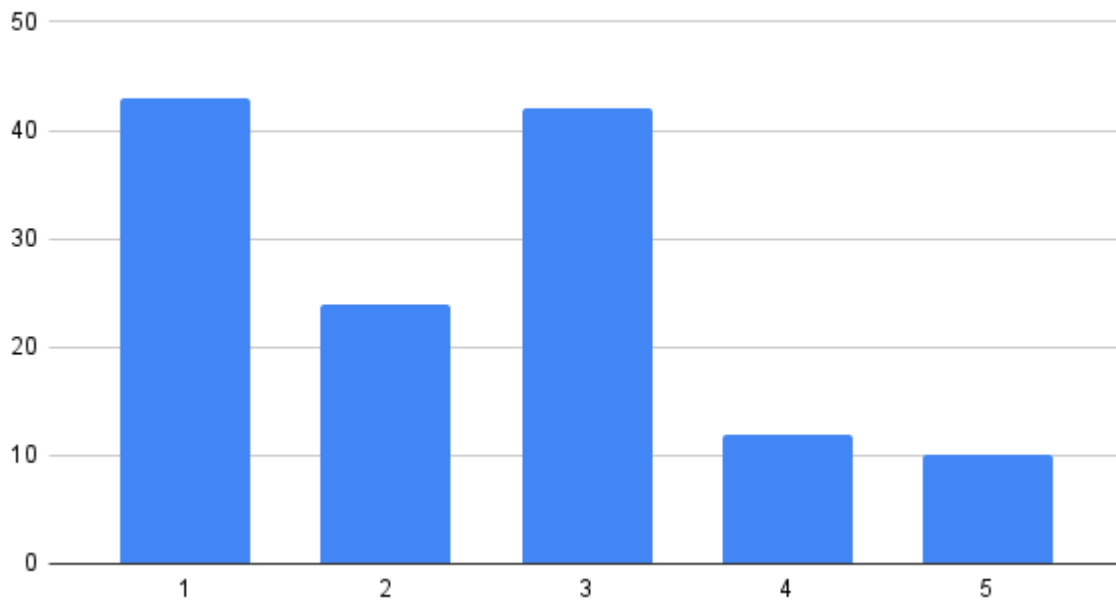


Figure 48- Section 2- Question 4 results

CAMHS understand Autistic experiences (U/S with Au Children)

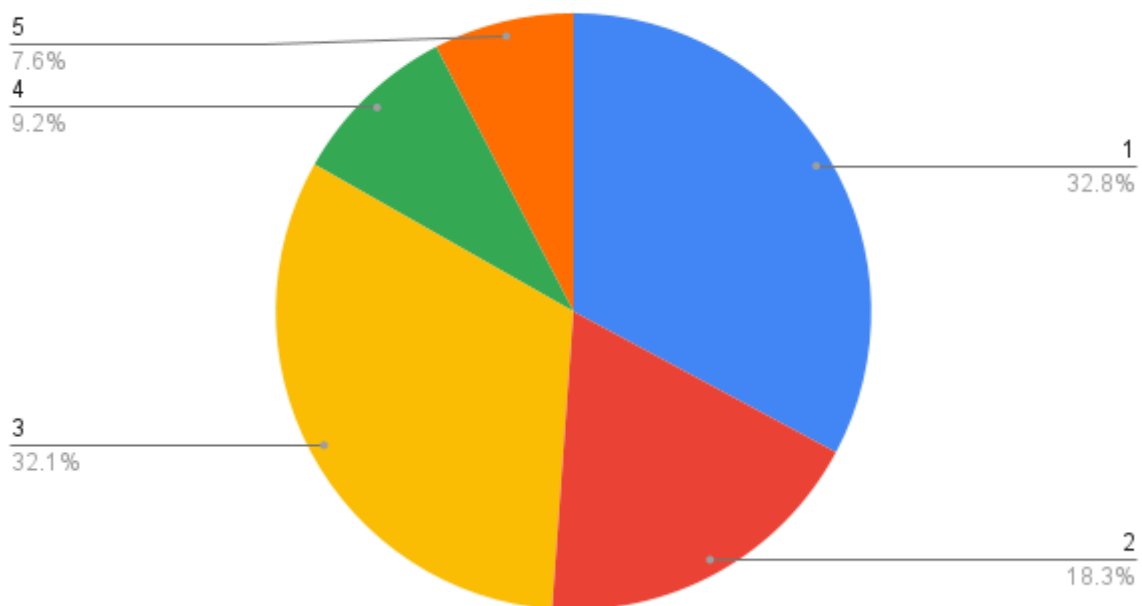


Figure 49- Section 2- Question 4 percentage



In total, 51.1% disagreed that CAMHS understand Autistic experience, while a further 32.1% had a neutral opinion. The lack of appropriate knowledge is again highlighted by the fact that only 16.8% of respondents agreed with this statement.

## CAMHS adjust their approach to suit Autistic needs

CAMHS adjust their approach to suit Autistic needs (U/S with Au Children)

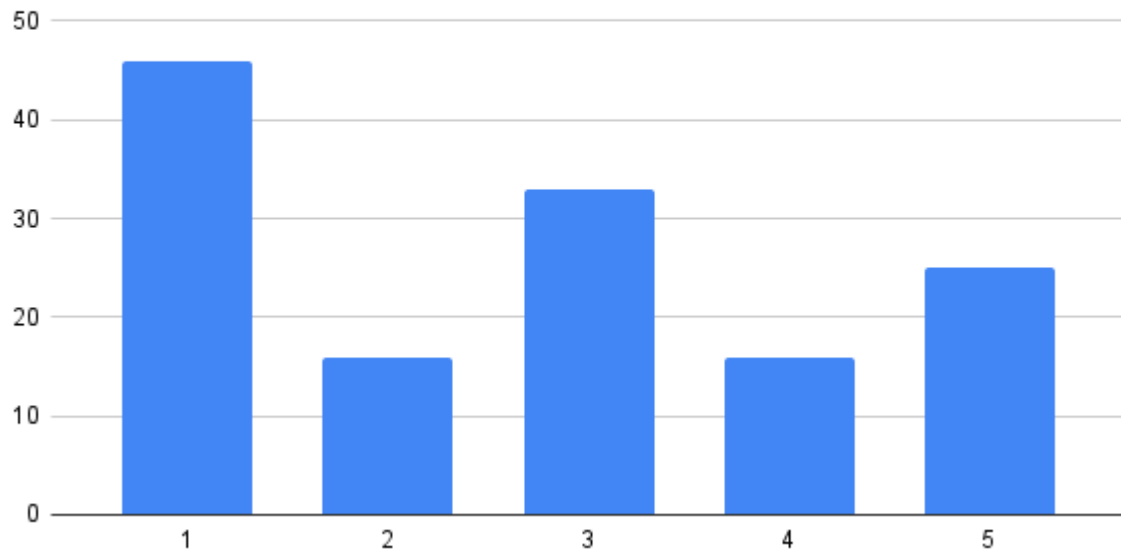


Figure 50- Section 2- Question 5 results

CAMHS adjust their approach to suit Autistic needs (U/S with Au Children)

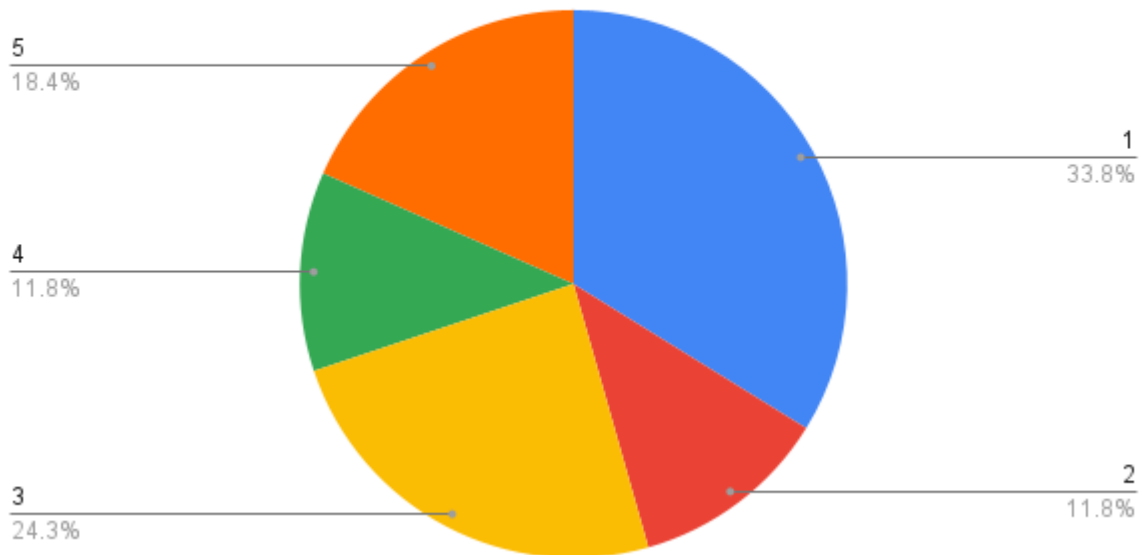


Figure 51- Section 2- Question 5 percentage

While a larger portion of respondents agreed that CAMHS adjust their approach (18.4% strongly agreed) it should be noted that 33.8% strongly disagreed.

In total 45.6% disagreed, 30.2% disagreed, and 24.3% has a neutral opinion.

## Conclusions

Results were reasonably consistent regardless of the respondents' Autistic identity. What is clear from this report is that there are significant failures ongoing in many domains of CAMHS. While we may see slightly more promising results in measures of dignity and respect, over all this area still needs extensive work done.

Something that stands out, in particular, is that mandatory autism training doesn't appear to be doing enough to improve experiences of CAMHS for Autistic people. This may indicate that training needs to have a heavier dependence on Autistic experts with lived experience. Current training may not have enough input from those with a vested interest or beneficiaries of services.

Service user involvement in strategy and policy development may also help mitigate some of the issues highlighted in this quantitative report.

Autistic children and young people are 28 times more likely to think about or attempt suicide (Willgoss, Accessed April 2024). For this reason we need CAMHS as a service to drastically improve its attitudes and accessibility as well as its treatment modalities.

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