Rejected Referrals Child and Adolescent Mental Health Services (CAMHS)

A qualitative and quantitative audit June 2018







Acknowledgements

Thank you to those who took part in this research, primarily the 363 children, young people and family members who participated in the qualitative element of the research. They shared often distressing and difficult experiences in the hope that doing so would help improve services for others. We hope we have been able to do justice to their stories.

Thanks also to the seven Health Boards who participated in the quantitative audit:

- NHS Ayrshire & Arran
- NHS Borders
- NHS Dumfries & Galloway
- NHS Fife
- NHS Forth Valley
- NHS Greater Glasgow & Clyde
- NHS Highland

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BACKGROUND TO RESEARCH

In 2017 the Scottish Government published its Mental Health Strategy 2017-27.¹ Action 18 of the strategy committed the Scottish Government to "Commission an audit of CAMHS rejected referrals, and act upon its findings." This research was commissioned in fulfilment of the first part of that action.

Scottish Government asked SAMH (Scottish Association for Mental Health) and Information Services Division (ISD) Scotland, of NHS National Services Scotland to carry out qualitative and quantitative work to examine referrals to CAMHS which were rejected.

The framework for Child and Adolescent Mental Health Services (CAMHS) in Scotland was most recently set out in Children and Young People's Mental Health: A Framework for Promotion, Prevention and Care.² This reiterated the tiered framework first set out in 1995, before NHS services were devolved to Scotland.³ A Framework for Promotion, Prevention and Care explains the tiered approach to CAMHS as follows.

"Child and adolescent mental health services (CAMHS) is sometimes used to embrace the range of services across agencies that contribute to the mental health and care of children and young people. These are sometimes referred to as universal or Tier 1 services and include those services whose primary function is not mental health care, such as general practice, schools and social services... Specialist CAMHS are sometimes referred to as Tier 2, 3 or 4 services. They include generic multi-discipline teams, single professional teams, targeted teams (e.g. for looked after children and young people), "outposters" (i.e. people who are CAMH-trained and employed, but who work in non-CAMHS settings), and specialist care teams (e.g. day patient, inpatient, intensive outreach)."

Information Services Division (ISD) Scotland states that the NHS in Scotland,

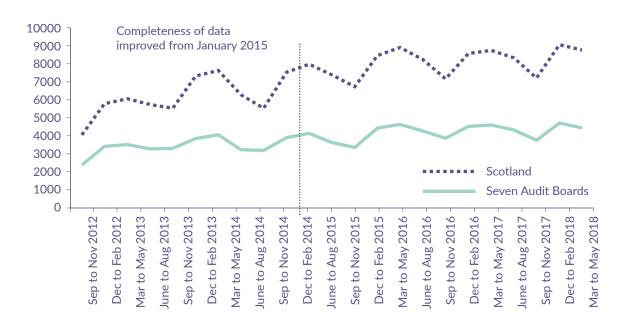
"provides mental health services for children and young people with a wide range of mental health conditions including Attention Deficit Hyperactivity Disorder (ADHD), anxiety, behaviour problems, depression and early onset psychosis. This treatment is provided through Child and Adolescent Mental Health (CAMH) services. These services, which are mainly outpatient and community based, are provided by a range of staff including psychiatrists, mental health nurses, clinical psychologists, child psychotherapists, occupational therapists and other allied health professionals."

The Scottish Government has set a standard for the NHS in Scotland from December 2014 for a maximum waiting time of 18 weeks from a patient's referral to treatment for specialist CAMHS. Since this target was set, ISD Scotland has published quarterly updates on waiting times for CAMHS. These figures include data on the number of "rejected referrals": that is, referrals that are made to CAMHS Tier 2, 3 or 4 services which are not accepted by the service. This information has been published quarterly since August 2012.

There has been concern from a range of people and organisations about the number of rejected referrals to CAMHS, and about what happens to the children and young people whose referral is not accepted.

Across Scotland, referrals to CAMHS have been increasing. Figure 1 illustrates this point and draws out the seven Health Boards participating in the quantitative element of this research, called Audit Boards for the remainder of the report. In 2017, 33,309 referrals were received.⁵ Although the data on CAMHS referrals was collected from 2012, it was not until January 2015 that all NHS Boards were able to submit complete data of sufficient quality. There were around 7,500 referrals during the quarter ending February 2015 compared to 9,000 for the same quarter in 2018, which is around a 20% increase over three years. It can also be seen that there is a seasonal pattern each year, with referrals to CAMHS during September to November at the lowest and March to May sees the higher number of referrals.

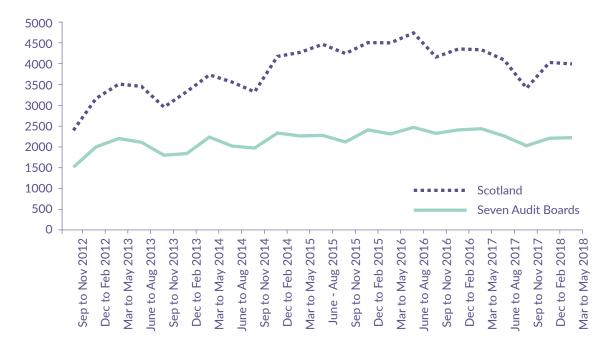
FIGURE 1
Number of children and young people referred to CAMHS by quarter



Source: ISD CAMHS Waiting Times

For the year ending February 2018, 15,864 children and young people started their treatment across Scotland (figure 2). This is a slight reduction in those starting treatment when compared with the previous two years, with 17,745 for year ending February 2017 and 17,476 for year ending February 2016.

FIGURE 2
Number of children and young people seen by CAMHS by quarter

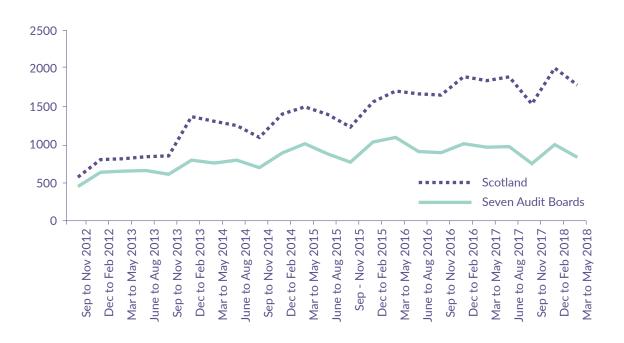


Source: ISD CAMHS Waiting Times

In 2017, 7,266 referrals to CAMHS were rejected across Scotland.

The most recent statistics, published in June 2018, show that for the quarter ending March 2018, one in five (20%) of all referrals to CAMHS were rejected. Although the overall number of referrals to CAMHS is increasing (Figure 1), the rejected referral rate has been broadly stable at one in five since December 2016 (Figure 3 shows the actual number of rejected referrals for each quarter). For comparison, the most recent statistics for psychological therapies referrals show a rejected referral rate of 5.7%. During the period the audit was carried out (February 2018), across all Health Boards, 1 in 5 referrals (21%) to CAMHS were rejected this compares with 19% for the Audit Boards.

FIGURE 3
Number of CAMHS rejected referrals by quarter



Source: ISD CAMHS Waiting Times

KEY FINDINGS

- During the period of the audit, across all Health Boards,
 1 in 5 children and young people's referrals to CAMHS were rejected
- Decisions on rejecting referrals usually happen quickly. Most decisions are made on the basis of paper referrals, without a face to face assessment. Children, young people and their families expect they will receive help after a referral, so a swift rejection without a face to face assessment is distressing and frustrating
- The Audit Boards report that 66% of the 285 rejected referrals include signposting. Yet there is a disparity between this and the extent to which children, young people and their families themselves recognised being signposted. Of the 253 people who participated in an online survey of their experiences, just 42% feel they have been signposted
- Children, young people and their families report that signposting is generic, unhelpful and often points to resources they have already explored. This research did not examine the type of signposting that is provided or the availability of the services to which people are signposted
- Some young people whose referral has been rejected report
 a belief that they will not be seen by CAMHS unless they
 are suicidal or at immediate risk of harm. There is a strong
 indication of a gap in services for children and young people
 who do not meet the criteria for the most specialist help

AIMS AND OBJECTIVES

To explore the experiences of children, young people and their families referred to CAMHS but who did not subsequently receive them.

Objectives

- 1. To understand the causes and reasons for rejected referrals across Scotland and the impact this has on children, young people and their families
- 2. To establish whether particular groups are disproportionately affected and, if so, to consider solutions
- 3. To understand what happens to a young person who receives a rejected CAMHS referral in terms of signposting to other services or further support
- 4. To understand outcomes for those whose referral was rejected, but who subsequently received support from other services
- 5. To understand referrals to CAMH specialist services in terms of their volume, purpose, source, and nature
- 6. To provide recommendations which will improve the experience of children, young people and their families referred to CAMHS Tier 2, 3 and 4 services, but who may not subsequently receive them (<u>rejected</u>) and understand outcomes for children and young people whose referrals are rejected
- 7. To provide recommendations around improvements and any ongoing data requirements

Methodology introduction

The research was divided into two elements: qualitative and quantitative. The quantitative element examined data supplied by seven Audit Boards relating to 285 children and young people whose referrals to CAMHS were rejected during February 2018. The qualitative element used interviews, focus groups and an online survey, involving 363 people over the period December 2017 to April 2018.

Methodology: quantitative

The quantitative element of this research was conducted by ISD Scotland and supported by staff in the participatory NHS Boards in Scotland.

All 14 NHS Boards across Scotland were invited to take part in the audit. The following seven NHS Boards participated:

- NHS Ayrshire & Arran
- NHS Borders
- NHS Dumfries & Galloway
- NHS Fife
- NHS Forth Valley
- NHS Greater Glasgow & Clyde
- NHS Highland

Within these seven Audit Boards in 2017, there were:

- 17.373 referrals
- 8,943 children and young people starting treatment
- 3,684 rejected referrals

The seven Audit Boards account for 52% of the referrals, 56% of the patients starting treatment and 51% of the rejected referrals across Scotland during 2017. The seven Audit Boards provide services to urban, remote and rural populations and within these areas there are a mixture of deprived areas and the more affluent. The latest performance figures for children and young people seen within 18 weeks by CAMHS varies across the Audit Boards. They are considered representative of the overall Scotland position – further information can be found here.

The Audit Boards were asked to collect data on any <u>Tier 2, 3 or 4 CAMHS</u> referral for a child or young person under the age of 18 received during 1 to 28 February 2018 (inclusive) where the referral was rejected. The month of February was chosen as there is less seasonal variation compared with other months (see figure 1).

Each Audit Board was provided with a specific list of data items to be collected for the audit and these consisted of data items that NHS Boards routinely collect about each patient. Audit Boards were asked to record the findings based on their current referral protocol and practice to ensure the methodology remained consistent. In addition, each participating Audit Board was asked to provide details of their referral criteria and the process for rejecting a referral.

The Audit Boards then provided this data to ISD, where the referral to CAMHS had been rejected. This data was then analysed.

In order for ISD to carry out this project, approval was sought from the <u>Public Benefit and Privacy Panel</u> as patient identifiable information was being collected. This work was approved by the Panel. ISD adhere to strict confidentiality rules and more information is available at <u>www.isdscotland.org/About-ISD/Confidentiality</u>.

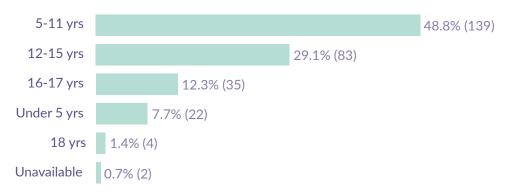
Quantitative sample profile

The total number of referrals received by the seven Audit Boards for the month of February 2018 was 1,528 and of these 285 (19%) were reported as rejected.

Data relating to these 285 cases was examined.

The Community Health Index (CHI) number was used to identify the age groups and gender of children and young people who had their referral to CAMHS rejected during February 2018. It is acknowledged that the gender represented by CHI may differ from the child or young person's gender identity or expression. As shown in Figure 4 almost half of the children and young people (49%) who had their referrals to CAMHS rejected were between 5-11 years of age and another 29% of the children and young people were between 12-15 years of age.

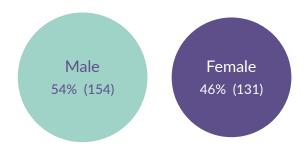
Age of the children and young people on referral in seven participating audit boards



Source: ISD CAMHS Rejected Referrals Audit

Figure 5 provides the percentage distribution by gender of those included in the quantitative study, it shows that more males than females had their referral rejected by CAMHS and that there was a slightly different split compared with the qualitative study.

FIGURE 5 **Gender distribution of rejected referrals in seven participating audit boards**



Source: ISD CAMHS Rejected Referrals Audit

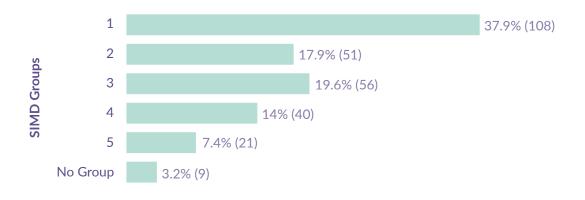
Location

During the audit the postcode of the children and young people was collected which was then matched to the publication of Scottish Index of Multiple Deprivation (SIMD) and used to identify the spread between the deprivation groups of the referred children and young people.

SIMD ranges from Group 1 'most deprived' to Group 5 'least deprived'. The results in Figure 6 shows that over half (56% - 159) of children and young people referrals that were rejected came from the most deprived areas (Group 1 and 2). This observation is likely to be linked to the rate of referral from these communities to CAMHS rather than disproportionate rejection of those referrals. However, no data is available nationally for identifying deprivation for all children and young people referred to and seen by CAMHS, but this pattern is reflected in other mental health information.⁸

Latest National Records Scotland published population figures show that there are 1,031,761 individuals under the age of 18 in 2016. For the Audit Boards, their population of under 18's in 2016 was 530,046 (52% of the total under 18 population). This is reflective of the sample of referrals and rejected referrals to CAMHS.⁹

FIGURE 6 **Distribution of rejected referrals by SIMD**



Source: ISD CAMHS Rejected Referrals Audit

Methodology - qualitative

The purpose of the qualitative research was to gather detail and depth of views from children, young people and their families who had experienced a rejected referral from CAMHS.

A flexible methodology was adopted which allowed adaptation as the project progressed. The eligibility criteria were that people had to have themselves been referred to CAMHS and had the referral rejected within the last two years, or have a child or sibling with this experience. This research also sought the view of GPs and teachers who have referred into the CAMHS system.

A screening survey was used, asking people to register their interest in taking part and provide some basic details to check their eligibility and gather data on gender and age of the young person who was rejected. The survey questions can be found at Appendix One.

A total of 540 young people and their families registered their interest, 304 of whom were eligible to participate. Those who met the criteria were then invited either to a focus group in their local area or to take part in a telephone interview. Initially, we expected that the majority of people would take part in focus groups. However, it became clear that these were difficult for many people to attend, primarily because of employment, caring commitments or the personal nature of their experience. The focus was therefore switched to conducting telephone interviews. Focus groups and telephone interviews used a topic guide to provide structure and to ensure all facilitators asked consistent questions of participants. The topic guide can be found at Appendix Two.

Focus groups and interviews were of most interest to parents and carers, rather than young people themselves. It was important to hear the voices of young people directly, so towards the end of the project, a semi-structured online survey was used. The questions for this survey can be found at Appendix Three.

FIGURE 7

Qualitative methodology process

Screening survey	Contact made with all eligible participants	Group sessions	Telephone depth interviews	Semi-structured online survey
 Short online survey designed to create awareness and check eligibility for participation Distributed to SAMH supporter database, a range of stakeholders and partners, and promoted via social media channels Captured details of potential participants for follow-up research 540 parents / family members / young people responded - 304 were eligible and willing to take part 106 teachers and GPs also registered interest 	 Invited to participate in group discussion sessions in central locations Telephone interviews offered to those living in outlying geographical locations 	 Group sessions held in Edinburgh and Glasgow Sessions lasted 1-1.5 hrs Topic guide designed to cover key aspects of referral journey Attendance issues prompted rethink on methodology Further groups cancelled where numbers not expected to be high enough Stirling groups went ahead in April A total of 31 participated in group sessions across 4 dates in Edinburgh, Glasgow & Stirling 	 Telephone depth interviews offered more widely to those registered in screening survey Greatest uptake amongst parents / carers Consistent topic guide used to allow for consistent analysis A total of 79 participated in a telephone depth interview 	 Semi-structured questionnaire designed to widen participation Online survey promoted via partners and social media Specifically targeted young people to increase numbers represented within overall sample A total of 253 completed responses were received

Source: SAMH

Trained facilitators ran all groups and depth interviews, which were all recorded and transcribed. Analysis of qualitative data was undertaken using NVivo software and online surveys were created and administered using Snap Survey software. All research was undertaken in strict accordance with the Market Research Society code of conduct and with child protection legislation.

We use quotations to illustrate findings from the focus groups and interviews. Quotes used are verbatim and have been anonymised. References to geographic locations have been removed, to avoid identifying individuals. We have presented some statistics from the online survey. We have also given the numbers involved in the different components of the qualitative research (e.g. interviews, focus groups and surveys).

Qualitative sample profile

In total the qualitative research heard from 363 people, of whom 267 (74%) were parents and carers, 95 (26%) were young people and 1 was the sibling of a young person who had been referred to CAMHS.

Four group sessions were held in Edinburgh, Glasgow and Stirling with 31 people participating. 79 people participated in a telephone depth interview. 253 people took part via an online survey.

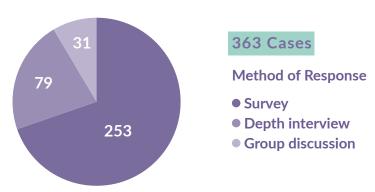
Young people were more likely to respond via the survey, while parents and carers were happy to take part in face to face or telephone interviews. Figure 8 illustrates the profile of respondents by method used.

Depth interviews were conducted with nine GPs from several different NHS Board areas. Almost all had over 10 years' of experience as a GP and all had experience of referring to CAMHS.

Twenty-four teachers with experience of referring to CAMHS participated in an online survey. Of those teachers 14 were from a primary school, 9 from a secondary school and one from an additional supports needs school. A survey was adopted for this group as we had initial interest from 106 teachers and did not want to exclude anyone from participating.

FIGURE 8

Profile of responses to qualitative research by method used



	Survey	Depth interview	Group discussion	Total
Young person	87	5	3	95
Parent /carer	166	73	28	267
Sibling	0	1	0	1

Source: ISD CAMHS Rejected Referrals Audit

Figure 9 shows the age and gender breakdown of the children and young people whose referrals to CAMHS were discussed across all methods of the qualitative research, these figures were taken from the screening survey. The largest group was aged 5-11 years (39%) followed by 16-18 years (29%) and 12-15 years (25%).

FIGURE 9

Age and gender of the child or young person whose referral was rejected

Gender of child person referred	
Male	160
Female	195
Self described	6
Not stated	2

Age of child or young person referred	
0-4 yrs	7
5-11 yrs	142
12-15 yrs	92
16-18 yrs	107
19-25 yrs	8
26+ yrs	1
Not stated	6

Source: ISD CAMHS Rejected Referrals Audit

Limitations

As with any research project, there are some limitations that should be borne in mind. Generally the data provided to ISD from the Audit Boards was of good quality. Some manual manipulation was required to get it to a consistent format. This is as a result of different IT systems used by NHS Boards to record CAMHS data. ISD shared the analysis and asked each Audit Board to confirm that that their data was accurate. It should also be noted that this project relates to only one month of data from seven Audit Boards.

The qualitative research was conducted with a self-selecting sample, meaning that only those willing to speak out about their experiences (referrers, children, young people and their families) participated, these were largely negative experiences.

Due to self-selecting sample and timeframes the research is also limited in terms of establishing if particular groups were disproportionately affected as was set out in the objectives. It would require a different approach to examine this but would be a worthwhile undertaking.

Due to the multiple channels used to recruit participants, it is not possible to identify whether there are any instances of someone participating in both a group or telephone interview and the online survey. It is anticipated that it is highly unlikely this has happened, simply due to the time and effort required by the participant, however it cannot be categorically stated that there are no duplicates. Due to the need for confidentiality and data protection, there is also the potential for a parent and young person to both participate without researchers being able to identify this. Again, it is reasonable to assume this is not a widespread issue as young people aged less than 16 years were required to gain parental consent to participate across all qualitative methods. In any case, the viewpoint of both parents and young people is valid and useful.

Although there is representation in the qualitative sample from almost all health boards, due to small numbers in each area, it is not possible to draw any conclusions about how CAMHS operates in an individual area.

"You start thinking, this is me getting help, I'm actually going to better myself, things are going to go right from now on, and then it's like constantly downhill from there. Every time you need to interact with CAMHS it's a nightmare."

(young person, group)

FINDINGS

BEING REFERRED

Both elements of the audit found that rejections are generally processed quickly. There was no evidence of any correlation between the source of a referral and its likelihood of being rejected. There is some commonality across the referral criteria used by NHS Boards and only one lists reasons that a referral may be deemed as inappropriate. There is substantial variation between the reasons for referral noted by NHS Boards and the reasons given by children, young people and their families. The qualitative element found parents and young people do not have a good understanding of the referral process.

When a referral is submitted, the widespread expectation is that the next stage is treatment. Many children, young people and their families receive a rejection letter within a very short timescale and feel angry, aggrieved, cheated and let down due to a feeling that no proper assessment process has been undertaken. Children, young people, their families and referrers often spoke of a lack of alternatives to CAMHS for children and young people with emotional, behavioural and mental health problems across all levels of severity.

Others who do get invited for assessment often believe this is the start of treatment, and are then left feeling in limbo when they are either rejected or then placed on a waiting list to access treatment.

"I didn't understand anything, I've never been in this situation where anybody in my family has got autism. So, it was all new and all daunting to me. I didn't get any information back from them to tell me this is the stuff we're looking for and things like that. I just didn't get any feedback from them at all." (Parent, depth)

Experiences prior to referral

The qualitative research found a lack of clarity for children, young people and their parents about the referral process. They do not understand what is meant to happen, particularly relating to assessment.

It was clear that CAMHS is rarely the first port of call. In most cases, before a referral to CAMHS is considered there has been an escalation of issues to a debilitating degree, such as:

School refusal / exclusion

"He was highly, highly stressed at school...the school weren't really aware, and that resulted in him refusing to go to school." (Parent, depth)

"It got that bad where I couldn't get her out the house, some days I couldn't even get her out of bed." (Parent, depth)

Behaviour becoming too difficult to manage

"His behaviour became more and more difficult to handle, and a lot more meltdowns, a lot more kind of emotional distress.... I felt that we were at a point where I had exhausted the strategies that I could try basically myself." (Parent, group)

Concern over potential harm (to children or young person or other family members)

"Self-harm, stuff like that which had kinda got a lot more dramatic in the space of a few months." (Parent, depth)

"She was self-harming, scratching herself and drawing blood with fingernails. She's got scars all over her body from doing this. She was displaying OCD behaviours, light switches on, off, on, off all the time." (Parent, group)

Anxiety, panic attacks, unable to control emotions

"Flying up with rage, not able to control his own emotions." (Parent, depth)

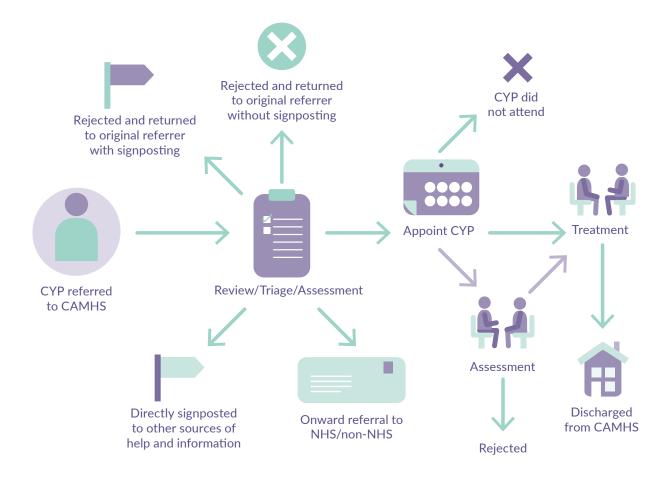
"I was struggling with anxiety, I was having panic attacks every single day and self-harming, and then that's when I got referred to CAMHS the first time." (Young person, group)

"I started to develop this really bad anxiety. I wasn't, like I was always kind of, you know, distant from other kids and stuff, so there was a little bit of social anxiety, but what it really boiled down to was this, like irrational fear of wasps and flying insects. Like I wouldn't leave the house during summer." (Young person, depth)

Referral process

Generally, once CAMHS receives a referral, the service will triage or review the content of the referral letter. If the referral has enough information and the service provides that care, then the child or young person will be added to the waiting list and an appropriate appointment given to begin treatment. In some cases an assessment appointment may be given but the waiting times clock does not stop until the child or young person is seen at their first treament appointment. If the details in the referral letter are not clear or there is not enough information, the service may contact the referrer for more information. Rejected referrals occur when the service does not provide that care and the referral is sent back to the original referrer. Figure 10 demonstrates this process.

FIGURE 10 Referrals process to CAMHS



Referral criteria

The participating Audit Boards were asked to provide information on their referral and triage/vetting processes as well as their criteria for accepting a child or young person into the CAMH service. Four of the seven Audit Boards provided all the requested information with the remaining three providing their referral criteria document.

Reviewing the criteria documents showed that there is some consistency in the written criteria amongst the Audit Boards however; some do provide more detail than others.

Common referral acceptance criteria include:

• Age: The child or young person should be between 0 to 16 years old or up to 18 years if still in full time education

Consent:

- This must be obtained from the parents/carer/guardian or young person before the referral is submitted to CAMHS

- The referrer must have physically seen the child or young person before referring them, with one Audit Board adding 'must be seen within five days of the referral'

• Severity of Condition:

- The child or young person must be experiencing moderate to severe difficulties, with two Audit Boards adding that these must be impacting their daily functioning
- These difficulties must have been present for 'some time'. Only one Audit Board stated a time period of more than 6 months

In addition to the referral criteria that were common to all Audit Boards, there were local variations that provided referrers with more detailed guidance. Some of the Audit Boards add more detail to their referral criteria document than others, such as:

• Geographical Criteria: One Audit Board states that the child or young person must live within the catchment area of the team they are referred to. They also list essential information that should be included in the referral letter. This Audit Board was the only one that added this criteria and gave further information on what should be included in the referral

Referral Pathways:

- One Audit Board has a flowchart to assist with referrals
- Three Audit Boards have a list of difficulties which also include a referral pathway and advice for each of the difficulty listed
- CAMHS Waiting Times Definition: Three of the Audit Boards reference the ISD CAMHS waiting times definition document and state the two level thresholds that are used (condition 1 basic threshold and condition 2 complexity and severity threshold)

Only one of the Audit Boards listed reasons for which a referral to CAMHS would be considered inappropriate. These include: response to normal life event, difficulties that only occur at school, child or young person whose parents are in dispute with legal proceedings or whose primary difficulty is substance misuse with additional difficulties described as offending behaviour.

Sources of referrals

There are many ways a child or young person can be referred to CAMHS. Both the quantitative and qualitative elements of the research found that the majority of referrals came from a GP. The qualitative research found that in a small number of cases, both the school and the GP were involved in the same referral.

The quantitative audit findings show that of the 285 rejected referrals submitted, 226 (79%) of these were from a GP. Other referrers were school nurse, teacher, and paediatric outpatient services. There is no significant difference between the referral sources for rejected referrals and those for other CAMHS referrals across the seven Audit Boards. This suggests that there is no correlation between the source of a referral and its likelihood of being rejected.

TABLE 1: **Sources of rejected referrals**

Source	Number	Percentage (%)
General Practitioner (GP)	226	79.3
Paediatrics Out-Patient Service	11	3.9
School Nurse	11	3.9
Teacher	9	3.2
Paediatrics In-Patient Service	5	1.8
Social Work Dept	5	1.8
Other	5	1.8
A&E (Adult)	3	1.1
Psychiatrist - other hospital	3	1.1
Voluntary Agency	3	1.1
Speech and Language Therapist	2	0.7
Dietician	1	0.4
Educational Psychologist	1	0.4
Total	285	100

Source: ISD CAMHS Rejected Referrals Audit

Reason for referral

There are many reasons a child or young person may be referred to CAMHS. Both the qualitative and quantitative elements of the audit collected data on the most common reasons for referral amongst those that were rejected.

Anxiety, low mood and depression, self-harm and suicidal ideation were more frequently mentioned by participants in the qualitative audit than in the data submitted by the Audit Boards. The Audit Boards were more likely to list behavioural problems, other reasons and anger issues as reasons for referral.

Figure 11 shows the various categories for reasons of CAMHS referral according to the data gathered from the Audit Boards. The 'other' category included a variety of reasons such as:

- referral was considered premature i.e. not all investigations were complete before referral to CAMHS
- the child or young person was referred for reasons such as 'stress' or 'needs counselling'

FIGURE 11 **Reasons for referral from quantitative element of audit**



Source: ISD CAMHS Rejected Referrals Audit

In the screening questionnaire which formed part of the qualitative research, children, young people and their families were invited to record the main reason they had for seeking referral to CAMHS. The results show anxiety was the most common reason for the young people to seek a referral to CAMHS.

FIGURE 12

Reason for referral, collected during qualitative element of the audit

Reasons for referral	
Anxiety	146
Low mood/ depression	87
Self-harm	67
Suicidal ideation	54
Other	52
Behaviour problems	47
Anger issues	41
ASD assessment	31
ASD / Autism / Aspergers	25
Eating disorder / eating problems	17
Sleep problems	15
ADHD	15
N/A	11

Note: it was possible to mention more than one reason

Source: SAMH CAMHS Rejected Referral Audit

There are other reasons for a CAMHS referral, beyond the possible existence of a medical problem. These include:

A requirement to go through CAMHS for certain issues

Some children, young people and families reported having to go to CAMHS to be assessed for Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) or Autism, or in order to be prescribed psychiatric medication.

Previous experience of CAMHS

Some families had previously been through CAMHS with another child or family member, and felt they now needed its input again.

"My oldest boy had been diagnosed with Asperger's, so he's on the autism spectrum and my youngest one was showing similar traits." (Parent, depth)

Lack of alternatives

Children, young people, their families and referrers often spoke of a lack of alternatives to CAMHS for children and young people with emotional, behavioural and mental health problems across all levels of severity.

"To be honest the GP was, I mean he was lovely, but he was a wee bit lost at where to refer him to. He says, "I don't think there is anywhere else that I can refer him to other than CAMHS." But he didn't think it was a CAMHS problem as it were." (Parent, depth)

• Feeling as though they have exhausted all other avenues

For many people, CAMHS was their last hope.

"We tried all the usual routes, paediatrician, going to the GP, but they all said this is CAMHS, we do need a bit of psychological intervention here." (Parent, depth)

"I'd actually gone for all the classes in Teen Triple P and Incredible Years and all of those classes." (Parent, group)

"I went to the school and they had said that they would get the school nurse involved. The school nurse then came back and said that it was something that they couldn't help with, and they were going to get Home Link involved. The Home Link worker said that she would meet with H a few times and look to doing Seasons for Growth...however, at that time she was also pregnant and she was off sick a lot. Which didn't help because then H never really got that support." (Parent, depth)

"I was put on Incredible Years. [Then] I think there was a few visits to the doctors. The school was doing wee bits and pieces to try and help, to get an educational psychologist on board but, again, we were given a few different books to read and things. I had done some research online because there wasn't really a great deal of information available." (Parent, depth)

Others reported previous CAMHS involvement for the child or young person being referred, and were seeking a follow-up or a transfer to a different geographic area. Reasons for this included:

- Previous ASD assessment
- Previous treatment given but discharged
- Moved health board

"We were under CAMHS in (one health board)....and when they tried to refer her to the CAMHS in (another health board), they told her she didn't meet their criteria, that she was Tier 2 and not Tier 3." (Parent, depth)

Referral screening time

The qualitative research found that when a referral is being made through a GP, it is submitted quickly. However, it was apparent that there was often a lengthy period pre-referral, where families are trying to manage without support, or looking for advice and support from third sector organisations, online resources or consulting with teachers. By the time parents and young people get to the referral stage, they are looking for immediate help.

"We've struggled for years and years and years and are still continuing to struggle with no help, no answers and J is in crisis." (Parent, depth)

Both the quantitative and qualitative elements found that most rejections were received quickly following a referral. Whilst this is not necessarily a bad thing, the qualitative element found that this can come as a shock to the child or young person and their family, who, having been referred, are expecting a face to face assessment, and then to receive help. Improvements in communication and better understanding of process would help.

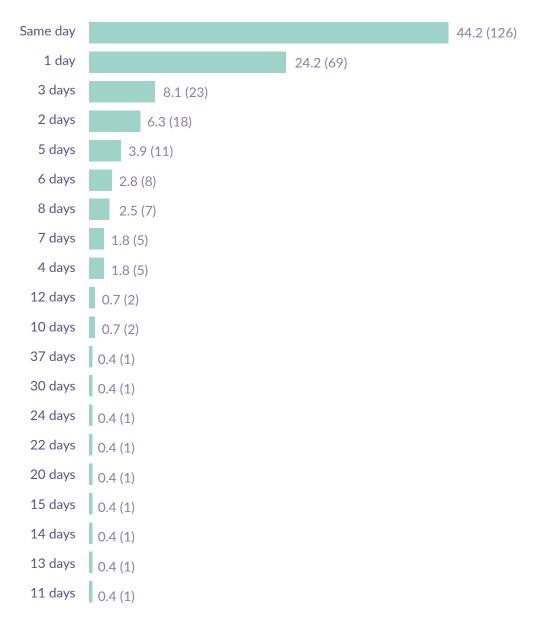
During the quantitative audit, data was collected on the date the referral was received by the service and the 'date the referral was screened' i.e. triaged or assessed by the service. The data showed that (Figure 13):

- 44% of referrals were triaged/assessed on the same day as they were received
- 44% are seen between one and five days, and
- 10% in less than 20 days (between six and 20)

The referrals that were screened between six and 20 days were across five Audit Boards, thus eliminating any pattern for referral screening processes. It was found that only two referrals (0.7%) were classed as 'pending' as they were awaiting a decision on the referral during the audit period. These two records were found to be triaged in the first week of March with a screening time of 21 and 30 days respectively.

FIGURE 13

Screening time upon referral to CAMHS



Source: ISD CAMHS Rejected Referrals Audit

It should be noted that referral screening time has been calculated based on seven days and these findings therefore do not account for weekends where screening may not take place.

It was also noted that one NHS Board uses a different practice to screen or assess referrals. Most children and young people at this NHS Board are offered an initial assessment appointment. From there they are seen by the service or directly signposted to other areas of help. The child or young person may be discharged after this assessment appointment which effectively means they are rejected, as this appointment serves as triage or review for the referral. The quantitative audit found that the main reason these children and young people were rejected during February 2018 was that CAMHS was unsuitable for them.

Children, young people and their families' expectations pre-referral

The main expectation at referral stage is that the child or young person will get help from CAMHS.

"I was hoping I could see a counsellor just to sort of talk through what I was worried about." (Young person, depth)

"We thought people were going to intervene, people were going to actually help us." (Parent, group)

"I didn't actually know that much about CAMHS, I hadn't ever heard of it before, so I really went in with no expectation.... I was just hoping that they'd help me." (Young person, depth)

"We're in limbo at the moment, I'm not sure whether this referral.... is going to be accepted. Obviously we're keeping our fingers crossed but we've had two in the last six months which have been knocked back and it's just devastating, absolutely devastating because I know that Z needs some kind of intervention." (Parent, depth)

People generally expect that it may take a little time (weeks) to hear back.

"I've read many articles, I've done lots of reading online and stuff and I knew how under pressure the service was, so I was aware that it was going to be a long wait." (Parent, depth)

This has the important consequence that almost no-one is prepared to hear within days that their referral has been rejected.

• For some, expectations are solely based on what the referrer tells them

"But the GP, she did the referral, she had said "Please be aware that this will just get completely rejected." (Parent, depth)

"We are failing our young people when it takes several months to hear back from a CAMHS referral, for it to be refused on the grounds that the young person does not have 'complex' needs based on minimal information written in a referral letter, without a one-to-one professional assessment. Alternatives to CAMHS also need to be put in place for young people who do not have multiple social, emotional or behavioural issues. e.g. emotional literacy education in schools or a GP accessible counselling service. Psychologists should be available and accessible to all young people who experience any form of mental health issue." (Parent, survey)

Information given at point of referral

29% of respondents to the online survey were given an idea of timescales at the point of referral.

The type of information given at the referral stage varies hugely based on the individual referrer:

Some give resources for use by parent and or young person whilst waiting for assessment

"I was like given a bit about what I could do in the meantime before obviously, if I got accepted.... I got given like resources and things like that to read through, I got told a bit about what they might be able to do for me but then that was kind of it." (Young person, depth)

"When I was referred the second time from my GP he gave the number for Breathing Space and for Child Line." (Young person, group)

• Some give an estimate of timescales

"He said that there would be quite a long waiting list." (Young person, depth)

"They would send a referral letter and to expect a long waiting list time for an appointment." (Parent, survey)

• Some express a lack of confidence that the referral will be accepted

"They'd probably reject him as taking on few children unless selfharming or expressing suicidal thoughts." (Parent, survey)

"We were told that our referral would probably be rejected due to our daughters young age." (Parent, survey)

Some give no information at all

"Not a lot, to be honest, the GP didn't really say anything." (Parent, depth)

Being Referred: Participants' suggestions for Improvement

In relation to being referred, parents and young people wanted:

- More clarity on the requirements for being accepted to CAMHS
 - "CAMHS should have a set deadline for when they acknowledge getting receipt of something and explain how they make the decisions." (Parent, depth)
 - "I think if we knew what the criteria really was, it would be easier for us." (Parent, depth)
- More information to be submitted prior to the referral:
 - Greater input from parents and young people themselves
 - A full picture to be presented, with information from the school, GP and other professionals involved with the child or young person
- More thought about the transition process between CAMHS and adult services
 - Because of long waiting times, young people can end up being ineligible by the time they are assessed and accepted
- A potential "fast track" referral process for children and young people who are looked after, adopted or at risk
- Suggestions of how to help and signposting to websites, third sector organisations and other resources at the point of referral
 - "If we at least had some things that we could take away from CAMHS and put into practice at home I would know that I was doing all I could do to try and bring the situation down, but I don't know exactly what it is I should be doing." (Parent, depth)

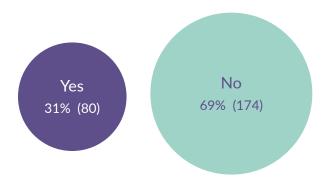
FINDINGS

BEING ASSESSED

Of the 253 people who took part in the online survey, 31% of people report getting a face to face assessment. Most rejections are made on the basis of the written referral. Where assessments are held, processes are inconsistent in terms of the time taken between referral and assessment, who attends the assessment and what information is given about what will happen next. In some cases the parent and child are both seen, in others only one or the other is seen. Practice also varies in terms of whether parents and children are seen together or separately, and this can cause difficulties for parents seeking to explain the situation. Young people find the assessment difficult and many leave feeling that they have not been properly listened to. Where the child or young person has a diagnosis of Autistic Spectrum Disorder (ASD), some people report being told that CAMHS could not help with an apparent mental health issue because of the ASD diagnosis.

One third of those referrals that are rejected get to the point of a face to face assessment: it was reported by the 253 people who took part in the online survey that no assessment meeting was held in more than two-thirds of cases.

FIGURE 14 Invited to assessment meeting with CAMHS



Source: SAMH CAMHS Rejected Referral Audit

How long do children and young people wait for an assessment?

The preceding section shows that, in this sample of rejected referrals, most people did not receive a face to face assessment. However, the qualitative element of this research did explore experiences of children and young people who are waiting for a face to face assessment where one takes place.

Perceptions of the time taken between referral and assessment vary. Many of those in the sample had been through multiple referrals and/or many steps in the process of getting help. That meant that their assessments of how long they waited could be vague.

Some waited months after their referral, while others were invited for an assessment relatively quickly.

"It was about, I'd say six, seven months maybe." (Young person, depth)

"First time it was two weeks, I think. Second time, rejected. Third time, rejected. Fourth time, it was a week but that was an emergency referral because I tried to commit suicide in school so that was an immediate referral. And then the fourth time it was through A and E so that was a week as well, so yeah. I've not had bad waiting times it was just when I kept on getting rejected I was just in a really, really bad place and I feel like say if I got the help that I needed then when I got rejected, I probably wouldn't have had as many suicide attempts or had to go up to A and E so many times." (Young person, group)

For those who have to wait longer, the effect is usually negative.

"You kind of just forget that it's done because you don't hear from them for so long, at first you're like it's a bit better because you know you've done something to try and get help but because it takes so long, that initial period is a bit more relief knowing that you've done something that's going to maybe get you help, it kind of just goes away and you just go back to feeling as rubbish before, you kind of just feel forgotten." (Young person, depth)

"I think not knowing if you're going to get accepted, rejected, it can make your family quite stressed, especially if things aren't getting better so it noticeably impacts everyone pretty much, especially my parents were quite like concerned." (Young person, depth)

What support are children, young people and their families offered when awaiting assessment?

Most received no or little support while waiting for assessment.

"They never spoke to me after the referral, not even a phone conversation, nothing." (Parent, depth)

"No, nothing, we were just left to deal with it." (Parent, depth)

"No other support. GP, obviously was very understanding but their hands are tied." (Parent, group)

Where support was offered, it tended to be via schools.

"The school were quite supportive at that point." (Parent, depth)

"I was still in contact with the school so they were also looking at other avenues because they were aware that there could be a long waiting list for any assessments from CAMHS." (Parent, depth)

What is the process for assessing a child or young person for CAMHS?

The qualitative research suggests an inconsistent approach regarding whether both the young person and the parent were at the assessment, or they were seen separately.

"We met with two psychologists then I was separated from my child (then 5) while they spoke to her." (Parent, survey)

"My son was observed in a different room while I had the opportunity to speak to the clinical psychologist." (Parent, survey)

"They spoke to both myself and my daughter. However, we were in the same room which made it very difficult to speak openly in front of my daughter and so I requested a time to meet them separately but it was declined." (Parent, survey)

Some people found this approach difficult. Parents reported feeling uncomfortable when asked to provide background details and answer questions in front of their child.

"I was mainly disappointed...because we would have spoke a lot stronger if he wasn't there. My son is very, very sensitive, and it was things you would not necessarily say in front of him." (Parent, depth)

Children and young people sometimes wanted the parent to be present and at other times not.

"I had my mum with me, and they were asking me loads of these questions and I started getting a little bit uncomfortable, just because I wasn't sure how to answer them, I wasn't very comfortable talking about it. Yeah, and they asked my mum if she wanted to leave the room, if that would help, and, that made me feel even worse, because it felt like I was hiding stuff from my mum. Yeah, obviously that's just like, they're just asking, to see it'll be, to make me more comfortable, but it just, it made me feel worse and I ended up speaking less." (Young person, depth)

There is a general sense that parents and young people don't feel they are being properly listened to during the assessment.

"I just felt that they didn't want to listen to what I had to say." (Parent, depth)

"He asked me and my parents questions about how I was feeling, questions about my past, he asked if I had ever experienced panic attacks but I didn't know what that was so answered 'no' when I had in fact had panic attacks and quite often. I told him I had tried to kill myself and he asked if my parents knew, and said he would not tell them, then he decided that exercise was the best thing for me and that they could offer me no more help." (Young person, survey)

For young people in particular the assessment process can be very difficult and quite traumatic.

"I basically had to spill all my deepest thoughts and feelings to a referral person who did nothing except take note of all of this for my file. I had self-harmed the night before the visit, as well as had been trying to kill myself at this point but could not bring myself to it. I told this to the person, as well as the fact I had a day in my head to try again. At the end of the session, they told me they could not help me for the THIRD time." (Young person, survey)

"I told them all about my life and what's gone wrong in it, I didn't get to explain everything and it was a really difficult experience, having to retell everything wrong about my life." (Young person, survey)

The research found some particular issues where the child or young person had been referred for possible Autistic Spectrum Disorder (ASD). Some reported difficulties in getting an appointment in the first place, while others were unhappy with the assessment process.

"So, within 40 minutes to 45 minutes I had been in, seen and spoke to people, went to the shop, come back, and was told that X was not on the spectrum." (Parent, depth)

Once a diagnosis has been given, there is often no further support provided. Where the child or young person already has a diagnosis of ASD, we found some parents being told that CAMHS could not help with an apparent behavioural, emotional or mental health issue because of the ASD diagnosis. This left families feeling there was nowhere else for them to turn.

"I was devastated, honestly, and I was very, very upset for her and I was angry that she had been discriminated against because she had a name, a title against her, autism spectrum disorder and that that was somehow stopping her from getting a service that other children with high levels of stress and anxiety were getting." (Parent, depth)

There seems to be little consistency in what information is provided at the end of the assessment, so young people and their parents leave without a clear understanding of what will happen next.

"I kind of thought once we have the assessment then it will only be another couple of weeks waiting and then I'll actually get help." (Young person, group)

"It was never really clear what they would do, it's not like you'd get a letter and you'll be informed about it and stuff like that, they never really said what would happen next." (Young person, depth)

"I think it becomes more confusing because you don't really know what's going to happen next after that, like they don't really give you the options of what might happen or an indication of what might happen in your case, there's just like a general assumption that you kind of know what's going to happen next." (Young person, depth)

In addition, the language used is not always clear, especially to young people, meaning they do not always understand what is being recommended by CAMHS.

"I still remember to this day, [CAMHS said] 'Your problems are relational in origin', which when you're 17, you're like, 'What does that mean?'. And even today no-one can tell me what that means." (Young person, group)

"It was confusing as well. Just the language was confusing....It wasn't a very clear and helpful letter to be honest." (Parent, depth)

Participants' suggestions for improvement: being assessed

In relation to being assessed, parents and young people wanted:

- Clarity around the assessment process, with a clearer triage process and how decisions are taken whether to conduct a face to face assessment.
 - "Say okay, if you score 10 points then you go to CAMHS, but if you score 5 or under then it's community based and here's the list." (Parent, group)
- An expectation that CAMHS will meet children and young people for assessment, in an environment in which they feel comfortable (particularly for those with an ASD diagnosis)
 - "That every child at least gets an initial appointment to see what the need is. If unable to progress with CAMHS, then appropriate guidance or information given." (Parent, survey)
 - "I don't see how they can reject anybody without seeing them." (Parent, group)
- The opportunity for parents and young people to meet CAMHS staff separately, where they feel it would be helpful
 - "There's not enough support, that if you've got to take the child with you to the appointment, make time so the adult or one of the parents can talk to the person without the child sitting there so that the parent can talk freely." (Parent, depth)
 - "Your initial discussion, you should be able to have it without the child being present. So, if you have concerns about their ability to cope there has to be a way that you can talk about your child's problems without the child being there.... I can't imagine somebody talking about me in those terms and me sitting there and having no voice and feeling no good about myself." (Parent, depth)
 - "If I had a parent with me, at any of the appointments that I did have with them, they would listen to them rather than what I was saying, and then give me like advice based on what my parents were saying." (Young person, depth)

- The involvement of a wider group of family and professionals who are working with the young person, to gain a more holistic picture
 - "The autism assessment was very good, he [YP] was spoken to for an hour and a half, there were three professionals there, a language specialist, a psychologist and the autism assessor herself and then afterwards they met with us, spoke with us, myself and my husband for an hour or so and they had received information from the school as well, they'd asked for information from the school." (Parent, depth)
- Make better use of multi-disciplinary child planning meetings where all those who are supporting the child or young person can gain a holistic picture
- A more person-centred approach by staff who would listen more, create a welcoming atmosphere, speak in plain English and not be dismissive or patronising

"If they made more of an effort to make, look for example, me or another patient feel more, more engaged, less like an object, less like something to be examined." (Young Person, depth)

"I don't see how they can reject anybody without seeing them."

(Parent, group)

FINDINGS

BEING REJECTED

Reflections from the qualitative research

- The most common reason cited by young people for their referral being rejected is that their case was not serious enough. This leads to a belief that unless the child or young person is suicidal or at immediate risk of harm, they will not be seen
- One in ten survey respondents sought help privately following a rejected referral. This suggests that other NHS or third sector services to which they may be signposted are either not appropriate or not available
- More than half of young people whose referrals were rejected took no further action, suggesting that the opportunity to help them has now been missed
- There could be a problem with multiple referrals for the same person, with 20% of participants mentioning that they sought another referral after being rejected. Sometimes these are consistently rejected, sometimes they are eventually accepted. We do not know what level of 'churn' is created by these multiple referrals but it suggests an opportunity exists to operate more efficiently by routing these referrals appropriately at the first time of asking
- Young people and their families report that while signposting does take
 place, it is generally not felt to be helpful. Few people spoke of being directly
 referred to or helped to access another service, suggesting that people are
 largely being left to select and try to access a service or information resource
 by themselves
- Some young people report being rejected because, by the time they were due for assessment, they were almost too old for CAMHS. This may suggest there can be a greater focus on structural issues than on the needs of the child or young person

There is a widespread belief that the reasons given for rejection are either inadequate or unjustified. Children, young people and their families reported that they often did not understand or did not agree with the reasons given for rejection, where any were provided. Many participants spoke of poor communication, a dismissive attitude and a lack of explanation for rejection. In some instances, the referrer does not pass the information on to the child, young person or family, leaving the family and or young person waiting.

The impact of being rejected can include worsening health, a financial impact of finding help privately and the effect of stress on family relationships. Signposting does take place but this was generally not felt to be useful, either pointing to websites or signposting to services that the family have already exhausted or that are unavailable or unsuitable. After rejection, some report paying for private help, some asked for another referral to be submitted and some did nothing.

More than half of the 87 young people who engaged with the online survey reported doing nothing after rejection. Multiple referrals are an issue, with 20% of participants in the online survey mentioning that they sought another referral after being rejected.

There are also issues with young people 'falling between the cracks', either because they have left school but are not yet 18 or because they are not attending school due to their emotional, behavioural or mental health issues.

Some young people waited so long that they were rejected because, by the time of their assessment, they were about to become eligible for adult services.

Why are children, young people and their families rejected from CAMHS, and what happens then?

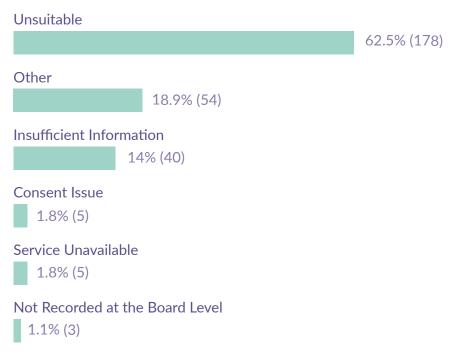
Current national data collection only records a count of the referrals that have been rejected by NHS Board CAMH services. The qualitative audit found a noted variation in the proportion of referrals which are rejected across NHS Boards. This may be due to the differing referrals processes.

Reason for rejecting a referral

The reasons for rejections were similar across both the qualitative and quantitative elements of the audit. Figure 15 shows various categories for the reasons for rejecting a CAMHS referral, drawn from the seven Audit Boards. Three out of five referrals (62%) were rejected as they were deemed <u>unsuitable</u>. This means that either the referral did not meet NHS Board criteria, the child or young person was at the early stage of mental illness or disorder, the child or young person had a mild mental illness or disorder, there was no mental health issue or the child or young person was outwith the NHS Board catchment area.

FIGURE 15

Reasons for rejected referral collected from seven Audit Boards



Source: ISD CAMHS Rejected Referrals Audit

Another common reason for rejecting the CAMHS referral was reported in the quantitative element as insufficient information referring to incomplete information in the referral documentation. This meant that the referral could not be reviewed or triaged for appointment or assessment.

The 'other' category in the reasons for rejecting CAMHS referral reported varied reasons, such as referral was a duplicate referral, inappropriate referral reason, referral did not have any indication of mental health issues or the child or young person referred was not physically seen by the referrer prior to referral.

It was also noted that there were five records (1.75%) where there was a 'consent issue'. On further investigation, this meant that consent had not been obtained from the child or young person (as the referrer had not physically seen them) or had not been obtained from the parent or guardian. It is important to note that no referrals were rejected due to the refusal of service by the child or young person. In other words, no child or young person refused to engage with CAMHS or were non-responsive to the CAMHS appointment letters.

Table 2 shows that just under half (49.4%) of the referrals considered 'unsuitable' were for children between the ages of five and 11 years. 'Unsuitable' was generally recorded where the referrals was deemed inappropriate for the CAMH service.

TABLE 2: **Age range of unsuitable referrals**

Age	Number	Percentage (%)
Under 5	10	5.6
5-11 years	88	49.4
12-15 years	53	29.8
16-17 years	16	9.0
18 years	9	5.1
Age not available	2	1.1
Total	178	100.0

Source: ISD CAMHS Rejected Referrals Audit

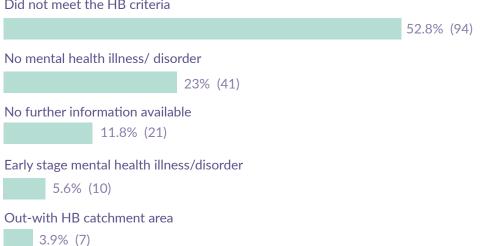
The main reason identified by the Audit Boards for referrals being rejected is that of 'unsuitable' (n=178 62%). Figure 16 shows a breakdown of these records as to why the referral was deemed unsuitable. Over half (52.8%) of these unsuitable referrals were because they did not meet the NHS Board criteria for accessing a CAMHS and almost a quarter (23%) were due to no mental health/illness identified. In these records, where no mental health/illness was identified, there were two common reasons for referral which were 'behaviour problems' and referral for an 'Autism Spectrum Disorder (ASD) assessment'. This may merit further investigation, given that behavioural problems are included in the definition of CAMHS.¹⁰

Data was also captured on the main reason that referrals were rejected by CAMHS and additional detail on why they were rejected. For example, of the 178 referrals that were deemed 'unsuitable', 94 did not meet the referral criteria of CAMHS and 41 referrals did not have a mental health disorder when reviewed by CAMHS. For those referrals that were rejected because of 'other' and insufficient information, no further information was available.

FIGURE 16

Reason for rejected referral in unsuitable category, collected from seven Audit Boards

Did not meet the HB criteria



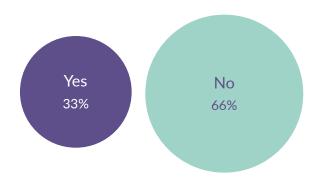
Mild mental health illness/disorder

2.8% (5)

Source: ISD CAMHS Rejected Referrals Audit

The qualitative research found a widespread belief that the reasons given for rejection are either inadequate or unjustified. People often did not understand the reasons given, as shown in Figure 17.

FIGURE 17 Understanding of the reason given for rejection, collected from the 253 participants of the online survey



Source: SAMH CAMHS Rejected Referrals Audit

Common reasons for rejection include:

- The referring issue is not serious enough or meets the threshold for a tier 3 or 4 service. This is the most common reason cited by young people themselves, and leads to a belief that unless the child or young person is suicidal or at immediate risk of harm, they will not be seen by CAMHS.
 - "We were told....we recognise that you have anxiety issues, this was to my daughter, but they're not severe and you're self-harming, but it's not severe enough for us to be able to offer you support. If things get worse, you're welcome to go back to your GP for a further referral." (Parent, group)
 - "She was not, is it Tier three level, Tier three and that they would not be able to support her in any capacity, but perhaps to go back to her GP to see whether or not something could be done elsewhere through the NHS as part of the hospital setting." (Parent, depth)
 - "They said that he doesn't have an eating disorder, he hasn't committed suicide or tried to commit suicide." (Parent, depth)
- The referring issue is not a mental health issue but rather a behavioural issue, related to an ASD diagnosis, a problem relating to lack of sleep or other nonmental health issue
 - "I remember a bit from the letter that says that my daughter didn't have a mental health problem." (Parent, group)
 - "His anxiety is a result of his autism and not understanding the world around him and it's not something that they can help with." (Parent, depth)
- The person does not meet the criteria with little or no further explanation
 - "They said on the letter that they had discussed it at one of their meetings and she didn't meet the criteria. They gave me a leaflet on sensory processing for autistic children, all of which I was already doing...so it wasn't really any help." (Parent, depth)
 - "They literally said, 'She doesn't meet the criteria" (Parent, group)
- The referral is inappropriate: this was mentioned in cases where children
 or young people had been sexually abused or assaulted, and cases where
 other services such as the police or social work were involved or cases where
 CAMHS felt another agency should be contacted.
 - "I got a letter through the door basically saying it was an inappropriate referral and that I was to be referred to Sleep Scotland. I think the CAMHS sent the GP letter to me rather than the parent's version because of the language that was used, it was almost like they were talking to the GP saying, "This is inappropriate, it needs to be referred to Sleep Scotland." (Parent, depth)
 - "CAMHS say, 'No, it's not an appropriate referral for us so go and see social work', and then social work are getting inundated with things and, to be honest, it's not their area of expertise either." (Parent, depth)"

"I eventually spoke to the girl. She was very nice and said, "I'm really sorry, she's been rejected. They don't feel it's appropriate and it explains it in the letter."" (Parent, depth)

• In many cases no further explanation is given

"It didn't have any information about why they were rejecting it, it didn't have any advice, it didn't have a contact number, nothing, it just said "We're rejecting the referral, go back and speak to your GP." (Parent, depth)

How are rejected referrals communicated to children, young people and their families?

In some instances, parents and or young people are told at the end of their assessment that no treatment will be given by CAMHS.

"He [my child] spoke with her for about 15 minutes, then I was called in to the room and told he wasn't severe enough and no further appointments would be offered." (Parent, survey)

"We got the referral that was straightforward, but when we got there they turned round and said it was us that was the problem, we were the bad parents." (Parent, depth)

In other cases, there is a further wait for a decision about whether children and young people will be accepted for treatment.

"I think we had one appointment and they never seen him again and we never heard nothing and I think I was told it was maybe lost on the system or some kind of system changeover, and they never got back in touch and nothing ever come of it." (Parent, depth)

Some people receive a direct letter to the parent or young person, with nothing sent back to the referrer. Some receive a copy of the letter sent to the referrer: this is often written in clinical language.

"I got a letter through the door, as I say very quickly, and the letter basically said along the lines of we've had a referral from your GP, we've discussed it and we won't see him. And attached are a list of various different things that you can use, look into, progress with in order to provide additional support. There was no attachment, so that information wasn't in the letter, and that was it." (Parent, depth)

Others hear direct from CAMHS in person or by phone.

"She [CAMHS nurse] basically said to me that because I'd left school, all my other options would have been adult mental health services, but they wouldn't do anything for me because I wasn't.... basically like my case wasn't serious enough for them to be able to treat me." (Young person, depth)

"I phoned CAMHS and they said, 'Oh, oh no, she never met the criteria, did the GP not tell you?'" (Parent, depth)

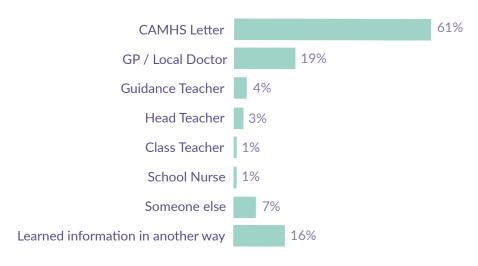
Some hear of the rejection via the initial referral route. Some people were invited to an appointment with their GP or a meeting with school, some were told by phone, either by the GP or a receptionist.

"Then I got a phone call, I don't know, maybe about 10 weeks later, ish, from the GP receptionist saying that CAMHS refused to take the referral any further because the GP had not seen [my son] and the discussion had not taken place with my son, at the consultation." (Parent, depth)

Some did not hear back at all.

"It wasn't technically rejected, we just didn't hear anything back." (Parent, group)

Who communicated the rejected referral from CAMHS, collected from participants of the online survey



Source: SAMH CAMHS Rejected Referral Audit

The language used in communicating the rejection can also be problematic – either from the perspective of seeming uncaring or dismissive; not being easy to comprehend; or blaming the parents.

"It doesn't have to be like that, it's just a little bit of dignity and a more respectful means of either offering some alternative or explaining why a decision has been made, rather than, "You're clearly not mentally ill, go away". It's shocking." (Parent, depth)

"Was told that my suicide attempt was me attention seeking and that there was nothing wrong with me." (Young person, survey)

"It doesn't tell you why. It just tells you it's been rejected and didn't actually give any reasons for the rejection really. We were both pretty baffled by it in terms of the way it was written, and the language in it...for us it wasn't very helpful in terms of understanding the reasons behind it and also what the next stage in the process was." (Parent, depth)

"When I received the follow up letter which basically accused us of being the problem I slumped into depression myself. Crucially, the letter mentioned absolutely nothing about my son's previous history, his selfharming or the fact that he mentioned in the meeting that he would attempt suicide again!" (Parent, survey)

In some instances, the referrer does not pass the information on, leaving the family and or young person waiting longer than they should; still assuming they are in the system.

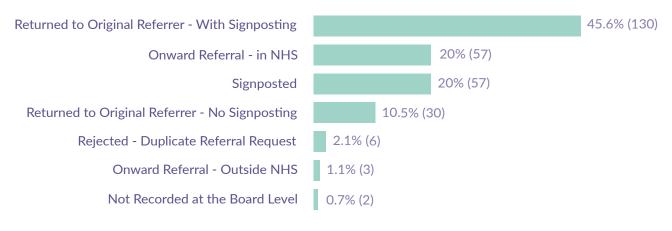
"I gave them the benefit of the doubt and waited three months. I phoned CAMHS, and I was told, "Oh did they not tell you you were rejected?" I said, "So when was this?" And they said, "A couple of weeks after the referral was made." I said, "Well I've been waiting for three months, and I've not had an answer." So, I phoned the doctors and they confirmed that it had been rejected." (Parent, depth)

"Well when I got rejected I was waiting... I waited all summer for an appointment because I already knew that they sent your appointment in the post so I was waiting all the time, all the time and then it got about one month, because I'm not very patient, so I phoned up the GP and was like, 'I've still not heard anything back', and it was then the GP said, 'CAMHS rejected your referral', and then I was heartbroken, so heartbroken because I was like I'm never going to get help." (Young person, group)

Actions taken following rejection

Figure 19 shows the categories for the actions taken by CAMHS following the rejection of the referral. Nearly half (46%) of rejected referrals to CAMHS were returned to original referrer with signposting, although researchers did not examine the type of signposting provided or the availability of the services to which people are signposted. This would infer either the referral was considered unsuitable for the referred service, insufficient information was provided or the service was not provided in the particular NHS Board area.

FIGURE 19 **Actions taken by CAMHS following the rejection of the referral**



Source: ISD CAMHS Rejected Referrals Audit

Other main categories reported for the actions taken following the rejection of the CAMHS were that the referral were signposted (20%), the referral was referred onward within NHS (20%), or returned to original referrer without signposting (11%). Figure 19 indicates that overall 66% of rejected referrals do include signposting. However, approximately one in ten referrals that are rejected do not have any follow up/signposting identified.

One in five (20%) of the rejected referrals were signposted directly and not returned to the original referrer. This means that the child or young person was either directed to online support via a self-help website or to other support services such as the third sector.

This research did not examine the type of signposting provided or the availability of the services to which people are signposted.

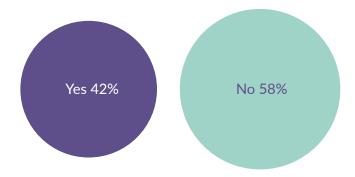
During the month of February, the seven participating Audit Boards report that 66% of the 285 rejected referrals include signposting. Yet there is a disparity between this and the extent to which children, young people and their families themselves recognised being signposted. Of the 253 people who participated in an online survey of their experiences, just 42% feel they have been signposted.

During the audit, demographic data was collected including the child or young person's Community Health Index number (CHI), postcode and gender. This data will enable ISD to interrogate other health datasets to find out if the child or young person used other statutory services such as Accident and Emergency. This will help with further establishing what happens to children and young people if they are rejected from CAMHS. An update on this will be provided once data is available, it is hoped this will be by spring 2019 – though caution should be noted as there are small numbers involved.

What support are children, young people and their families offered when their referral is rejected?

Children, young people and their parents often did not feel well supported at the point of rejection. Those who had a more positive experience tended to report that their referrer was both supportive and persistent in seeking to get them support. This seems to be down to the attitude and persistence of the individual referrer. Although signposting did happen in around two-fifths of cases (as shown in Figure 20), in general it was not felt to be of high quality.

Were people signposted to another service or resource? collected from participants of the online survey



Source: SAMH CAMHS Rejected Referral Audit

"She [CAMHS nurse] gave me the website Moodjuice....and basically for any other thing like helplines she said I would have to go back to my doctor and speak to them, because she didn't know." (Young person, depth)

In many instances, young people and their families have already exhausted these avenues prior to seeking a referral to CAMHS. For some, the signposting feels generic and not particularly useful.

"The only thing they suggested, and to put it really bluntly and to look back, it was a load of bollocks, it was just links to websites.... I did visit the websites, and they were like generic, top 10 tips to deal with anxiety." (Young person, depth)

In other cases, the options suggested are unavailable or unsuitable.

"We had nowhere to turn. The support they suggested wasn't actually available to us. I had to find out for myself what was available it was taking too long so we went private and got a counsellor because she was in crisis. In [our area] there were no NHS or third sector options for her?" (Parent, survey)

Parenting courses are often suggested.

"CAMHS refused to see us again saying that I needed to go on a parenting course." (Parent, depth)

Following a rejected referral, just under a quarter of those responding to our survey contacted another service: we do not know how many received help from this service or found it useful. A similar proportion used online or other resources. More than one in 10 paid for private help. A fifth asked for another referral to be submitted. More than half of the 87 young people who engaged with the online survey reported doing nothing after rejection.

What people did after being rejected from CAMHS, collected from participants of online survey



Source: SAMH CAMHS Rejected Referral Audit

What impact do rejected referrals have on children, young people and their families?

The effect of having a referral to CAMHS rejected can include:

Issues escalate / worsen

"When I kept on getting rejected I was just in a really, really bad place and I feel like say if I got the help that I needed then when I got rejected, I probably wouldn't have had as many suicide attempts or had to go up to accident and emergency so many times." (Young person, group)

"The [assessment] experience affected my daughter and she opted not to be referred back there and just to continue seeing the school nurse who she has a really good relationship with. Unfortunately she has since self-harmed, making lots of quite superficial cuts on her wrist. She did this during the night when we were all sleeping. She needs help which was denied her from CAMHS so we are taking her to see somebody privately, shouldn't have to do this but my daughter has been let down and we just can't sit back and wait for something serious to happen." (Parent, survey)

Financial impact of finding alternative, private, help

"We saw a child psychotherapist in Glasgow for maybe September to the Christmas time. But I got to the point where I thought I need to get back to the doctor and re-refer and try and get him support through the NHS because I can't sustain... £280 a month. But at the same time you're feeling extremely guilty because I'm thinking that's the only support that my son has. And he didn't want it at first, but then eventually he really felt the benefit, and he was really upset when I said that we need to stop this, I can't keep this up. He was really angry with me, and that was really difficult because then you're thinking I'm putting financial implications before my own son. But at the same time I thought we can't sustain this, we need to try and look for other ways to help you." (Parent, group)

Impact on family relationships

"Because the thing is, when you feel that you've got nowhere to go, me and my husband have talked about splitting up and my husband keeping X and me moving out with the other three children, because it's really disruptive for the other three children as well." (Parent, depth)

There can also be an emotional impact from a rejected referral.

Feeling let down, with nowhere to turn

"You kind of feel like the one place that maybe could have told you what to do, have just kind of shut the doors on you and you just feel helpless, you just don't know what to do with yourself or where to go." (Young person, depth)

"It just affected everything, every aspect of your life it just affected, because you were walking on eggshells and you just never, there was just nowhere to turn, absolutely no help at all out there." (Parent, depth)

"It's just massively stressful. It's just another added stress on an already stressful situation. We just feel very much if they're not offering any kind of input then who is, because we've exhausted all avenues. We feel there's nowhere else we can turn for help with my son especially. It's massively stressful. I mean you're still dealing with the issues that you're dealing with, so you're still dealing with the behaviour of whatever's gone on, on top of the kind of stress of thinking, 'So what do we do now?' It's just really, really stressful." (Parent, depth)

"We were very upset, felt very let down and not taken seriously. I think when you're in the midst of trying to support a young person who's having serious mental health issues and you get told that it's not serious enough, it's a pretty horrible experience." (Parent, depth)

Feeling alone and in despair

"For a while I thought that there would have been no help available to me, and that basically I would have to lump it for the rest of my life and find different ways to cope with how I'm feeling. It really upset me, because I genuinely thought that there was nothing that anybody could do for me. Like I said, I would just have to like live with it for the rest of my life. Like feeling as low as I did at the time, and it was a really horrible thought. Because every day was quite difficult, and it was like a new challenge in itself. I would never want to go back to how I felt at that point, once the CAMHS nurse said there was nothing that I could do. Even like just thinking back, like now, I never want to feel like that again, I felt so alone." (Young person, depth)

"I felt really isolated by it because I wasn't sure why I wasn't getting the help and I felt completely misunderstood." (Young person, depth)

"When I was then told I was rejected I was like well, it made me feel rejected because it made me feel am I not worthy of help, am I not deserving, am I not ill enough? These are the questions that go through my head, was I not ill enough? Was I not severe enough? Was I not mentally ill enough? And it was just thoughts like them and I feel no person should feel like that."

(Young person, group)

• Feelings of guilt or failure among parents

"For me I feel like I've let her down to get things to this point. So going to the doctor in the first place was a huge step. And then letting her down again by not actually getting any help from it. At least she was too young to know." (Parent, group)

Feeling angry

"Disgusted. Angry. Let down. Confused. Unheard. Ignored. Irrelevant. Unworthy. To name the first few off the top of my head I honestly don't understand their logic and how they can completely dismiss my son and in turn our family! My eldest son really needed their help and support and we got nowhere! CAMHS should be absolutely ashamed of themselves for the way they have treated my family, and I'm under no illusion that we aren't the first they have done this to!" (Parent, survey)

Multiple referrals

Multiple referrals are an issue, with 20% of those responding to our survey mentioning that they sought another referral after being rejected. It was common for young people and their parents to speak of being referred and rejected several times. Some reported being accepted after two or three rejected referrals.

In some cases several referrals are submitted, sometimes by different referrers, for the same case.

"The issues were like self-harm, stuff like that which had kinda got a lot more dramatic in the space of a few months, so that was my first referral to them; we've had several attempts. So then the second one was I attempted suicide and that went to my GP and that got rejected again, and then on the third one, that was another suicide one, and it got a bit further into the process but got rejected just at the end of the process and then the fourth one was just needed to get a referral somehow, so we put another referral in and it got rejected because I was too close to being 18, even though it was like a year and a half away; and then they put a referral in at the start of this year and I got into the adult one straightaway." (Young person, depth)

"So, the first time I was referred I was accepted and my social worker put a referral in and that was fine, I had six sessions with her and then the person was nice and then I was discharged. But then things went downhill rapidly and then I was referred from my GP and then they rejected me and then my social worker then said, 'Well, my referral was rejected, so I put another referral in and it was rejected from her. And then my GP put another referral in and it was rejected." (Young person, group)

Falling between the gaps

Another issue raised was that of young people who have left school but are not yet 18 years old.

"I think more needs to be done for young people that are at that awkward position, where they're not 18 yet, but they have left school. Because there's quite a few services for young people that are still at school, and there's quite a lot of services for adults." (Young person, depth)

"My doctor still put the referral through and he knew that I'd left school because of the anxiety... it was really upsetting, because it was the actual CAMHS nurse that told me that there was nothing that she could do for me." (Young person, depth)

"The second referral was actually accepted, but when I got to ... I actually turned up to the place for like my first meeting with the new CAMHS nurse, and she basically told me that there was nothing that she could do for me, because at that point I'd left school because my anxiety was so bad." (Young person, depth)

A further issue relates to the transition between child and adult services – in a few cases the waiting time from referral to being seen meant that a young person became ineligible during the process.

"She was in fifth year at school when the process started of referral to CAMHS...It got to the point where it was three and a half months short of her 18th birthday and that's a really significant timeframe because actually what happened was they wouldn't accept a referral because it was too close to the 12 week window in which they refer young people. They basically refuse to take a young person if they're within 12 weeks of their 18th birthday." (Parent, depth)

Suggested improvements: being rejected

In relation to being rejected, parents and young people wanted:

• Detailed reasons why a referral is being rejected. These should be provided to the young person and their parent as well as the referrer and should be written in Plain English, with empathy, acknowledging that the child or young person and family are in severe distress

"Surely there's more helpful ways to respond to people, more compassionate ways to respond to people, because it felt just like we were dismissed."

(Parent, depth)

"They [CAMHS] should have to justify to families and to the other professionals involved why a referral has been turned been down and not to say, 'We can't see them at this time'. They should be accountable to families and to the people who have referred families to them, the other professionals involved, as to why the referral hasn't been accepted and where else families can go so that people in crisis are not just abandoned." (Parent, depth)

- It should be mandatory for rejections to include relevant signposting to other services
- If no other services are available there needs to be careful consideration before leaving children and young people with nothing

"You can't leave people in limbo, if you're rejecting them, you still can't leave them in limbo." (Parent, depth)

 A mechanism for checking in with families after six months to make sure they're getting help

"There's no system in place to track it, to monitor it, to follow-up on it." (Parent, group)

"I also feel if their advice and recommendations don't work that you should be able to get back in touch." (Parent, survey)

 Clarity about what to do next, whether a second opinion can be sought, and how best to do this

"There's no appealing the decision process that I could see and I think there should be." (Parent, depth)

Someone to talk to

"Being able to talk to somebody. Somebody that understands what you've gone through and maybe somebody can say, "Well, try this till you get help" (Parent, depth)

"I think there should be a counsellor in school trained in mental health training if CAMHS are not willing to provide help." (Young person, survey)

Participants' suggestions for change: overall

Participants also made suggestions for changing the overall CAMHS process.

Greater recognition of importance of providing support to children and young people before crisis point

"Prioritising mental health care as a way to reduce cost of long term physical/social effects e.g. alcoholism, drug use, self-harm, obesity, inability to work." (Parent, survey)

"If you catch them early, most of these conditions are treatable, they have a much higher success rate of treating them if they're got early rather than when they're in deep crisis." (Parent, group)

Availability of more options for non-Tier 3 & 4 help and support

"There really needs to be something else that schools, GPs, social workers, can offer quickly." (Parent, depth)

"I think there's a massive gap in the service that maybe CAMHS can't address, and that's fair enough, but there needs to be something else." (Parent, group)

"Either you get the top notch CAMHS, highly paid psychotherapist for two years or something similar or nothing, there's nothing else, there's no tiered approaches it feels like, so clearly there needs to be a variety of different types of interventions at different levels." (Parent, depth)

"I think reconfiguring the system to allow for different levels of intervention at different levels of need and at different times, so you can drop in and out, rather than it being all or nothing when you're deemed to be ill enough." (Parent, depth)

"If the resources were re-looked at and there was more generic help for parents, you go to a support group but if you had the same amount of people, once a month somebody coming in and just talking about things, that would give an awful lot of information to people." (Parent, group)

"The service is stretched and therefore only those with severe symptoms are being seem. Even after they are seen you are directed to a charity for on-going support post diagnosis (in the case of ASD) we are as a country missing out on those with great potential with relatively mild symptoms who get no NHS support. These children with the right support could go on to lead completely normal lives and required no adult help. Without support they will struggle to get an education and will not reach their potential." (Parent, survey)

Increased resources

Funding, so more children and young people can be seen, more quickly, and for as long as they need help

"Probably more money into the system, because I suspect they're greatly over-stretched, but a rethink entirely, a complete branch rethink about how they organise themselves, about the staff they employ, and the abilities of the staff they employ." (Parent, depth)

"The funding needs to be increased so that children and young people can be seen for as long as they need to be seen, not for as long as the cost says they can be." (Parent, depth)

"I believe that the system is desperately underfunded and that that is the only reason that my daughter was rejected and not given the help she needed." (Parent, survey)

"Give more funding to provide more resources to allow all children some real help before they reach a point of no return." (Parent, survey)

Increased staffing

"We need more clinical psychologists." (Parent, group)

"They need more therapists." (Parent, group)

Alternatives to CAMHS/more support available in schools

"They should also go into the schools more, there should be a CAMHS counsellor or a CAMHS support worker in schools." (Parent, group)

"If they had somebody coming in to the school, even once a month, to have some kind of discussion. But, you know, there are a number of play based, art based, music based, therapist, yoga, mindfulness, all of those things that we know make a difference." (Parent, depth)

"If there was a counselling service in the school, you know, that the children could drop in, it could be as simple as there's a wee girl upset, she's, her dog's died, she could go in there and speak to somebody to somebody who's been bereaved to somebody who's taking drugs, whatever. To me a service like that should be at the school, even (one) that parents could drop into." (Parent, depth)

"I feel like I'm so glad that I'm not 16, 14 anymore because I've now got a lot more support than I could ever dream of and I'm incredibly grateful for that. I just feel like if I could get the help and support from CAMHS, I wouldn't be in the state that I was in, I wouldn't have had to have so many hospitalisations, I only had four psychiatric ones but I had countless ones through self-harm and doing things to cause harm to myself. But if CAMHS helped me I would have thought that I wouldn't have had so many and I wouldn't have self-harmed as much as I have done." (Young person, group)

FIGURE 22

Words most used in the qualitative interviews that describe people's feeling about CAMHS process



Source: SAMH CAMHS Rejected Referral Audit

REFERRERS' VIEWS

GENERAL PRACTITIONERS' (GPs') VIEWS

The main issues that GPs raised were:

- High number of rejections
- Lack of time with the child, young person or parent
- Lack of clarity on CAMHS criteria
- A feeling of being professionally disrespected when referrals are rejected
- Lack of alternative services
- Generic and unhelpful signposting

GPs' suggested improvements in the following areas:

- Provision of community and early intervention services
- Clearer guidelines on the referral and assessment process
- Full assessments in all cases
- More multidisciplinary referrals
- Mandatory and relevant signposting

As part of the qualitative audit, interviews were conducted with nine GPs. GPs are approached to submit referrals by parents, schools and young people themselves. The referral process itself is considered fairly straightforward and similar to other types of referrals: the GP dictates a letter which is submitted via a gateway system.

GPs tend to submit their referral within a few days of seeing the person and agreeing to refer. Five of the nine GPs interviewed suggested they were making fewer referrals nowadays due to the volume of rejections received. Two GPs said CAMHS is the largest rejecter of referrals of any department, and a further two referred to it being very difficult to refer into CAMHS.

"The number of rejections is highest in CAMHS for any service. Adult Mental Health Service might change your 'urgent' to a 'routine' but they will still see the patient"

GPs: concerns about referrals

GPs do not always believe they are best placed to make referrals, particularly in instances where the initial recommendation to refer has come from school. Some would prefer a multidisciplinary approach to making referrals. However, the necessary interface for co-ordination between schools, GPs and others involved is not necessarily established or perceived as easy to set up.

GPs are not always clear on the pathways in the system: for example, in cases where the school nurse is also the primary mental health worker in the area.

One mentioned a perception that referrals from a secondary service are more likely to be accepted, therefore their practice is to refer to other services, rather than CAMHS direct.

"I think schools often don't feel that they're in a position to make that referral, even though they probably hold the key information, quite often the key information"

"We find that CAMHS is a very difficult service to refer in to...and our perception is the easiest way to get a CAMHS referral is to refer to a second service, who are more likely to be able to get a positive response from them [CAMHS], so it's either the school service or community paediatric service"

"Sometimes we feel like we're piggy in the middle almost; that the school has concerns but the parent comes to us to get the referral"

Time pressures

GPs reported concern that a standard 10 minute appointment is insufficient to gain a full enough history and background to write a detailed referral.

"Often the reason the referral is not accepted is because there's not enough information, and the reason there's not enough information is because we've had 10 minutes, whereas this individual, this child, this adolescent, whatever, has been in the school 300 days of the year, eight hours a day, and the school has a file as thick as you can imagine"

"Usually it's [referral request] driven by the parents who are usually at the end of their tether and so it's usually quite a pressurised consultation and it usually has a pressure effect on the rest of that consulting afternoon"

Lack of transparency over criteria for acceptance by CAMHS GPs reported that the referral form is essentially a 'blank sheet' and some report multiple instances of referrals being returned for more and or specific information. They would welcome more detail on the form about the information CAMHS require.

• Negative perceptions exist about the CAMHS service in general Some GPs reported feeling that CAMHS do not have the same pressured workload as GPs. Some raised a sense that CAMHS is generally difficult to deal with and expressed frustration about the perceived extremely narrow definition of situations in which they will provide support and or treatment.

GPs: rejections

GPs do not feel they refer to CAMHS lightly: they state that referrals are made where they have exhausted other avenues and have no other options.

"It's only the very, very pinnacle of patients that I would refer because my expectation of the referral being accepted for anything lower is so low"

"We're referring to CAMHS because we're stuck. If there was something else we could be doing, that would or will have been done, it's not that we're just testing the water with CAMHS"

"I feel that I am an experienced GP who sees a lot of distressed young people and I don't refer lightly. If I make a referral it's because it's outwith my scope or my timescales and I just find it rude to have it rejected"

Rejection causes anger and disappointment for GPs, and a feeling of lack of respect for their professional opinion.

"Obviously, I expect if I'm making a professional decision to refer someone, that the vast majority would be accepted. I'm an experienced GP. I've got experience in mental health issues and I do believe my job is to manage referrals into the service, to manage people as best we can in primary care, but if we can't manage them in primary care I do expect the services in secondary care to take that on; it does seem that there's significant barriers to achieving that"

There is a strong feeling that children and young people should at least be seen, assessed before being rejected.

"I personally would expect at least some level of assessment to be made, especially when you've got four or five separate professionals all agreeing that a specialist service is required"

GPs are often left to explain to the young person or parent that the referral has not been accepted, which can put them in a difficult situation. They often cannot explain why the referral has been rejected and have limited alternatives for providing support to the young person. The responsibility for care remains theirs, often in a worsening situation.

"Then the onus is on you, so it's more time that we didn't have in the first place, to try and address a problem that we don't have the skills or resource to address"

"The difficulty for us is then trying to explain to parents that I don't know what else to do"

This can have a longer term detrimental impact on the relationship, as the child, young person or family feels the GP has let them down. Several GPs mentioned that adult mental health services have a better managed system / process for referrals and treatment.

"It does destroy trust...because basically they'd come to see me for help and I'd not managed to secure that for them; why would you come and see that doctor again?"

Rejection letters from CAMHS often do not give what GPs feel are satisfactory or detailed reasons for rejection, or provide a clear route for GPs to follow up for more information. GPs criticised the language and lack of clarity of rejection letters, particularly where these are copied to parents or young people.

"You just get a, what I find a very disrespectful reply back saying 'your patient doesn't meet the criteria' and there's no discussion with me...and they don't speak to the patient directly"

Signposting from CAMHS is not always included in rejection letters. Where it is included GPs feel it is often fairly generic and that children, young people and their families have often already accessed available third sector and or other support.

"Often there will be a suggestion of using other local services, most of which we would have already considered and considered not adequate for the needs and that's why we're referring to them [CAMHS]"

In some areas, particularly rural, there is no local alternative service provision. Ultimately the lack of available service provision for those not accepted by CAMHS is the major problem for GPs.

"I'd probably find it less difficult to not be able to get people into CAMHS if there were other alternatives"

GPs: recommendations for change

GPs would like to see:

- The development of alternative service provision for those who don't meet CAMHS Tier 3 and 4 criteria
- More structured guidelines for referral letters
 - "Because they do want quite specific information it perhaps would be more useful if they did have a much more specific form to fill out almost, so that we could give them specific information that they do need"
- Schools empowered to make more referrals directly
- Greater clarity around assessment decision processes, such as criteria for accepting referral, information on who makes decisions and how they are made, a named contact for follow-up and details of an appeals process
- Greater respect for the opinion of primary healthcare professionals
- Full assessments to be carried out for all cases
- Clear reasons for rejection provided
- Universal and relevant signposting where referrals are rejected

TEACHERS' VIEWS

Twenty-four teachers responded to our survey, all had an experience of rejected referrals.

The main issues that teachers raised were:

- Waiting times
- Lack of support after a referral is rejected
- Lack of information, both during the referral process and after the referral had been rejected

Teachers suggested improvements in the following areas:

- Improved interagency working and communication
- Standardised referral form with space for the views of the young person, parent and other agencies involved
- Improved other tiers of support

Teachers: concerns about referrals

The most common reasons teachers reported making referrals were for anger or physical violence, issues at home and self-harm.

Only two teachers said that an assessment was carried out by CAMHS. Seven said that an assessment wasn't carried out and nine were unsure. Of these two cases where an assessment was carried out, one teacher said they were given no information during / after the assessment. The other indicated they were told to continue with the strategies they were working on at school and there was to be no further CAMHS input at this stage as it was not deemed severe enough.

The most common way teachers heard the referral had not been accepted was by a CAMHS letter (eight teachers).

Five of the referrals discussed were rejected as they were not considered to be an appropriate referral. Three were not considered severe enough. One was rejected because not enough information was provided.

Teachers were asked about what happened after a referral was rejected.

Common themes included:

- A lack of follow up by CAMHS
- The school trying to support the child without the support of CAMHS
 - one teacher noted that the school were now 'funding regular counselling for a pupil'.
 - Another mentioned that the referral had been resubmitted.

- One teacher told of how the Additional Support Needs (ASN) Manager and school head teacher "both wrote to CAMHS to request fuller assessment and review of decision. This was refused."
- Contacting other agencies such as the educational psychologist, GP, play therapy or paediatrician.
- Continued decline in the mental health and educational performance of the child:
 - "Child had to be moved to another class and taught by member of Senior Management Team."
 - "The child has now had to be put onto a reduced timetable as unable to cope on p5 setting for full days. Little academic work being completed. A very upset, vulnerable little boy."

Teachers were asked about the impact of rejected referrals. A common theme was a negative effect on the mental health of the young person concerned.

- "The pupil in question continues to struggle with mental health issues, without specialist support."
- "Distress and behaviour continued to deteriorate until eventual crisis."
- "He feels he is stupid and it"s another person who "isn"t interested" in helping him."
- "They said it proved that no one cared."

Teachers also spoke of trust with agencies being broken:

- "Left feeling helpless "The young person felt helpless like no one out there could help her. It also made it very difficult for them to trust support - what"s the point as they won"t do anything/ the advice I am given is pointless etc."
- "He asked me why I didn"t get someone for him to talk to about his 'big feelings.' Because of his Nana's issues I had said I would attend appointments with him in school and I had a letter from Nana witnessed by SW (social worker) to do this. I think he felt like no one cared about him. It was another agency not to bother. Very limited SW intervention too."

Thinking about the overall CAMHS process, teachers commonly raised their focus on the most severe cases:

"They seem to take very little on. Only seem to want to deal with severe cases that can be medicated / level 4 service but in our authority there is no Tier 3 service for children with attachment difficulties which are now having a significant impact on their day to day lives. Sometimes cases are too severe for homelink and educational psychology and no impact by their actions so all channels exhausted. Agreement then made to refer to CAMHS who then decline and the child/family is left with nothing."

Teachers also spoke about a lack of assessments and a feeling that the system was not fit for purpose.

- "Completely inadequate assessment as no contact was made with school whatsoever to request information. Process was perfunctory at best."
- "I genuinely feel that the process is pointless as CAMHS have not engaged with any young person that I have referred."
- "Not fit for purpose, too long and reliant on a medical jargon to justify acceptable or non-accepted referrals. No emphasis on early intervention as we understand in education as being crucial for inclusion and engagement"
- "Terrible expect better."

Another common issue raised by teachers was the impact on their own emotional and mental health.

- "There was no discussion with the school before a decision was made. I am extremely upset and angry with the way this child was treated however it seems many young children I have referred have been rejected."
- "Frustrated and helpless. We are told to encourage pupils and parents to seek help from professionals yet they are turned down or we are given ridiculous and unrealistic advice."
- "Had a very unpleasant training session from CAMHS recently, felt they were asking us to stop referring and do more ourselves. We are already doing as much as we can."

Teachers' suggested improvements

Improved communication

- "A one to one chat with the referring adult to pick apart the concerns. If someone had spoken to me about the use of strategies I could have explained all the things we had done with little or no impact."
- "Improve the communication by providing updates. Employ more staff as it is a service which is very much needed but can"t cope with demands."
- "Consultation between CAMHS staff and educators."
- "Include requests for information in the initial referral to avoid duplicating work."
- "Better communication/information sharing with school as partners in promoting wellbeing of the child."
- "CAMHS teams must work much closer with schools to see how engagement can be achieved well with vulnerable children! Children with mental health issues are not going to slip to a strange place to see a stranger once a month and expect to engage well with the process."

Shorter waiting times

"Length of waiting time (18 weeks is simply too long)."

"Improved waiting times (if not able - which I understand - maybe some practical advice based on the referral of what we can be doing in the meantime with the young person to support them), streamlined forms."

Support for children and young people who are not considered severe enough for CAMHS

"There almost needs to be something in the middle between education and CAMHS. I understand that resources are stretched but to just pass pupils back to education who are not the professionals puts pressure both on schools to deliver and also the pupils themselves. I also strongly believe that CAMHS need to seek advice and info from schools before making decisions about a pupil"s needs based only on a referral from a GP or from the info given by pupils and family."

• Other comments for improvements included:

"A huge shake up of the CAMHS service. Has been failing children and families for too long. Don"t feel as if they play an active part in the 'interagency team'."

"That CAMHS appreciate that schools do not refer children willy-nilly; there is always a good reason for the referral."

"For me it was brick wall after brick wall and lack of continuity, no communication, no accountability, no action, nothing. It was just a process that isn't fit for purpose."

(young person, group)

RECOMMENDATIONS

The recommendations are structured into four sections: further research, meeting the needs of children, young people and their families, practical changes to the existing system, and improving data collection.

This research has identified a strong indication of a gap in provision for children and young people whose needs do not fit the CAMHS Tier 3 and 4 eligibility criteria. The first set of recommendations focus on work to further explore this gap, while the second make recommendations for changing CAMHS to better meet the needs of these children and young people. Other work is also being undertaken by Audit Scotland, Health Improvement Scotland and the Youth Commission, and these projects may also provide helpful data.

There is also evidence that CAMHS is not well understood by those referring into it or those who are referred to it, and that it can be a difficult, confusing and distressing system to navigate. The third set of recommendations therefore focus on changes that can be made to the current system, to create a service that is not only more appropriate for children, young people and their families but also more efficient. However, these recommendations will only improve processes, when this research suggests the system may be in need of fundamental reform. As such they should be seen as a set of short-term measures, pending further research and more substantial reform.

The first three sections are informed by the qualitative element of this research. The final set of recommendations are drawn from the quantitative element of this research, and relate to improving data collection.

Recommendations section 1: further research

This report dealt with a subset of those children, young people and their families who are referred to CAMHS but not accepted, so it is not possible to draw conclusions about the entire CAMHS system. However, there are indications that there may be serious problems. The following recommendations suggest work to explore the CAMHS system as a whole.

Recommendation 1

The Scottish Government should explore the views and experiences of staff working in CAMHS regarding the system's fitness for purpose, current good practice and innovation, and opportunities for improvement in processes as well as the system overall.

The Scottish Government should also explore the views of children, young people and parents who do access CAMHS to explore their experiences of the referral system and processes.

Recommendation 2

The Scottish Government should request that ISD explore how data can be gathered about Tiers 1 and 2 of CAMHS, so that a full picture of the service being provided to children, young people and their families can be gained.

Recommendations section 2: meeting the needs of children, young people and their families

Notwithstanding the efforts of many CAMHS professionals and the recent increase in workforce and investment, it is clear that many children, young people and their families who are rejected from CAMHS do have genuine and in some cases urgent need of help. From speaking to individuals who took part in this research, this help does not appear to be available. Time and time again we heard that there is a gap in provision for whom CAMHS is not the most appropriate service.

Recommendation 3

The Scottish Government should consider whether the tiered model of CAMHS continues to be fit for purpose. In the short term it should change the language used to describe services: references to specific tiers are confusing and unhelpful to children, young people and their families.

Recommendation 4

The Scottish Government should review and if necessary restructure the current system so appropriate services are easily accessible to children and young people with behavioural and emotional problems, alongside a mental health problem not severe enough to fit the eligibility criteria for CAMHS. The Scottish Government should consider whether achieving this aim requires nationwide provision of schools-based services.

Recommendation 5

In carrying out Recommendation 4, the Scottish Government, Health Boards and Integration Joint Boards (IJBs) and local government should ensure services are funded at an appropriate level, available consistently nationwide and measure both waiting times, outcomes and patient satisfaction.

Recommendation 6

In creating the system suggested at Recommendation 4, the Scottish Government should develop a multi-agency assessment system, with a focus on quickly referring young people to the appropriate service and eliminating the inefficiency of multiple referrals. This should build upon areas of existing good practice.

Recommendation 7

In creating the system suggested at Recommendation 4, all CAMHS teams should publish information on the circumstances in which they will conduct a paper-based assessment. There should be an expectation that face to face assessments will take place in almost every circumstance.

Recommendation 8

In a well-functioning system, there should be no need for rejected referrals. However, if they do occur, the Scottish Government should require personalised and meaningful signposting to be mandatory

Recommendations section 3: making immediate changes to CAMHS

Making and receiving a referral

Recommendation 9

Where this does not already happen, all CAMHS teams should establish regular sessions when a member of staff is available by telephone to discuss potential referrals with referrers, to reduce the number of inappropriate referrals received.

Assessing a referral

Recommendation 10

All CAMHS teams should review their assessment procedures to ensure they offer appropriate opportunities for young people to speak to professionals without parents being present, and for parents to speak to professionals without children being present, with regard to issues of capacity and consent.

Recommendation 11

All CAMHS teams should train those conducting assessments to introduce themselves, explain their role and clearly set out what will happen during the assessment and the possible outcomes, this should also be included in the appointment letter.

Rejecting a referral

Recommendation 12

All CAMHS teams should send notification of rejected referrals to both the referrer and the child or young person, or where appropriate their parent or guardian. Notifications should be written in clear, non-medical language and should clearly identify the team who has made the decision to reject the referral.

Recommendation 13

Notifications of rejected referrals should wherever possible and appropriate include a direct re-referral to a more appropriate service, without requiring the child, young person or their family to start the process again.

Support for referrers

Recommendation 14

All CAMHS teams should publish information on what support is available in a crisis, and where children, young people and their families should be referred in a mental health crisis, including out of hours services.

Recommendation 15

The Scottish Government should work with Royal Colleges and appropriate NHS bodies to create training and/or targeted and regularly refreshed resources for GPs to ensure they understand when a referral to CAMHS is appropriate and what other services are available, building on current examples of good practice and taking into consideration the local context .

Recommendation 16

CAMHS teams should ensure all those who can refer into them have child-centred and developmentally appropriate information which they can provide to children, young people and their families at the point of referral, setting out what will happen next and signposting to sources of information.

Recommendation 17

Normal practice should include a conversation between the referrer and CAMHS teams before rejecting all but the most clearly inappropriate referrals, to establish whether any other information is available. Good practice should be that child or young person planning meeting minutes are included.

Recommendation 18

All bodies responsible for children's services should intensify efforts to ensure GPs have sufficient information about non-CAMHS services in their area and are aware of resources such as the ALISS database.

Availability of services

Recommendation 19

The relevant and responsible bodies should review their CAMHS and adult mental health services to ensure all those aged up to 18 can receive a service, regardless of educational status. For those who are approaching the age of 18 are either helped within CAMHS or quickly routed into adult services.

Recommendation 20

The relevant and responsible bodies should encourage and support the establishment of peer support groups for parents caring for children with emotional, behavioural as well as mental health issues.

Recommendation 21

The relevant and responsible bodies should review their mental health services to ensure they are available for children and young people who have Autistic Spectrum Disorder, or a learning disability alongside a mental, emotional or behavioural problem.

Recommendation 22

The relevant and responsible bodies should review their mental health services to ensure provision exists for children, young people and their families where the child is no longer attending school but has emotional, behavioural and mental health difficulties.

Recommendations section 4: data collection

Recommendation 23

ISD should agree with Scottish Government and NHS Boards ongoing data needs around rejected referrals to improve the experience and outcome for children and young people.

Recommendation 24

ISD should work with third sector organisations to understand the services they provide to children and young people and explore sharing data between these organisation and statutory services to ensure full pathway information is available and used for improving services and experience.

Recommendation 25

The Scottish Government should request ISD to begin enhanced data collection and publication of rejected referral information on a routine basis. This would allow for further analysis in such areas as SIMD, geographical areas and service delivery differences. In particular, the Scottish Government should request research comparing the demographic profiles of those who are rejected from CAMHS with those who are not, to establish whether particular groups are being especially disadvantaged.

Recommendation 26

The Scottish Government should request ISD to undertake further work to understand what happens next to the children and young people e.g. usage of other services. This could be achieved through linkage of records included in the audit to other services.

Recommendation 27

ISD and Scottish Government should work with NHS Boards to standardise the definitions of all data items relating to CAMHS including 'Referral Source', 'Reason for Referral' and 'Rejected Referral Reason'. These should be adopted and implemented by all Health Boards to ensure consistency and comparability. This would include less use of 'Other' categories.

Recommendation 28

The term 'rejected' is emotive and distressing. However, the qualitative element of this research indicates a lack of evidence that referrals are genuinely being 'redirected', which is the preferred alternative term. The Scottish Government should act on the recommendations in this report to create a system that minimises inappropriate referrals and ensures that those which do occur are demonstrably redirected. Only at this point should a change in language be considered.

Recommendation 29

NHS Boards should have clear referral protocols available to all referrers, including GPs and teachers, which clearly define the process of referrals and what services the NHS Board provides through:

- Enhancement of existing referral pathways and development of standard referral pathways which are clearly written, freely available and easily understood by all referrers
- The development and use of a standard referral form, clearly indicating which information is essential before a referral can be considered. This form should include space for input from GPs, schools, parents and the child, so that as much information as possible can be provided. It should also include space to indicate what services and approaches have already been tried, to avoid unhelpful signposting in case of rejection.
- Considering the development of standard referral criteria which applies to all services across Scotland.

GLOSSARY

Rejected Referral - can be described as 'when the request to a healthcare professional or to an organisation to provide appropriate healthcare to a patient is deemed as not appropriate'.

Tier 1

Child and adolescent mental health services at Tier 1 are provided by practitioners working in universal services who are not mental health specialists. This includes:

- GPs
- health visitors
- school nurses
- teachers
- · social workers, and
- youth justice workers and voluntary agencies

Tier 1 practitioners are able to offer general advice and treatment for less severe problems. They contribute towards mental health promotion, identify problems early in the child or young person's development and refer to more specialist services.

Tier 2

Mental health practitioners at Tier 2 level tend to be CAMH specialists working in teams in the community and primary care settings (although many will also work as part of Tier 3 services). They can include, for example:

- mental health professionals employed to deliver primary mental health work, and
- psychologists and counsellers working in GP practices, paediatric clinics, schools and youth services

Tier 2 practitioners offer consultation to families and other practitioners. They identify severe or complex needs requiring more specialist intervention, assessment (which may lead to treatment at a different tier), and training to practitioners at Tier 1 level.

Tier 3

Tier 3 services are usually multidisciplinary teams or services working in a community mental health setting or a child and adolescent psychiatry outpatient service, providing a service for children and young people with more severe, complex and persistent disorders. Team members are likely to include:

- child and adolescent psychiatrists
- social workers
- clinical psychologists
- community psychiatric nurses
- child psychotherapists
- occupational therapists, and
- art, music and drama therapists

Tier 4

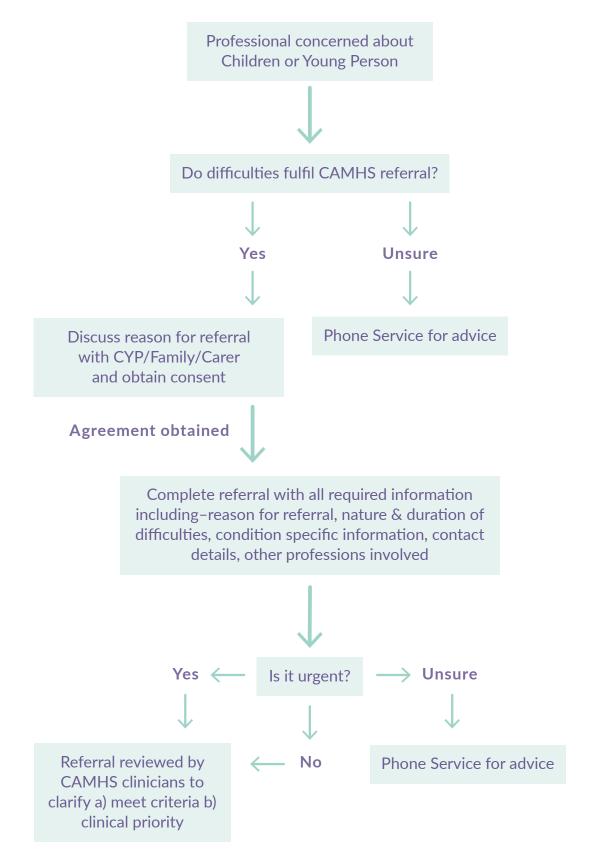
Tier 4 encompasses essential tertiary level services such as intensive community treatment services, day units and inpatient units. These are generally services for the small number of children and young people who are deemed to be at greatest risk (of rapidly declining mental health or serious self-harm) and/or who require a period of intensive input for the purposes of assessment and/or treatment. Team members will come from the same professional groups as listed for Tier 3. A consultant child and adolescent psychiatrist or clinical psychologist is likely to have the clinical responsibility for overseeing the assessment, treatment and care for each Tier 4 patient.

Source of Tier Information - www.icptoolkit.org/child_and_adolescent_pathways/about_icps/camh_service_tiers.aspx

Unsuitable - A referral can be deemed unsuitable if:

- The information provided does not meet the health board provider referral criteria
- Early stage mental health illness/disorder no other services involved
- Mild mental health illness/disorder no impact on life
- No mental health illness/disorder
- Out with Board catchment

Referral Flow Chart



Dataset

Dataset				
No	Data Item Name	Definition		
1	Location Code	Each location in Scotland, at which events pertinent to the Scottish Health Service take place, is allocated a location code		
2	Unique Patient Identifier	A locally derived patient identifier		
3	CHI	The Community Health Index (CHI) is a population register, which is used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index		
4	Postcode	The postcode is a basic unit for identifying geographic locations. A postcode is associated with each address in the UK		
5	Sex	The state of being male or female		
6	Referral Source	A source of referral category is a broad category of organisation and/or professionals who may make a referral, e.g. consultant in other provider unit, GP, self		
7	Team	The identification of the locally 'named' team that the CYP has been referred into that has then rejected the referral e.g. team 1, team 2, Lothian team, etc		
8	Referral Received Date	Date referral received is the date on which a health or social care service receives a referral		
9	Reason for Referral (presenting problem)	A reason for referral is a health problem which occasioned a referral. This may be a definite diagnosis, an unconfirmed diagnosis or signs and symptoms		
10	Referral Accepted	The referral has been vetted/triaged and been accepted or rejected for the service		
11	Date Referral Rejected	The date that the referral has been rejected by the service/team		
12	Rejected Referral Reason	The reason why a referral was not accepted by the service provider		
13	Rejected Referral Action	The action taken following the rejection of the initial referral		
14	Free text field	For any comments regarding service or referral		

NOTES

- 1. Scottish Government, Mental Health Strategy 2017-2027
- 2. Scottish Government, <u>Children and Young People's Mental Health: A Framework for Promotion</u>, Prevention and Care, 2004
- 3. UK Department of Health, Together We Stand: Commissioning, Role and Management of Child and Adolescent Mental Health Services, 1995
- 4. ISD Scotland, Child and Adolescent Mental Health Services Waiting Times in NHS Scotland, March 2018
- 5. ISD Scotland, Child and Adolescent Mental Health Services Waiting Times in NHS Scotland, March 2018
- 6. ISD Scotland, CAMHS in Scotland: Waiting Times, Service Demand and Workforce, June 2018
- 7. ISD Scotland, Psychological Therapies Waiting Times in NHSScotland, June 2018
- 8. See, for example, Scottish Government, February 2016, A National Clinical Strategy for Scotland, p21, table of Longstanding illness by Scottish Index of Multiple Deprivation (SIMD) quintiles 2014, www.gov.scot/Resource/0049/00494144.pdf
- 9. National Records Scotland Population Projections for Scottish Areas (2016-based)
- 10. ISD Scotland, Child and Adolescent Mental Health Services Waiting Times in NHS Scotland, March 2018

APPENDICES

APPENDIX ONF

Child and Adolescent Mental Health Services: SAMH screening survey

Introduction

Have you, or has someone in your family been referred to but not accepted by a Child and Adolescent Mental Health Service (CAMHS) since January 2016?

This happens to one in five young people who are referred to CAMHS and is also known as a "rejected referral". At a national level we want to learn more about this situation. So the Scottish Government has asked SAMH to gather evidence from children, young people and their families to help understand and improve the situation.

This work is being done as part of the Government's Mental Health Strategy. The research will help to answer those questions and make recommendations for the future.

This survey will help us to identify people who would like to take part in this research. It will take about five minutes to complete. We will then contact you to arrange the best way for you to participate.

We can't always prevent young people from experiencing a mental health problem, but we can give them every chance to get the help they need, when they need it.

Thank you for participating.

Survey questions

Q1 Which of these categories best describes you?

young person

parent/carer

sibling or other relative

teacher SKIP TO Q11

GP SKIP TO Q11

other (please state) SKIP TO Q12

Q2 How old are you?

5-11 years ASK Q3

12-15 years ASK Q3

16-18 years SKIP TO Q4

19 – 25 years SKIP TO Q4

26 years or older SKIP TO Q4

ASK ALL AGED UNDER 16 YEARS

Q3 If you are under 16 years old, please ask a parent or guardian to read the following information, and give their consent for you to take part in this survey.

The Scottish Government has asked SAMH to gather evidence from children, young people and their families who have been referred to but not accepted by a Child and Adolescent Mental Health Service (CAMHS) since January 2016. The purpose of this short survey is to help us to identify people who would like to take part in this research, and to collect their contact details to arrange the best way for them to participate.

The online questionnaire should take no more than 5 minutes to complete. All information provided will be treated in confidence and used only for research purposes.

Do you agree that your child can participate in this online survey?

Yes

No CLOSE *

Please provide an email address or phone number that can be used if we are requested to confirm your consent:

NOW GO TO Q4

ASK ALL YOUNG PEOPLE, PARENTS/CARERS, OTHER FAMILY MEMBERS CODES 1-3 AT Q1

Q4 Have you been referred to CAMHS but not accepted, between January 2016 and now?

Note: this might also be known as being "rejected" or "declined" from CAMHS.

Yes, I was referred but not accepted

Yes, a member of my family was referred but not accepted

No CLOSF *

Q5 What was the primary reason for being referred?

Q5	What was the approximate date of the referral?
	Drop down list - month & year (Jan 2015 to Dec 2017)
	unsure
Q6	And what was the approximate date you (or the person concerned) received notification that the referral would not be accepted?
	Drop down list month & year (Jan 2016 to Dec 2017)
	unsure
Q7	Who told you (or the person concerned) you would not be accepted to CAMHS?
	Class Teacher
	Headteacher
	Guidance teacher
	School nurse
	Someone else
	Learned the information in another way (please write in)
Q8	Can we contact you about taking part in the research? This could involve taking part in a focus group, a telephone or video interview or a more detailed online survey.
	Yes
	No
Q9	Please enter your contact details below. Please note this information will only be used for the purposes of this research. We will not identify anyone by name in the research that we produce as a result of this work.
	Name:
	Postcode (first part only)
	Email:(include email format check)
	Tel no:

Q10 Ge	ender
--------	-------

Male	
Female	
Prefer to self-describe _	
Prefer not to say	

Thank you for your interest in participating. We will be in touch soon with information about the next stage of the research.

Q11 Teacher/GP

Thank you for your interest in this research. We will be undertaking some specific research with teachers and GPs later in our research process. If you would like to be involved, please fill in your details below.

Email address:	(include email format check)
Workplace postcode (first part only)	

Q12 Other

Thank you for your interest in this research. At the moment we are specifically looking for children, young people and their families who have experienced a CAMHS rejected referral. Please follow us on @ SAMHTweets for updates on this and other work. You can also find out more about the Scottish Government's Mental Health Strategy.

*CLOSE MESSAGE Thank you for your interest in this research.Please follow us on @SAMHTweets for updates on this and other work. You can also find out more about the Scottish Government's Mental Health Strategy

APPENDIX TWO

Rejected referrals Topic Guide for focus groups and depth interviews

Introduction (10 mins)

- By moderator
- Name, organisation, short intro to SAMH
- Reminder that you are acting as a researcher today
- Introduce any colleagues viewing / note taking
- Housekeeping: fire alarms / process, toilets, what to do if you want to leave the session

Explanation of purpose of session or interview

- To understand what happens when young people are referred to Child & Adolescent Mental Health Services but do not receive treatment / support from them
- Collecting experiences of young people and their families for a report to Scottish Government.
- Aiming to gather feedback on 350 cases where young people have been in this situation.
- Our aim is to improve the experience of young people (and their families) who are referred to Child & Adolescent Mental Health Services

Introduction to the format of the session

- Around 1 hour
- Group discussion, rather than individual Q&A
- Share experiences in confidence

Explanation of research and group discussions

- No right or wrong answers
- Everyone's views are important, please don't be afraid to speak up
- If you are upset or need to leave the focus group please let a member of SAMH staff know, who can assist you

Reassurance over confidentiality and MRS Code of Conduct

- We will not disclose any of your details
- We will anonymise all of our reports
- We will only use the information you provide for the purpose of this research
- Child Protection Statement: The only exception to this is if anyone divulges information during the discussion that indicates a child is in a situation where there is an immediate risk of harm. In that case I have a duty of care to pass this information on to local child protection services.

- Explanation of recording audio recording to ensure we correctly capture
 the detail of what we are being told. This will be transcribed and analysed for
 use in our report.
- Individual introductions:
 - First name, age, who you live with, what you do for a living/with your time, your favourite film / band / song?

Being Referred (15 mins)

Let's talk first of all about the process of being referred to Child & Adolescent Mental Health Services. Everyone should have already filled in the short questionnaire about the reasons for referral, so I'd like to focus on talking about your experience of the process...

- Who did you approach to help?
- Who suggested a referral to CAMHS?
- PROMPTS: young person, family member, GP, teacher, someone else
- Why was a referral to CAMHS suggested?
- How long did you have to wait for a referral?
- What were your expectations at that stage?
- PROBE: timescales.
- What information were you given?
- How well did you understand the process / what would happen next?

Being Assessed (15 mins)

- How long did you wait for an assessment?
- What support, if any, were you offered during this time?
- Did you take any action whilst waiting for your assessment?
- PROMPTS: chase the referrer, look for information.
- How did you feel during this time?
- What impact, if any, did the waiting time have on you and your family?
 - PROBE: emotional, behavioural, impact on condition, impact on family life etc
- What did you think of the assessment process?
- What information were you given during / after assessment?
- How well did you understand the process / what would happen next?

Being Rejected (20 mins)

- What happened next?
- NOTE language used to describe 'rejection'
- How did you find out that your referral had been rejected? Who told you?
- PROMPT: Letter from CAMHS, told by referrer (GP, teacher etc)
- What reasons were you given? What did the letter / referrer say?
- Did you understand the reasons given?
- How did you feel about it?
- What impact did it have on you and your family?
- PROBE: emotional, behavioural, impact on condition, impact on family life etc
- Were you referred / recommended to contact another service?
- IF YES: which service?
- Did you contact the service yourself?
- Did you get help from this service?
- Did you get help / support elsewhere (for example from a different service that you found out about through another channel)?
- IF YES: which service?
- How did you find out about this service?

Sum Up (5 mins)

- Overall, how do you feel about the CAMHS referral process?
- What do you think could be improved?
- What, if any, type of support would have helped while you were waiting during the process?
- IF NOT ALREADY MENTIONED: Did you get any support? Where from?
- What do you think are the most important points for SAMH to take to the Scottish Government about the CAMHS referral process?
- Any final comments?

Thank & Close

APPENDIX THREE

Young People Survey

Introduction

Have you, been referred to but not accepted by a Child and Adolescent Mental Health Service (CAMHS) since January 2016?

This happens to one in five young people who are referred to CAMHS and is also known as a "rejected referral". At a national level we want to learn more about this situation. So the Scottish Government has asked SAMH to gather evidence from children, young people and their families to help understand and improve the situation.

This work is being done as part of the Government's Mental Health Strategy. The research will help to answer those questions and make recommendations for the future.

We can't always prevent young people from experiencing a mental health problem, but we can give them every chance to get the help they need, when they need it.

Thank you for participating.

Survey questions

Q1 Which of these categories best describes you?

young person

parent/carer SKIP TO Q

sibling or other relative SKIP TO Q

teacher CLOSE & PROVIDE LINK TO TEACHER SURVEY

GP CLOSE & CAPTURE DETAILS FOR TELEPHONE INT

other (please state) CLOSE

Q2 How old are you?

5-11 years ASK Q3

12-15 years ASK Q3

16-18 years SKIP TO Q4

19 – 25 years SKIP TO Q4

26 years or older SKIP TO Q4

ASK ALL AGED UNDER 16 YEARS

Q3 If you are under 16 years old, please ask a parent or guardian to read the following information, and give their consent for you to take part in this survey.

The Scottish Government has asked SAMH to gather evidence from children, young people and their families who have been referred to but not accepted by a Child and Adolescent Mental Health Service (CAMHS) since January 2016. The purpose of this survey is to help us understand the experiences of young people who have been through the referral process.

The online questionnaire should take no more than 10 minutes to complete. All information provided will be treated in confidence, anonymised and used only for research purposes.

Do you agree that your child can participate in this online survey?

Yes

No CLOSE

Please provide an email address or phone number that can be used if we are requested to confirm your consent:

Q4 Gender

Male

Female

Prefer to self-describe _____

Prefer not to say

NOW GO TO Q4

Q5 Have you been referred to CAMHS but not accepted, between January 2016 and now? Note: this might also be known as being "rejected" or "declined" from CAMHS.

Yes, I was referred but not accepted

No CLOSE

Q6 When was the referral made? Don't worry if you can't remember exactly, an approximate date is fine.

Drop down list - month & year (Jan 2015 to Apr 2018)

unsure

Q7	And what was the approximate date you were told that the referral would not be accepted?
	Drop down list month & year (Jan 2016 to Apr 2017)
	unsure
Being Q8	Referred Please tell us about the reason you were referred to Child and Adolescent Mental Health Services (CAMHS)
Q9	Who made the referral?
	GP / local doctor
	Class Teacher
	Headteacher
	Guidance teacher
	School nurse
	Another health professional e.g. health visitor, paediatrician, occupational therapist
	Someone else
Q10	What information were you given at the referral stage about what would happen next?
Q11	Were you given an idea of the time it would take to hear back from CAMHS?
	Yes
	No

	ssment Were vou	invited to an assessment meeting with someone fro	m CAMHS?
_	Yes	ASK Q12	0,
	No	SKIP TO Q14	
	Unsure	SKIP TO Q14	
2	What did	you think of the assessment process?	
3	What info	rmation were you given at the referral stage about vext?	vhat would
1	What hap	pened next?	
5	Who told	you that you would not be accepted to CAMHS?	
	Class Teac		
	Headteach		
	Guidance		
	School nui	rse	
	Another he therapist	ealth professional e.g. health visitor, paediatrician, oc	cupational
	CAMHS le	etter	
	Someone	else	

Q16	What reasons were you given for the referral not being acc	ceptea?	
Q17a	Did you understand the reasons that were given? Yes SKIP TO Q18 No ASK Q17b		
Q17b	IF NO – why not?		
Q18	How did you feel about not being accepted?		
Q19	What impact, if any, did it have on you?		
Q20	Were you recommended to contact another service or direct resources? Yes No	ected to other	

Q20b	IF YES – what/where?	
Q21	What did you do next?	
	Contacted another service	
	Used online / other resources	
	Paid to see a private healthcare professional	
	Asked for another referral to be submitted	
	Something else	
	Nothing	
OVER Q22	RALL How do you feel overall about the CAMHS referral proces	ss?
Q23	What, if anything, do you think could be improved?	-
Q24	What type of support would have helped while you were the process?	going through
		-
		-
		-

Thanks & Close Message

Teacher Survey

Q1.	What type of school do you teach in?
	Nursery school
	Primary school
	Secondary school
Q2.	Have you ever made a referral to CAMHS that was rejected? (was not accepted by CAMHS)
	Yes
	No
Q3.	How often do you make referrals to CAMHS?
	Weekly
	Monthly
	Six monthly
	Other (please specify)
Q4.	Can you give a brief outline of the situation? (Including at what stage you became involved and your role in the referral process)
Q5.	How long did it take to prepare and submit the referral? Less than an hour
	Half a day
	A week
	Other (please specify)

making the referral?	
Was an assessment undertaken by CAMHS?	
Yes	
No	
What information were you given from CAMHS during/afte assessment?	r the
	,
What was your role, if any, in communicating with the young family?	g person /
	g person /
	g person /
Would you say that this experience was typical or not typical	
Would you say that this experience was typical or not typical assessments?	
Would you say that this experience was typical or not typical assessments? Yes	al of CAMHS
Would you say that this experience was typical or not typical assessments? Yes No	al of CAMHS

What reasons were given for the referral not being accept	ed?
Not an appropriate referral	
Not enough information was provided	
Was not considered severe enough	
What happened next?	
What, if any, impact did the rejection have on the young p	erson?
How do you feel about the CAMHS referral process?	
What, if anything, do you think could be improved?	
What do you think are the most important points for SAM Scottish Government about the CAMHS referral process?	H to take to the
s there anything else you would like to tell us about the ref	erral process?
	Not an appropriate referral Not enough information was provided Was not considered severe enough What happened next? What, if any, impact did the rejection have on the young p How do you feel about the CAMHS referral process? What, if anything, do you think could be improved? What do you think are the most important points for SAM

Topic Guide for Referrers

Introduction (10 mins)

- By moderator
 - Name, organisation, short intro to SAMH
 - Reminder that you are acting as a researcher today
- Explanation of purpose of session
 - To understand what happens when young people are referred to Child & Adolescent Mental Health Services but do not receive treatment / support from them
 - Collecting experiences of young people and their families for a report to Scottish Government.
 - Aiming to gather feedback on 350 cases where young people have been in this situation.
 - Our aim is to improve the experience of young people (and their families) who are referred to Child & Adolescent Mental Health Services
 - Important to understand the perspective of referrers (teachers & GPs)
- Introduction to the format of the session
 - 45-60 mins
 - Group discussion, rather than individual Q&A
 - Share experiences in confidence
 - No expectation of breaching patient-doctor confidentiality
- Explanation of research and group discussions
 - No right or wrong answers
 - Everyone's views are important, please don't be afraid to speak up
- Reassurance over confidentiality and MRS Code of Conduct
 - We will not disclose any of your details
 - We will anonymise all of our reports
 - We will only use the information you provide for the purpose of this research
- Explanation of recording audio recording to ensure we correctly capture
 the detail of what we are being told. This will be transcribed and analysed for
 use in our report.
- Individual introductions:
 - First name, school / GP practice, job role, length of time in job

Knowledge Of / Relationship with CAMHS (5 mins)

- How much do you know about Child & Adolescent Mental Health Services?
 How familiar are you with their services?
- How often do you tend to come into contact with them?
 - How often do you make referrals to CAMHS? When was the last time you made a referral?

Referrals (15 mins)

I'd like to spend most of the time we have talking about the referral process, and your role in it. It would be useful if you could think of the last referral you made, if you have made several recently.

- Can you give a brief outline of the situation?
- At what stage did you get involved?
- Who suggested a referral to CAMHS?
 - PROMPTS: young person, family member, GP, teacher, someone else
- Why was a referral to CAMHS suggested?
- What did you do next? What was your role?
- How long did it take to prepare and submit the referral?
- What information, if any, did you give to the parents / young person at this stage?
- What were your expectations of what would happen next?
- And what were the parent/young person's expectations?
- Would you say that this experience was typical or not typical of making a referral?

Assessments (15 mins)

- Was an assessment undertaken by CAMHS?
 - How long was the wait for an assessment?
- What information, if any, were you given during this time?
 - Did you pass this on to the young person?
- Did the young person/ parents ask for any support during this time?
- Was any action required whilst waiting for the assessment, such as chasing CAMHS?
- What impact, if any, did the waiting time have on the young person?
 - PROBE: emotional, behavioural, impact on condition, impact on family life etc
- Did you have any involvement / role during the assessment process?
- What information were you given during / after assessment?

- What was your role, if any, in communicating with the young person / family?
- Would you say that this experience was typical or not typical of CAMHS assessments?

Rejections (15 mins)

- How did you hear that the referral had been rejected by CAMHS?
 - Is this typical?
- Did you understand the reasons given?
- What happened next?
- Are other services usually recommended? By CAMHS? By you?
 - IF YES: which services?
- How much involvement did you then have with the young person / their family?
- What impact did rejection have on the young person?
- Would you say that this experience was typical or not typical of a referral being rejected?
- Is the CAMHS similar to the process for making referrals to other health areas?

Sum Up (5 mins)

- Overall, how do you feel about the CAMHS referral process?
- What do you think could be improved?
- What do you think are the most important points for SAMH to take to the Scottish Government about the CAMHS referral process?
- Any final comments?

Thank & Close

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