Rejected Referrals Child and Adolescent Mental Health Services (CAMHS)

A qualitative and quantitative audit

Summary Report | June 2018

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SAMH for Scotland's mental health
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BACKGROUND

In 2017, the Scottish Government published its Mental Health Strategy. This included a commitment to commission an audit of rejected referrals to Child and Adolescent Mental Health Services (CAMHS) and act on its findings. SAMH (Scottish Association for Mental Health) and Information Services Division (ISD) Scotland, of NHS National Services Scotland undertook this work to fulfil the first part of that commitment. The full report is available.

Across Scotland, referrals to Child and Adolescent Mental Health Services (CAMHS) have been increasing. In 2017, 33,309 referrals were received.[1] Since January 2015, when NHS Boards were able to submit complete data to ISD, there has been a 20% increase in referrals. Statistics published in June 2018 show that, for the quarter ending March 2018, one in five (20%) of all referrals to CAMHS were rejected[2]. For comparison, the most recent statistics for psychological therapies referrals show a rejected referral rate of 5.7%.[3]

A range of people and organisations have expressed concern about the number of rejected referrals to CAMHS, and what subsequently happens to the children and young people whose referral is not accepted.

Aims and objectives

This research explored the experiences of children, young people and their families who were referred to CAMHS but who did not subsequently receive their services. The research aimed to understand the reasons why referrals were rejected; the impact on children, young people and their families; what happens afterwards (in terms of signposting to other services or support); and outcomes for those whose referral was rejected. It also aimed to understand referrals to CAMHS services in terms of their volume, source and purpose; and to investigate whether particular groups are disproportionately affected.

1 ISD Scotland, Child and Adolescent Mental Health Services Waiting Times in NHS Scotland, March 2018

2 ISD Scotland, CAMHS in Scotland: Waiting Times, Service Demand and Workforce, June 2018

3 ISD Scotland, Psychological Therapies Waiting Times in NHSScotland, June 2018

Methodology

The research was divided into two elements: qualitative and quantitative. The qualitative component (led by SAMH) gathered the views and experiences of children, young people and their families who had experienced a rejected referral. It also sought the views of GPs and teachers (both primary and secondary) with experience of referring to CAMHS. A variety of methods were used, targeted at different types of participants, including online surveys, telephone interviews and four group discussions. The research took place over the period December 2017 – April 2018. A summary of the sample is given below.

TABLE 1

Methods used and sample in qualitative element

	Online Survey	Telephone Interview	Group discussion	Total
Young person	87	5	3	95
Parent / Carer	166	73	28	267
Sibling	0	1	0	1
GP	0	9	0	9
Teacher	24	0	0	24

Source: SAMH CAMHS Rejected Referrals Audit

The quantitative component (led by ISD) examined data relating to 285 children and young people whose referrals to CAMHS were rejected during February 2018. The data was provided by seven out of 14 geographic Health Boards in Scotland who participated in the audit – NHS Ayrshire and Arran, NHS Borders, NHS Dumfries and Galloway, NHS Fife, NHS Forth Valley, NHS Greater Glasgow and Clyde, and NHS Highland (described in this report as 'Audit Boards').

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

- Young people whose referral has been rejected often 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

Being referred

There was some commonality across the referral criteria used by the Audit Boards including: that children and young people should be between 0-16 years or up to 18 years if still in full time education; the referrer must have physically seen the child or young person before referring; the child or young person must be experiencing moderate to severe difficulties. Only one Audit Board listed reasons for inappropriate referrals to CAMHS. Both elements of the research found that the majority of referrals came from a GP. There was no evidence of any correlation between the source of a referral and its likelihood of being rejected.

There is substantial variation between the reasons for referral noted by Audit Boards and the reasons given by children, young people and their families. 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 Audit Boards. The Audit Boards were more likely to list behavioural problems, other reasons and anger issues as reasons for referral.

From the qualitative element it was clear that CAMHS is rarely the first port of call. In most cases, before referral to CAMHS is considered there has been an escalation of issues to a debilitating degree. 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.

Both the quantitative and qualitative data 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. Often families are unaware of the possibility that the referral will not be accepted. They report feeling angry, aggrieved, cheated and let down due to a feeling that no proper assessment process has been undertaken.

Being assessed

Most rejections are made on the basis of the written referral and in more than two-thirds of cases, no assessment meeting was held. 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. Young people find the assessment difficult and many leave feeling that they have not been properly listened to.

Statistical data is not available on how long children and young people wait for an assessment. The qualitative work identified that some waited months after their referral, while others were invited for an assessment relatively quickly. Most people reported receiving no or little support while waiting for assessment.

Being rejected

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 agree with the reasons for rejection, where any were provided. After rejection, some report paying for private help, some asked for another referral to be submitted and some did nothing.

The reasons for rejections were similar across both the qualitative and quantitative elements of the audit. Three out of five referrals (62%) were rejected as they were deemed unsuitable. 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 out with the NHS Board catchment area. Insufficient information was another common reason for rejecting the referral.

The Audit Boards reported that 66% of the 285 rejected referrals in February 2018 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% felt they had been signposted.

The qualitative research found that children, young people and their parents often did not feel well supported at the point of rejection. Any signposting to other sources of support was felt to be generic, not useful and not of high quality, and often pointed to avenues previously exhausted by the young people and their families. Parents and young people wanted better communication, a person centred approach, meaningful signposting and a better transitions process.

Referrers' views

Issues raised by GPs included a lack of clarity on CAMHS criteria, lack of time with the child, young person or parent to make the referral (standard 10 minute appointment) and the high number of rejections. GPs reported a feeling of being professionally disrespected when referrals are rejected, a sense that there is a lack of alternative services and a feeling that signposting is generic and unhelpful. 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. GPs suggested a number of improvements including provision of community and early intervention services, clearer guidelines on the referral and assessment process, more multidisciplinary referrals and mandatory and relevant signposting.

The main issues that teachers raised were waiting times, lack of support after a referral is rejected and lack of information, both during and after the referral has been rejected. They reported that receiving a rejection had a negative effect on the mental health of the young person concerned. Teachers suggested a number of improvements including better interagency working and communication, a standardised referral form with space for the views of the young person, parent and other agencies involved and improvements to other tiers of support.

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
- improving data collection.

This research has identified a strong indication of a gap in provision for children and young people whose needs to not fit the CAMHS Tier 3 and 4 eligibility criteria.

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

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