healthwatch
in Greater Manchester

CARE PATHWAY TO CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

"I'm currently fighting to get back in, fighting – Why do we have to fight?"

September 2024

Acknowledgements

We extend our thanks to all individuals who contributed to this project, and we have endeavoured to accurately represent the stories we have heard.

Overall, around 1200 people contributed to this project which includes parents/carers, children and young people and professionals who work in Greater Manchester, supporting families at each stage along the pathway.

We extend our sincere thanks to all who shared their stories with us. We hope we have lived up to our duty to share the highly emotive stories we have heard and to have represented voices as accurately as possible. This report contains mention of themes some may find distressing including self-harm and suicide. Staff and participants were offered ongoing support and directed to services for care as required.

Healthwatch Trafford led on the management of this project and other local Healthwatch across the borough contributed both by being part of the steering group and by gathering data for their respective areas. Where resources were stretched, there were occasions where data gathered was done by other Healthwatch teams and this is indicated as required through the report. Thanks to all local Healthwatch staff involved.

This report is being shared with the public as well as local and regional partners and healthcare providers. It is our expectation that recommendations made are seriously considered by commissioners and providers of health and care services across Greater Manchester and that feedback is received and acted upon.

Table of contents

Glossary of terms

Below we have listed some commonly used acronyms in this document and their meanings:

- A&E is Accident and Emergency
- ACE team is Autism, Communication, Education team
- ADOS is Autism Diagnosis Observation Schedule
- ADHD is Attention Deficit Hyperactivity Disorder
- ARFID is Avoidant Restrictive Food Intake Disorder
- ASD/C is Autism Spectrum Disorder Condition
- BAME is Black and Minority Ethnic
- CAMHS is Children and Adolescent Mental Health Services
- CBT is Cognitive Behavioural Therapy
- CMFT is Central Manchester University Hospitals NHS Foundation Trust
- CYP/YP is Children and Young People/Young People
- EHCP is Education, Health, and Care Plan
- ELSA is Emotional Literacy Support Assistant
- FASD is Foetal Alcohol Spectrum Disorder
- GM is Greater Manchester
- GMMH is Greater Manchester Mental Health
- GP is General Practitioner
- HV is Health Visitor
- HW is Healthwatch
- ICS is Integrated Care System
- LD is Learning Disability
- LGBTQIA+ is Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual plus
- MASH is Multi-Agency Safeguarding Hub
- MFT is Manchester Foundation Trust
- MH is Mental Health
- MHP is Mental Health Professional
- NHS is National Health Service
- OCD is obsessive compulsive disorder
- PALS is the Patient Advice and Liaison Service
- PCNHSFT is Pennine Care NHS Foundation Trust
- PCF is Parent Carer Forum
- PTSD is Post Traumatic Stress Disorder
- SENDCo is Special Educational Needs and Disabilities Coordinator
- SEND is Special Educational Needs and Disability
- SENDIAS/S is Special Educational Needs and Disability Information Advice Support Service
- SMS is Short Messaging Service, also known as a text
- SPD is Sensory Processing Disorder
- TAC is Team Around the Child

Executive Summary

In recent years, demand for mental health services for children and young people has increased significantly[1] causing unacceptable delays in access and severe challenges in communication across the care pathway. This is undoubtedly affecting the experiences and outcomes of families accessing or attempting to access, the pathway to CAMHS – with similarities made between current experience and a game of snakes and ladders[2].

Whilst referral pathways and CAMHS are, or have been, under review in most localities, issues persist. As such, this project was planned to establish whether the current mental health care journey is effective in identifying and helping children and young people to access timely and effective support, leading to positive outcomes for families and carers.

With joint efforts from Healthwatch across Greater Manchester, we have gathered experiences of the pathway to CAMHS from the perspectives of children and young people, parents/carers, and professionals. We have undertaken surveys, held focus groups and recorded testimonies, resulting in over 1200 responses.

Through this project we have heard of the challenges parents/carers had navigating the pathway: more than half found it 'very difficult' to find out how to get support, and in our survey the majority told us they were either 'dissatisfied' or 'very dissatisfied' with information provided to them about their child's available options. Through the case studies and focus groups parents told us how they found the pathway confusing and often felt they weren't listened to, acknowledged and/or believed. We also found many examples where parents acted as the driving force behind their child's access to care, and they told us of the extent and type of support available when navigating the pathway.

We also heard about the impact on whole families. Parents often felt overwhelmed by the process, and it impacted their own emotional health and wellbeing. Parents felt scrutinised, and it had, in some cases, affected their relationship with their child. Furthermore, many parents told us of the negative impact their experience had made on their work and financial circumstances.

Echoing findings from our 2019 report[3] on children's mental health services, lack of clarity and communication issues were highlighted by all groups of participants. High proportions of children and young people and parents/carers cited barriers such as being unsure who to contact and being worried about communication between staff; professionals were more likely to rate communication as 'somewhat effective' or 'not so effective' between professionals themselves, parents/carers, and children and young people. Communication concerns raised by parents referenced disjointed services, the importance of follow-up between professionals and families, a lack of adjustment made for children's needs, and feelings that decisions made by professionals about children and young people were done without full understanding of the child's condition.

Professionals raised concerns about a lack of follow-up both with themselves and directly with families as well as wider issues with the perception some families have of CAMHS. Similarly, many calls for improvements were made via the survey in relation to communication. These include requests for clarity on what the pathway should look like and what the CAMHS offer is, and more personalised communication as opposed to generic responses.

Parents/carers and children and young people shared the wait times they had experienced and the impact these had (coupled with a lack of communication and support), also similar to our 2019 report. The majority of responses revealed waits of over one year between referral and initial assessment, and almost half had waited over a year between assessment and intervention. During the wait, parents and carers reported that their child's condition progressed leading to negative experiences, and a lack of communication and support.

In response to our survey, the majority of parents/carers told us they had either accessed or considered accessing private care. Of those who did not go ahead with this, many told us this was either due to the financial impact or concerns about re-accessing the NHS pathway after the outcome of a private assessment.

From professionals we heard of challenges arising from referrals not being accepted, and the action they took in these instances. Most frequently, we were told professionals would pursue alternative support either within the existing setting, by looking elsewhere and/or less often, or through advice/signposting in

the rejection letter. Some comments indicated subsequent challenges such as lack of resources and availability. We also heard from many professionals who persist with accessing support for the child or young person via the pathway in ways such as challenging the decision and/or re-referring. Other feedback in relation to this includes the powerlessness and frustration professionals feel when referrals are rejected, difficulties managing families' expectations and concerns with accessibility.

In addition to the calls for improvement to communication mentioned above, professionals made many more suggestions which cover an array of aspects of the Pathway to CAMHS. These include calls to reduce wait times and to ensure communication and support during the wait is effective for families, comments relating to simplifying and speeding up the referral process and calls for thresholds to be standardised, more clearly communicated and to be opened up for increased access. Further suggestions were made for clarification of, and additional funding, for alternatives to CAMHS, more recruitment and training for staff, and ideas for increasing accessibility.

This report outlines what we did, including the methods used to capture data, then presents the findings as a collective picture of the whole Greater Manchester region. We have also made a number of recommendations based on our findings. At the end of the report are borough profiles which show a breakdown of the data gathered for each borough. Please note that we have not looked at the inpatient care provided by the Greater Manchester Mental Health Trust known as Tier 4 provision, out of area placements or Social Services provision for children in crisis.

Key Findings

➢ The main barriers to accessing services cited by both parents/carers and children and young people were **waiting times**, **uncertainty around who to contact**, **appointment times/availability** and **concerns around communication between staff**.

➢ Most parents, carers, children, and young people told us it **was difficult to find out how to get support** and they were **dissatisfied with information provided** about the available options for support.

➢ The **parental role is pivotal** in getting a child access to care. Many parents we heard from were the driving force behind ensuring progress along the pathway.

➢ Accessing the CAMHS care pathway can have an **overwhelming impact on the wider family's emotional health and wellbeing** and can also negatively impact their **work and financial circumstances**.

➢ 95% of parents/carers were **not kept up to date** with the progress of their referral.

➢ We were told **services were disjointed** which resulted in contradictory, out-of-date information being shared, missing or incorrect information being passed between professionals and parents having to repeatedly share their story.

➢ Large proportions of families **waited over 1 year** between assessment and intervention, and **lack of communication and support** during the waiting period had significant impacts such as deteriorating health and missed schooling.

➢ Almost 80% of parent/carers told us they either accessed or considered accessing **private care**.

➢ Over two thirds of **professionals** told us their overall experience of the pathway was **poor**.

➢ **Professionals call for improvements** in an array of areas including communication, wait times, the referral process and more.

Recommendations

Improve awareness of mental health support services available to enable all stakeholders to make informed choices about where and how to access help and support

 - ➢ Providing clear information about what support services are available (including CAMHS), what they do, what the thresholds are, and who they are appropriate for will ensure families are directed to the most suitable services in the first place. This will help to reduce challenges in accessing the pathway and in turn lead to fewer inappropriate referrals, which can result in unnecessary demand on some services.
 - ➢ Each Greater Manchester borough should make available a list of provision in their area. This local directory should also include details of self-help materials and support groups as well as information about the option to obtain a private assessment.
 - ➢ A commitment to continued support by professionals for children and young people and parents/carers if a referral is rejected.

Provide clear information for families and other professionals on what the CAMHS Pathway is and what can be expected

 - ➢ The majority of both parents/carers and children and young people told us it was difficult to find out how to get support, and over half of children and young people told us they didn't understand what to expect at each stage of the pathway. Having easily accessible information available to both families and professionals will help to manage the expectations families have around what will happen. This in turn should ease families' experiences and ensure staff working at various stages along the pathway can devote time and resources more effectively.
 - ➢ Information should include how complaints/queries should be handled.

Action needed to ensure equal access to the care pathway

 - ➢ Our findings suggest both families and professionals are concerned about the accessibility of the pathway. As well meeting young people's accessibility needs, parental needs should be considered as we have identified the huge part the parental role plays in navigating care. More flexibility and adjustments should be considered in terms of the

environment in which referral appointments take place and the times available. Care should be taken to ensure information and communications are accessible for families with additional needs.

Create a Single Point of Entry for Greater Manchester

➢ Having a Single Point of Access for children and young people, parents/carers and professionals, agreed by all providers, would help to resolve many of the issues reported; families not knowing where to go for support, services having been found to be disjointed, families having to repeat their story numerous times, issues with missing or inaccurate information being passed between services and issues with contacting CAMHS. A specification should be co-produced for this service to ensure the needs of all stakeholders are met.

Improve communication and support during the waiting period

➢ The majority of parents told us they weren't kept up to date with the progress of the referral and lacked support with their child's health during the waiting period.

➢ Communication was cited by parents/carers as being key to their ongoing understanding of the process. Good communication reduces frustration and allows for more informed choices (for example, if the likely wait time was felt to be too long). It also reduces the likelihood of parents/carers feeling overwhelmed.

Treat parent/carers as equal partners in their child's access to the Pathway

➢ We heard from many parent/carers who felt they had not been listened to or believed and had been ignored. We also heard how many felt they were not involved in decisions made about their child's care. Addressing this and involving families in the care for a child or young person can have a positive impact on outcomes and in turn, ease the process for many families.

Project background

The Healthwatch in Greater Manchester partnership began this project after hearing (through local intelligence and external research) that demand for children and young people's mental health services had increased and that as a result, long waiting times for appointments and interventions were having an impact on the mental health and wellbeing of young people.

Overall, performance in Greater Manchester is in decline. From the data we have access to, we know that national targets are not being met. In GM, that target is to see a national median of 5125 children and young people per month[4].

We know that the Integrated Care Board, the 10 borough partners in Greater Manchester, and NHS and voluntary sector providers have all looked at children's mental health at some point in recent years and whilst there have been some improvements, these are insufficient to effect the significant change required.

Commissioned community services treated over 420,000 children and young people in 2020/21. Treating nearly 40% of children and young people with a diagnosable mental health condition, means the NHS over-achieved on the Five Year Forward View commitment of 35%.[5]

Lord Darzi recently published independent investigation of the NHS in England which states that the nation's mental health has deteriorated most significantly in children and adolescents, over the past decade. Mental health referral rates for this group have "increased by 11.7 per cent a year from around 40,000 a month in 2016 to almost 120,000 a month in 2024"[6].

The Children's Commissioner report 'The State of Children's Mental Health Services'[7] found that between 2018/19 and 2021/22 there was an 84% increase in referrals to children and young people's mental health services. It also found that 75% of young people experiencing mental health problems waited so long that their condition worsened or were unable to access any treatment at all; in 2021-22 one in three children referred were turned away by specialist services. The CQC 2020/21 State of Care report[8] found that mental health services for young people have struggled to meet demand since COVID. There was mixed communication between services and families, with many unaware of what help was available.

They also raised the risks of online support, such as missing physical cues and possible risks within the home.

In March 2024, the Children's Commissioner published findings[9] sourced from NHS England that showed there were still 270,000 children and young people waiting for support following a referral to CAMHS with nearly 40,000 waiting over two years. It was also found that while 32% of those referred received support, 39% had their referral closed before accessing support. This is an increase from findings published by the Education Policy Institute in 2019[10], which found that 26% of referrals to specialist CAMHS were rejected as they did not meet thresholds. A study from early 2022 analysing the experiences of young people on mental health service waiting lists[11] found that there were many consequences to long wait times: *"delays in treatment were found to exacerbate existing mental and physical health symptoms and attempts to cope with these long waits ranged from adaptive to maladaptive strategies. Seeking out alternative forms of intervention was also reported, and young adults might opt for medication, private or university services to get support quicker and help sustain them while waiting for psychological therapies."*

Further detail is found in the National Children's Bureau's 2022 report 'Storing Up Trouble'[12], which found significant variation in the thresholds applied to referrals. More than 80 per cent of Directors of Children's Services surveyed as part of the inquiry said that there were variations in thresholds for accessing early help.

In the process of conducting the project we have been made aware that more evidence has been reported, both by commissioned organisations[13] and via mainstream media[14], further justifying the need for our research.

This project follows on from a 2019 Healthwatch report looking at experiences of CAMHS in Trafford, Bury, Rochdale and Oldham. While there were compliments relating to individual staff members, there was overwhelming concern about access, the difficulty of getting a referral, and thresholds being too high for acceptance. People were unable to reach CAMHS or, if they did, get answers to questions between consultations. Readers will see that similar concerns continue to this day.

What we did

Methodology

We used a mixed-methods approach for this project. The aim of the quantitative method used (surveys) was to enable a large population of Greater Manchester residents to provide feedback on their experiences and for us to draw trends from this. Qualitative methods (focus groups, case studies and interviews) allowed us to gain a deeper understanding of the real-life experiences of families and professionals. The combination of these two approaches enabled us to triangulate the data and present a comprehensive reflection of experiences and impressions of the pathways to CAMHS.

Sections below outline methods used, how these were implemented, inclusion criteria, how participants were recruited, and the process of analysis we followed.

Surveys

In February 2024, we launched three different surveys each aimed at capturing experiences of children and young people, parents and carers and professionals. Inclusion criteria included:

- consent provided from children and young people, parents and carers, and professionals to take part
- participants who lived or worked in the Greater Manchester area
- participants who accessed the pathway within the past 2 years (for parents/carers and children and young people)
- participants having worked in relation to the pathway within the past 2 years (for professionals)
- aged 13 and above (for children and young people)[i]

In order to provide the widest possible opportunity for people to take part, the surveys were shared in the following ways:

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[i] The lower age limit was decided following consultation with the Information Commissioners Office (ICO) due to this being the age from which individuals can provide their own consent for their personal data to be shared.

- via contact lists of key professional contacts both at regional and borough levels
- the social media pages of local Healthwatch across GM
- promoted locally to key stakeholders at meetings, events and more.
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Healthwatch Wigan and Leigh ran their own project on access to CAMHS which meant they conducted their own survey for the area. As such, findings from their survey are presented separately but are referred to throughout the analysis, given the similarity in the questions asked.[ii]

Data gathered from the surveys helped to inform the next stages of the project as key issues such as waiting times and communication were established, and therefore follow-up questions were formulated to provide depth.

Focus Groups and Case Studies

Parent/carer focus groups and case studies were held by local Healthwatch teams across Greater Manchester[iii]. Participants were recruited via both an opt-in selection within the surveys, and through local advertising. Documents were created to standardise the data capture process, however, there was flexibility within this to enhance the accessibility for the greatest number of participants. Groups were held in person, online, and through conversations with individuals over the phone or face-to-face.

Interviews

We held one-to-one interviews with professionals in job roles linked to the pathway or directly part of the pathway itself. Inclusion criteria included:

- consent provided to take part
- professionals who had worked in a role which has involved supporting children and young people
- had worked in the above role within the past 2 years

[ii] A small number (3) of respondents to the survey we ran were Wigan and Leigh residents and these are included in the overall Greater Manchester data we present.
[iii] No focus group or case study data was collected from Wigan and Leigh.

- had worked within the Greater Manchester region

To recruit participants, we mainly used purposive sampling. This involved inviting a cross-section of survey respondents who had volunteered to take part. This purposive sampling included using data we had on job titles and the boroughs that individuals worked in to invite an even cross-section of people. In total, we invited 41 of 68 volunteers to interview, four of whom accepted, and an additional volunteer was recruited directly through their local Healthwatch.

Sampling

The self-selective sampling nature of all elements of the research we have carried out means that participation was limited to those who volunteered to take part. We acknowledge that this could have resulted in more extreme experiences shared with us compared to others who may not have chosen to participate. That said, we have attempted to ensure that the data we have gathered is presented accurately and would assert that it is necessary to bring to light all cases – particularly those of an acutely negative nature - in order to make recommendations for improving services for all.

The CAMHS Care Pathway

What is a referral pathway?

A referral pathway is the journey undertaken by an individual and/or their carer when accessing support. This involves identifying the needs of the individual then ensuring they have access to the most appropriate sources of help and advice.

What is CAMHS?

Child and Adolescent Mental Health Services (CAMHS) are specialist NHS services that help children and young people up to the age of 18. They offer assessment, diagnosis, treatment, and support for young people who are experiencing problems with their emotions, behaviour, or mental health.

The range of issues that CAMHS can help with includes sadness low mood or depression, anxiety or worry, low self-esteem or confidence, problems with eating, relationships, anger management, trouble sleeping, repeating the same actions or behaviours, hearing voices, or seeing things, and suicidal thoughts or feelings.

How are services delivered in Greater Manchester?

Mental health services for children and young people in Greater Manchester are delivered in line with the THRIVE framework (i-THRIVE refers to the implementation of the THRIVE framework principles.). Children and young people can and do enter the care pathway via different routes and at different stages of their condition.

> *"The THRIVE Framework is an integrated, person centred and needs led approach to delivering mental health services for children, young people and families which conceptualises need in five categories; Thriving, Getting Advice and Signposting, Getting Help, Getting More Help and Getting Risk Support. Emphasis is placed on the promotion of mental health and wellbeing, and for children, young people and their families to be empowered to be actively involved in decisions about their care through shared decision making."* [15]

Those who need advice and signposting

Those who need focused goals-based input

Getting Advice

Getting Help

Thriving
Those whose current need is support to maintain mental wellbeing through effective prevention and promotion strategies

Getting Risk Support

Getting More Help

Those who have not benefitted from or are unable to use help, but are of such a risk that they are still in contact with services

Those who need more extensive and specialised goals-based help

"All Child and Adolescent Mental Health Services (CAMHS) in Greater Manchester are now using the I-Thrive Model to navigate Children, Young People and their Carers to the most appropriate mental health or wellbeing services."
–CMFT CAMHS SERVICE: GUIDANCE AND REFERRAL FORM VG April 21[16]

How should pathways work?

Pathways are multi-agency and generally follow a prescribed sequence of events. Once concerns are raised about a child's mental health, each local area will have a procedure to follow which usually results in a decision being made about whether a referral to CAMHS is appropriate. Referrals may come from health and care professionals such as GPs, health visitors, youth or social workers, or via school/education, and in some areas, self-referrals are accepted.
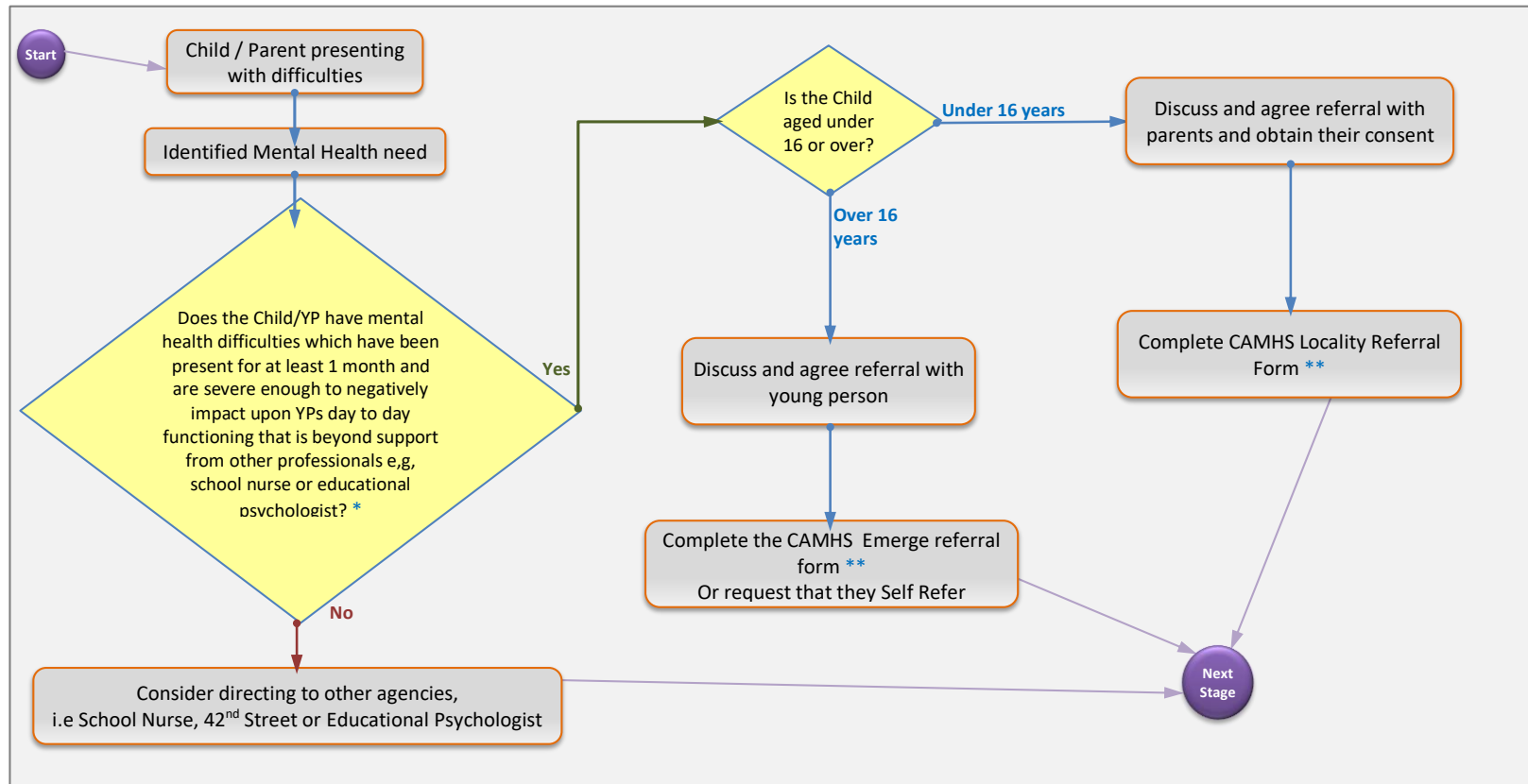
It may be that other options are explored while waiting for a CAMHS referral to be processed, or as an alternative source of support. The resources available in Greater Manchester are detailed later in this section and range from self–help digital resources to voluntary sector organisations, to paying a private provider.

Whilst the precise pathways may differ between boroughs and providers, the overarching principles and approach will be largely the same. The example given in the following graphic is from MFT by way of illustration:

Central Manchester University Hospitals NHS
NHS Foundation Trust

Routine Referral Flowchart for Specialist Mental Health Interventions   (CAMHS)   **Royal Manchester Children's Hospital**

Start

Child / Parent presenting with difficulties

Identified Mental Health need

Does the Child/YP have mental health difficulties which have been present for at least 1 month and are severe enough to negatively impact upon YPs day to day functioning that is beyond support from other professionals e,g, school nurse or educational psychologist? *

Is the Child aged under 16 or over?

Under 16 years

Over 16 years

Yes

No

Discuss and agree referral with parents and obtain their consent

Complete CAMHS Locality Referral Form **

Discuss and agree referral with young person

Complete the CAMHS Emerge referral form **
Or request that they Self Refer

Consider directing to other agencies,
i.e School Nurse, 42nd Street or Educational Psychologist

Next Stage

Notes: * Please also see emergency access pathway via Duty CAMHS Practitioner if any urgent concerns
         Safeguarding concerns direct to Social Services.
       ** Referral forms can be downloaded from : http://www.cmft.nhs.uk/childrens-hospitals/our-services/child-and-adolescent-mental-health-services

(CMFT CAMHS SERVICE: GUIDANCE AND REFERRAL FORM VG April 21)[3]

Available Resources and Support in Greater Manchester

Commissioned Services:

- The ICB commission Kooth[iv] and the SilverCloud platform[v] on behalf of the 10 Boroughs in Greater Manchester. Digital services offer key advantages including anonymity, variety of support, low or no waiting times and easy accessibility, including out of hours support[17].
- The ICB also commissions 42nd Street[18] within Greater Manchester, which provides tailored support for young people aged 13-25 (including face to face support where appropriate).

In person help and support:

- Primary Care - some GPs provide support and/or make referrals to NHS or voluntary sector services commissioned by the ICB.
- Schools, some of which provide direct support or through their teachers, Special Educational Needs Coordinators (SENCo), Educational Psychologists and other professional staff who either support or refer for additional help.
- Some individual boroughs, including Children's Commissioning groups (NHS/Local Authority) choose to invest in some counselling services in the voluntary sector in their locality.
- Public Health directorates (based in local authorities) identify needs, provide guidance and in many cases also commission health visitors and school nurses.
- Community health services, including doctors, psychologists, nurses and allied professionals

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[iv] Online mental health support for young people: https://www.kooth.com/

[v] Online mental health support for adults which offers programmes for parents supporting their child through mental health difficulties: https://gm.silvercloudhealth.com/onboard/greatermanchester/

- Child and Adolescent Mental Health Services provided by either Manchester University NHS Foundation Trust, Pennine Care NHS Foundation Trust, and Greater Manchester Mental Health NHS Foundation Trust.

Additional providers:

- Private providers - clinics who charge for their services (for example assessment of conditions such as ADHD and Autism).
- Local voluntary sector organisations.
- National charities.
- Digital resources: These platforms are very broad and cover different areas, but findings show that most young people are not aware of all the support that is available and would like to know more. [17]

Provider case study: 42nd street

In addition to the increase in demand for services there have also been challenges with funding that have affected the ability to meet demand. For example, 42nd Street experienced an incremental increase in need from young people dating back to before the pandemic, particularly with young people who feel able to access with the service as a result of experiencing complex psychosocial issues, discrimination, structural inequity and trauma. Although the charity was able to offer high quality comprehensive support throughout the pandemic, they experienced a sharp increase in referrals following the pandemic – tripling in some areas. The charity received some additional non-recurrent NHS investment for two years, but this was not enough to meet demand or address the surge and backlog of young people waiting. The charity has now secured more short-term funding from a variety of resources which is being used to target support to some of the most vulnerable and disadvantaged young people adversely impacted by increased thresholds and gaps in mainstream services.

Overall findings for Greater Manchester

This section presents findings based on the data gathered from across the Greater Manchester region.

Who we heard from

Parents and carers

90% respondents described themselves as White – British, 1% as White – Irish, and 1% as White – other. A further 1% told us they were Asian or Asian British – Pakistani, and 0.3% as Asian or Asian British – Chinese. 1% respondents told us they were mixed race.
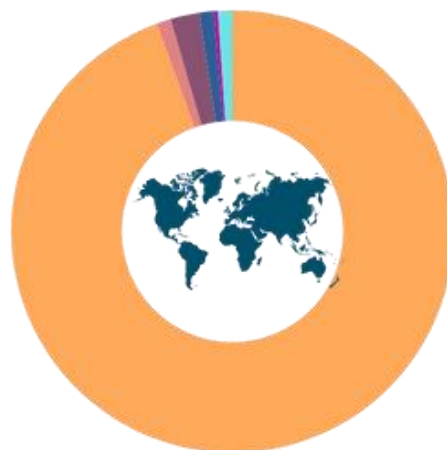
2% of respondents were aged 66-79
31% were aged 45-65
51% were 35-44
13% were 18-34

88% of people who took part identified as straight/heterosexual
1% identified as lesbian
3% as bisexual, and
1% as other
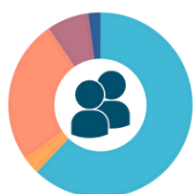
59% people told us they were married or in a civil partnership. 3% were cohabiting, 24% were single, and 7% were divorced or widowed. 2% chose 'other'.

Most respondents identified as female (95%).
2% as male, and 1% identified as non-binary,

13% people told us they could not work due to a disability or ill health, and 1% were seeking employment. 11% were unemployed and not seeking work. 66% respondents were employed, 2% students, and 2% were retired.
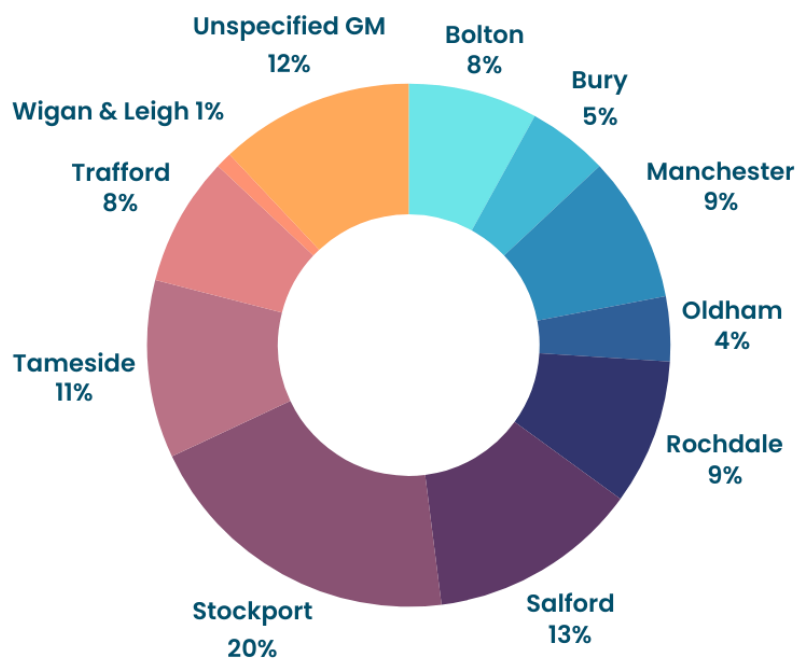
28% parents who responded considered themselves to have a disability, and 66% did not. 6% preferred not to say.
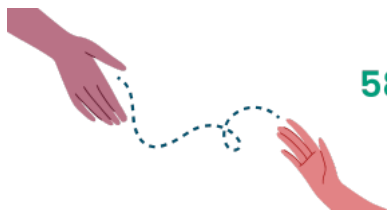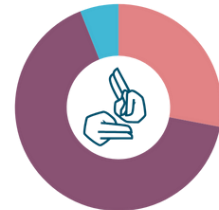
58% of respondents described themselves as carers.

Professionals

When asked where they worked, the professionals who took part in our survey responded as follows:

- Unspecified GM 12%
- Bolton 8%
- Bury 5%
- Manchester 9%
- Oldham 4%
- Rochdale 9%
- Salford 13%
- Stockport 20%
- Tameside 11%
- Trafford 8%
- Wigan & Leigh 1%

86% professionals had worked in Greater Manchester for over two years. **7%** within 12 months and two years, **5%** between six months and a year, and **2%** for less than six months.

Responses came from people across the professional spectrum and different fields of expertise. We heard from people including family/community workers (14%), SENCos (14%), mental health workers (10%), social workers (8%), GPs (6%), school nurses (4%), teachers (3%), head and assistant headteachers (3%), nurses (3%), safeguarding leads (3%) and youth workers (2%).

We asked people to tell us what age groups they worked with, and to tick all that applied. Most respondents (73%) had worked with Key Stage 2 (KS2) children, aged 8 to 11 years. 69% had worked with KS3 (12–16-year-olds), and 65% with KS1 (5–7-year-olds). 54% had worked with 0–4-year-old children, and 59% with 17 to 18-year-olds. Only 32% worked with those 19 to 25 years, and 14% answered 'unspecified'.

0–4 (Early Years)

5–7 (KS1)

8–11 (KS2)

12–16 (KS3)

17–18

19–25

? Unspecified
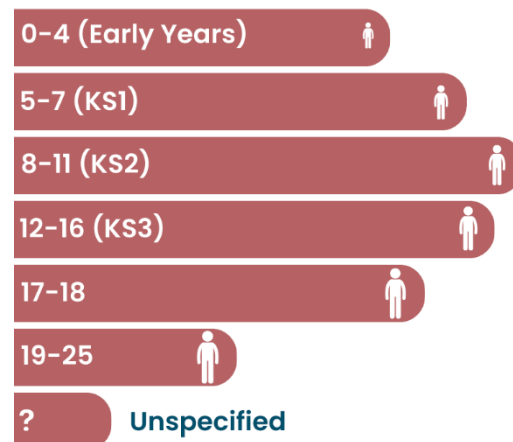
Children and young people

From our children and young people's survey: **13.8%** told us they were employed, **6.2%** were unemployed due to disability or ill health, **9.2%** were seeking employment, and **64.6%** were students.
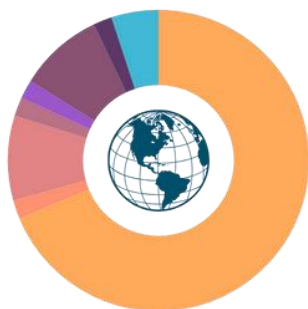
79% of respondents identified their ethnicity as White British, Irish, or White other. 2% told us they were Black Caribbean. 2% said they were Indian, 9% Pakistani, and 2% said they were Asian or Asian British other.

24.6% respondents identified as male, **67.7%** identified a female, and **3.1%** as non-binary.

60% of people said they were heterosexual/straight, 2% said they were gay, 3% told us they were lesbian, and 24% responded that they were bisexual.

37.3% children and young people told us they were disabled, and **17.6%** said they were carers.

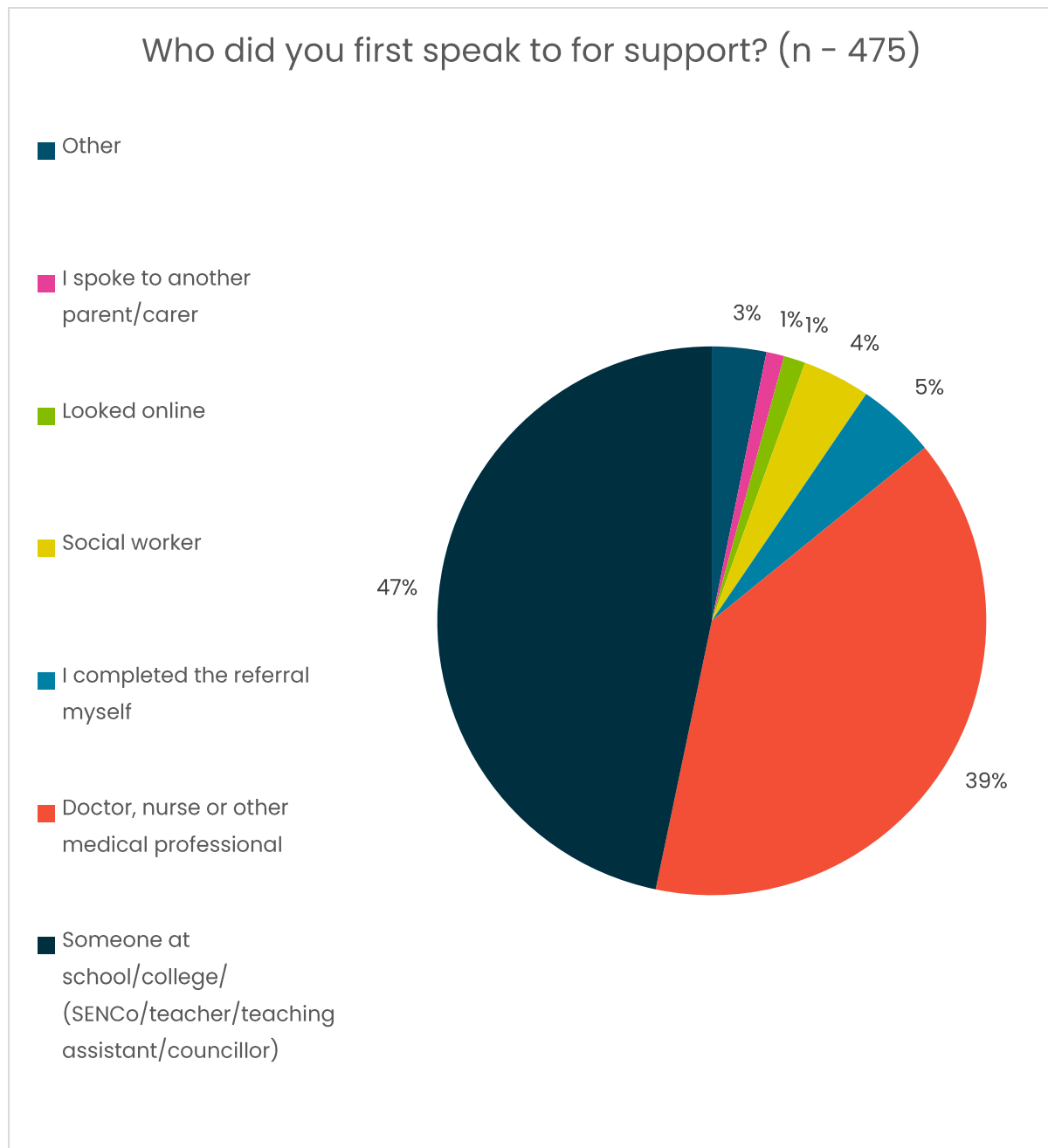## What we heard from parents/carers and children and young people

Given the interconnectivity of the experiences of parents/carers and children and young people as well as the similarities in what we heard, we have presented the findings together. We first outline the conditions we were told children were diagnosed with or were on the pathway to be assessed for, then we show the services families accessed for support. We then show themes identified around navigating the pathway, the impact on family, wait times, communication and accessing private care. We indicate within each section, where the perspectives presented are those of parents/carers or children and young people.

Conditions we were told about

Below is a word cloud of the conditions children and young people were being assessed for or had been diagnosed with. These were reported within both the parents/carers and children and young people's survey, and the larger the words appear, the more often they were mentioned. As illustrated, we heard mostly about experiences in relation to autism, anxiety, depression, and ADHD.

Services Accessed

Who did you first speak to for support? (n – 475)

Legend:
- Other
- I spoke to another parent/carer
- Looked online
- Social worker
- I completed the referral myself
- Doctor, nurse or other medical professional
- Someone at school/college/ (SENCo/teacher/teaching assistant/councillor)

Pie chart values:
- 47% (Someone at school/college)
- 39% (Doctor, nurse or other medical professional)
- 5% (I completed the referral myself)
- 4% (Social worker)
- 1% (Looked online)
- 1% (I spoke to another parent/carer)
- 3% (Other)

We can see that school/college and doctors were mostly likely to be the first port of call for parents looking for support for their child/children. Although this reflects the CAMHS pathways across the region, many parents and carers told us of experiences where they had been signposted between services and couldn't understand why. For example, after difficulties finding support through their child's school, one case study participant from Bolton told us they visited their GP but were redirected back to school:

"I couldn't understand why a medical doctor couldn't help my child with a medical condition."
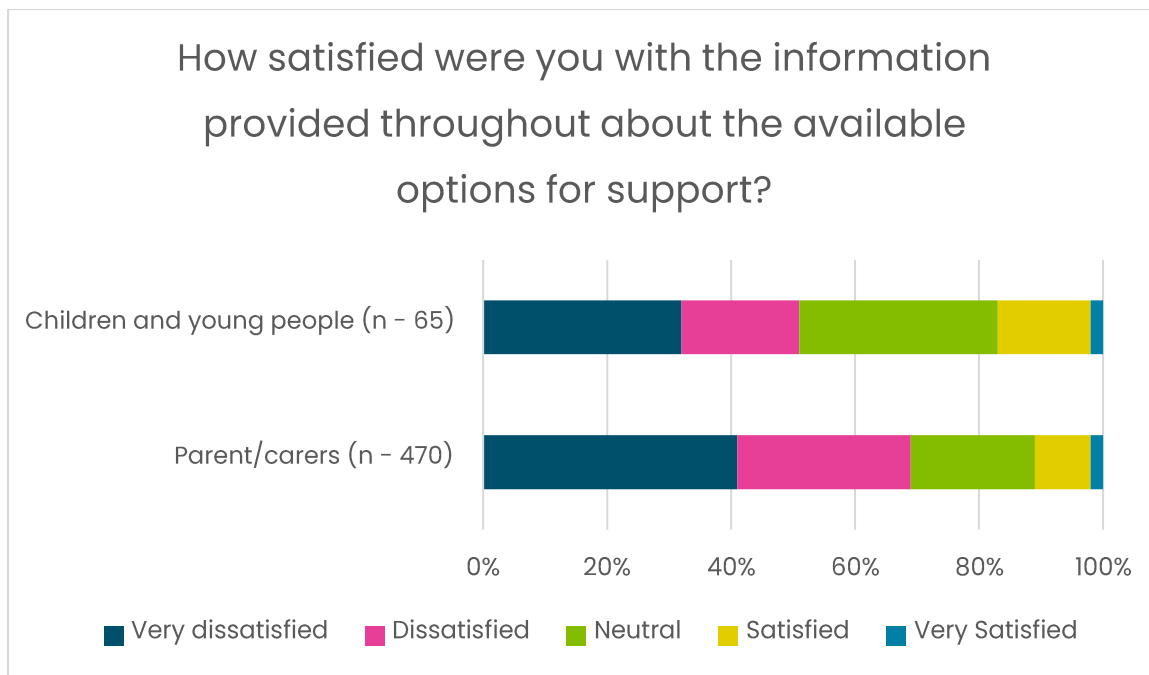
Navigating the pathway

From the survey, almost 40 percent of parents/carers and over 40 percent of children and young people selected 'unsure who to contact' as a barrier to them accessing the Pathway to CAMHS. For Wigan, 30 percent of parent/carers selected this option.

Finding out how to get support was:
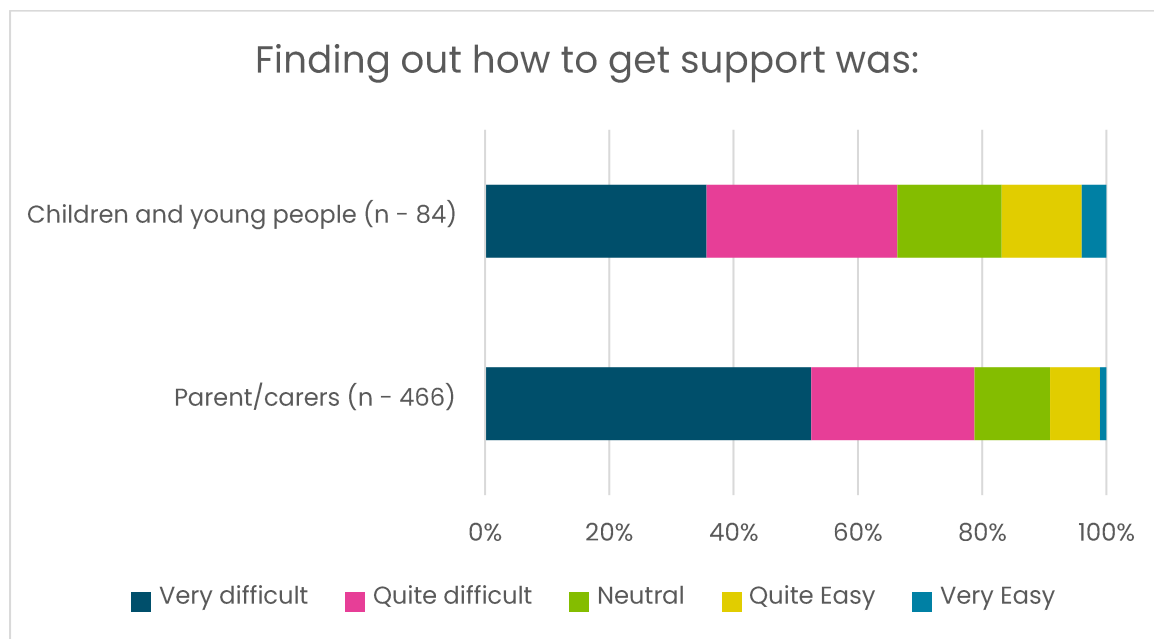
In Wigan, responses to this were mixed with only 18% finding it 'very difficult' to get support and a further 13% finding it 'quite difficult'.

The majority of both parents/carers and children and young people surveyed told us they found it to be either 'very difficult' or 'quite difficult' to find out how to get support. Initially finding out how to get support was found to be easier for children and young people.

How satisfied were you with the information provided throughout about the available options for support?

Responses to this question in the Wigan survey were mixed with 24% feeling 'dissatisfied' and 22% 'very dissatisfied'.

Over half of children and young people and over two thirds of parent/carers told us they were either 'dissatisfied' or 'very dissatisfied' with the information provided about the available options for support.

Difficulties navigating the pathway were highlighted by our case study and focus group participants. People told us where the pathway was confusing to parents, the extent to which parents felt listened to, acknowledged and believed when accessing the pathway, examples of parents as the driving force behind their child's access to care and the extent and nature of support parents were able to access to navigate the pathway.

Pathway Confusion

Many parents told us it was difficult to understand how to initially access the pathway to CAMHS. A Bolton parent reflecting on their overall experience told us *"[they] did not understand the process."* Following the referral of their child, a further parent said there was *"no explanation as to what would happen next."* HW Bury found the parent in their case study was confused by the referral process, and per the Bolton focus group:

28

"You don't hear anything, you don't know who you're speaking to, you don't know what the assessment stages are, you don't know what support is available"

Parents in the Stockport focus group expressed confusion over who could initiate referrals (e.g., whether schools or GPs could refer directly to specialist services), what the steps were, and what criteria needed to be met. Concerningly, HW Stockport also found parents were worried about inequality in the system. Some families seemed to get faster or better services based on how they navigated the system or due to geographical differences.

We heard from many parents who felt professionals didn't sufficiently explain process to them in an accessible way. Families felt abandoned navigating the complex referral and diagnosis process:

"We did not receive any information at all. A very sketchy overview was provided by the school SENCO but this was not clear" (HW Stockport)

"You are told you will hear from us, but you are not told what the process is." (HW Salford)

"There is a complete lack of 'what happens next' or 'what happens if'"

"Didn't understand anything. No help or where to get support" (HW Tameside)

Within the HW Bury focus group parents called for the referral process to be streamlined by removing unnecessary bureaucratic steps to make the experience easier for parents:

"I think understanding the pathway and what it looks like as some form of a timeline visual would be helpful for parents."

There was confusion around what support children were or were not eligible for while they were on the pathway. In reference to Safezone, one Rochdale parent said:

"Whilst we were waiting on our first assessment from CAMHS was told we could not attend this although we were on a waiting list. I am not sure this info from CAMHS was correct?"

Conversely, there were some occasions where parents were able to understand the process. The focus group held in Oldham found that out of five participants, four understood the initial process and in the Tameside focus group one parent told us they understood the entire process. The parent in the Tameside case study told us their school SENCO did explain the process to them, and in Trafford one parent said their GP did the same and that practice reception staff were helpful.

Parents not listened to, ignored, and not believed

Many parents had a keen sense that they were not listened to or believed, or were even ignores when seeking support. In Rochdale, we heard that while parents were involved in decisions concerning their son, they felt failed when people didn't listen or follow through. Parents in the same focus group felt ignored by Health Visiting services:

"Raised numerous early concerns which were all ignored."

"Been raising with our HV since grandson was 2 – we knew there was something not right and we felt he didn't get a proper 2-3 [year-old] assessment."

From the Bolton case study:

"Whenever I raised concerns with the school or our GP, I do not feel I was listened to"

And in the Salford focus group:

"I was fed up with everybody I spoke to, and they just didn't believe me"

"Parents feel gaslit or blamed for reaching out for help."

In the Stockport focus group, parents reported that health professionals sometimes lacked empathy and did not take the time to understand the child's individual needs or the family's concerns. They felt dismissed by health and care

professionals when they attempted to voice concerns or offer input into the treatment process. This dismissal was particularly disheartening when parents felt that they had important insights into their child's condition that were being overlooked.

One parent in Bury called for parents to be listened to sooner in the process, and in Stockport the focus group suggested the use of technology such as portals, apps, or SMS updates which could provide easier access to information and direct lines of communication.

Despite the challenges outlined above, some described instances where they had a breakthrough. For example, after changing GPs the family from the Rochdale case study said:

> *"Upon our initial booking in and first visit [the GP] went through our whole history and listened, responded and reassured us he was going to help. He also put actions in place and we feel finally getting somewhere."*

Similarly, the family from the Bolton case study identified that despite the terrifying ordeal of the child's first panic attack, the parent felt there was a positive outcome:

> *"The Doctor [in A and E] restored my faith in what I had known all along and that I wasn't making things up."*

Parents as the driving force behind their child's access to care

We have identified that parents often play a pivotal role in access to the pathway and subsequent support. Through parents' accounts of their experiences, it was evident that often they themselves had instigated a large proportion of any access to the pathway their children had. This was summed up by the parent who took part in the Trafford case study:

> *"I feel like the driving force behind identifying what may/may not be the issue and finding out about what's available. There seems to be nobody taking a holistic view of my daughter's mental health... I have to make things happen, but I don't know if I am making the right things happen."*

Similarly, within the Stockport and Tameside focus groups parents sometimes found that they needed to fight assertively for necessary support.

In some cases, parents were advised to start observing and managing their child's behaviour at home or in school. This often involved monitoring the child's behaviour and providing feedback to health and care providers but without much guidance on specific strategies or support mechanisms. A parent from the Salford focus group expressed that they felt they could do a better job themselves of looking after their child's mental health:

> *"If we hadn't been there as parents to support him, he wouldn't be where he is today."*

The parent who took part in the Salford case study told us about how they pushed for treatment when their child's mental health deteriorated and led to suicidal thoughts and self-harm: A self-referral to CAMHS was initially rejected as the impression was that the child's anxiety was caused by their autism (which had already been diagnosed). The parent challenged this, citing that their child had always been autistic but hadn't always been suicidal. With support from the GP and school an additional referral was accepted. Without the parent pushing for action, the child was at risk of not receiving any of the care they needed.

In discussing the behavioural difficulties their child had been having at school, one parent in the Oldham focus group told us of the benefit they had found accessing a self-help course, which had helped them to manage their child's behaviour and recognise triggers at home. They felt there were potential benefits for primary school teachers if they were to do the same, and that this could prevent children from repeatedly being sent home from school. They said:

> *"I feel I am being failed by the services and a good job I am now on top of things"*

One Rochdale parent went as far as re-writing a list of local, regional, and national services provided by a GP as it originally contained out of date and inaccurate information. The parent then sent the new version of the document to Children's Services in the hope that it would be of use to other parents.

However, sometimes professionals did act to progress a child's access to care:

> *"Private Nursery school asked the Health Visitor to attend a joint meeting with my daughter and I, which was enlightening and helpful, yet worrying"*

In Oldham, a parent attended a 6-week course on ADHD to help identify their child's triggers and manage their behaviour. In this case it is not clear how the parent accessed the course, but it is not the only instance of people seeking information elsewhere. In Stockport, many parents resorted to educating themselves through research, contacting advocacy groups, or relying on advice from other parents in similar situations due to a lack of information about the pathway. They called for educational programmes to help parents understand mental health conditions, treatments, and how to navigate the health system, empowering them to better support their children during the waiting period.

Parents across the boroughs highlighted difficulties finding information:

> *"There needs to be a point of access for parents and families in situations like ours where we do not know where to turn."*

> *"there is so much to navigate and in the absence of securing an accurate diagnosis you are a little overwhelmed by it all. There is no offer of support or direction in the initial stages, and this would be helpful to support behaviour management etc."*

> "[I looked on the] *internet – No advice really offered by anyone else."*

> *"constant 'googling'"*

Parents had to repeatedly make contact with services to get an update, including one parent from Bolton who repeatedly raised concerns with their child's school over the course of six years. Many parents referred to their experience as a fight:

> *"We have fought to be able to get on the pathway to CAMHS and hit nothing but barriers."* (Rochdale case study)

> *"Cannot get our foot through the door, fighting a losing battle for referral"* (Rochdale focus group)

> *"Had to fight pretty hard against the school and CAMHS to get finally referred, to get in."* and *"I'm currently fighting to get back in, fighting - Why do we have to fight?"* (Salford focus group)

When parents are forced to seek information elsewhere due to an absence in support from professional services, the risk is that the parents are accessing inaccurate information or guidance. This in turn can risk the child and family's wellbeing. Parents should be involved in a structured and supported way – to ensure parents have their say, contribute to decisions and are able to support their child at home in guided, well-informed ways (see 'Impact on the family' p.38)

Parental involvement in decision making

We asked the focus groups to comment on the extent to which they felt involved in decisions made about their child. We were told:

Oldham:

> *"We didn't feel like we were involved in decisions as they decided what support was needed – which during the interim was none"*

> "Regarding the school I am not involved in really any decisions"

> *"Once he was diagnosed with ADHD myself and my child were involved with the decisions around his medication but on the managing emotions and emotional regulation work, they decided not to put him in the group though I said he would be fine in that setting."*

> *"On reflection I think I was involved in most of the decisions"*

Stockport:

> Parents felt excluded from decision-making, often having to contend with decisions imposed on them.

> The system's complexity and the variability in procedures between different areas or services added to the confusion. Parents often encounter inconsistent

information when dealing with different professionals or when moving between services.

There was a strong desire among parents for more control over the treatment options and pathways chosen for their children. Parents wanted to ensure that the decisions made were in the best interests of their children, reflecting both medical needs and the family's unique circumstances.

"We have been very involved in the decisions made and have instigated all of them"

Rochdale:

"Professionals have tried telling me what is best for my child – I know what is best and they need to understand I know my child and their needs."

"One point I'd like to make is these decisions are being made for and around our children, yet why are they not more involved in the process? The professionals don't really communicate directly to them!"

Trafford:

"I am now satisfied with the involvement in making decisions about my child as the teacher was able to listen and respect [my input]*"*

Manchester:

"As soon as I said my daughter was adopted, she said that post adoption support would be best to provide support and said she would close the referral. It felt like such a snap-decision. No speaking with a colleague or manager.

Just that's it. No one spoke with or saw my daughter as we were not offered any type of assessment. I didn't feel able to challenge the decision, in fact, I think I was in shock. My daughter continues to struggle with her mental health (she is in Year 10 now and self-harms regularly)"

Tameside:

"I was blocked from being involved. I had to do everything."

Support for parents navigating the pathway

Underpinning what we have identified about the role parents play in accessing CAMHS support for their children is a sense that often they navigate the process devoid of support. From the Oldham case study we heard:

"Whilst I have family to help, I also require support."

Those who took part in the Tameside case study shared that they themselves are neuro-divergent:

"We also need extra support in this process"

With reference to the lack of interim support for their child, one Salford focus group parent said:

"She had these outbursts. And again, I just didn't know what to do with these outbursts. You don't know what to do. You don't know if you're causing more harm, I don't know, by saying the wrong thing. I just don't know."

Some highlighted positive examples of where they had found support. For instance, parents often spoke of the benefit in speaking to other families in similar situations. This support was often found in informal settings or specific parent support groups. One parent told us of the positive experience they'd had through accessing Point (a parental support charity based in Oldham):

"They were brilliant, offering practical help getting assessed and diagnosing ADHD. This answered lots of questions and allowed access to funding for 1:1 support at school and other services."

A Rochdale parent felt similarly, but with a caveat:

"The team [at Home Start] *have been most helpful but not easy information to find and no one has ever said to us 'do you know about Home Start in Rochdale?'"*

In Stockport, it was noted that written or online resources did not replace the need for direct, professional intervention and that although support groups and workshops were useful, they were not widely available to all.

In light of the difficulties they had found, parents gave direct suggestions as to what support they feel would be helpful. In Bolton, one parent simply commented on the benefit of receiving some support would be better than none at all.

An Oldham focus group parent said:

"For me personally as a parent I would like a drop-in support session or someone I could telephone when struggling, for advice/reassurance"

Similarly, the Stockport focus group found many parents felt that having a dedicated point of contact within the health services—such as a case manager or care coordinator—would improve communication. This person could help navigate the system by explaining the process, answering questions, and relaying information. It was also highlighted that parents require both emotional and practical support in order for them to support their child effectively.

Navigating the Pathway: Summary

Through our analysis, we have identified a number of key challenges. **Confusion in regard to accessing the pathway** is characterised by a **lack of understanding** of the process overall, difficulties understanding how/where a referral is initiated, a lack of understanding for which services children and young people may or may not be eligible to access and an absence of professionals sufficiently explain the process. Much of what we have identified here is echoed in other reports[13] and highlights the need for clear information to be provided about support services available.

Despite some instances of a breakthrough, we also heard of **parents not being listened to, ignored, and not believed**. What we heard highlights the impact interactions between professionals and families can have on the overall experience. Hayes, Fleming and Wolpert[19] identify the potential to improve young people's levels of satisfaction with mental health services by "treating [families] as equal partners."

The **ways in which parents educate themselves vary**, as is the reason why they accessed such education/training (whether that be something they decided to

do themselves or whether it had been advised by professionals). This means there is **no guarantee that parents are accessing materials or courses appropriate to their family's needs** and the quality or accuracy of the information sourced. Whilst Mertan et al.[20] identified that a considerable proportion of information shared on the forum they researched, corresponded with verified guidelines, they highlight the need to ensure that accurate mental health information is accessible to families.

From the above findings, there is a strong sense that the outcome of the access a child or young person gets to the pathway is dependent upon the role the parent plays. This puts **huge pressure on parents** who may already be in difficult circumstances given worries around the health and development of their child and indicates a potential health inequality. External research[21] echoes

> *the importance of the role of adults within adolescent help seeking* [and suggests that] *developing ways to make CAMHS more accessible to young people could facilitate more independent help seeking... particularly for those who feel they do not have an adult to confide in.*

We have also found that many of the challenges faced related to issues relating to **communication**. These, among other communication concerns are discussed in a specific section below.

Impact on the family

We found clear evidence to suggest that families' experiences with the Pathway to CAMHS often had an impact on wider aspects of their lives, including their emotional health and wellbeing as well as work and finances. We also heard of parents feeling scrutinised throughout the process and the impact their experiences were having on their relationship with their child.

Overwhelming experiences

Many parents felt overwhelmed in the process of supporting their child to access support for their mental health, and some parents noted that the situation had led to marital strain and increased familial tensions.

In their case study, HW Stockport found that this led to significant emotional distress for the child and their family, leaving the parent feeling overwhelmed and unsupported and HW Salford found parents were feeling isolated, coping with outbursts and not sure if they were doing the right thing:

> *"It's hard to put into words because it's like a time that I just want to forget"*

> *"It's just this whole nightmare – but where the hell do I go? I need some support with this. My child has pretty high levels of suicide ideation, she's basically refusing to go to school, and all we're told is well she has to go to school otherwise you'll go to jail."*

> *"It's been this nightmare, absolutely fighting. You become hyper-vigilant, looking after this life, well 2 lives coz you've got to look after yourself too so that you can look after them."*

Another family first tried to access support for their child when they were in year 5, and he will be nearly in year 9 by the time he gets seen:

> *"it's too long to be dealing with [the child's] outbursts alone all this time"*

In Oldham, a parent spoke of their difficulty coping whilst waiting for their child to be assessed, compounded by being a single parent with other children. HW Stockport were told:

> *"You cannot manage your CYP or family life during this time"*

The word cloud below shows the emotions which came up in the case studies and focus groups:

burnt-out isolated helpless frustrating fatigue lonely confused disempowered traumatic ill-equipped distraught despair stressful overwhelmed

Parents' own mental health was impacted as a result of their experience of the Pathway to CAMHS. HW Stockport found that parents who have been battling the

system for some time have a form of PTSD, and professionals working in this field need to be more aware of how to identify this and support parents.

> *"I ended up on antidepressants to help me cope"* (Oldham focus group)

> *"You're trying to look after yourself so you can look after them and then there's nothing, and your own GP is like, well, it's not your health, so we can't really do anything for you. Then when your health does suffer, they say well you just need to be less stressed."* (HW Salford focus group)

Many parent/carers felt their parenting was under scrutiny. In both HW Tameside and Stockport found that where parents were initially offered parenting courses this could be frustrating as it implied issues were parental rather than child based. We heard:

> *"Everyone kept saying that it was my parenting. I kept being told to do courses"* (HW Tameside focus group)

> *"I have questioned myself as a parent, had sleepless nights, thinking I did something wrong… – Parent blame is huge!"* (HW Bolton case study)

HW Trafford heard that the experience the parent had led to confusion about their relationship with their child and HW Stockport found through their focus group that the stress of managing the child's needs without adequate support puts a strain on family relationships.

Impact on parents' work and financial circumstances

Many parents and carers told us that their work and/or finances had been impacted. For example, HW Rochdale found in their case study that both parents had lost numerous working days:

> *"This has had a huge impact on our [family's] mental health and financial status."*

Similarly, HW Bolton heard through their case study that one parent had to leave work to provide care, which has had financial and mental repercussions.

The HW Salford focus group heard of a parent who had given up their job to look after their child and another whose employer discussed the possibility of them

losing their job due to absences supporting their child during a two-year wait for treatment.

> *"I can't be reliable to hold down a job"* (Oldham focus group)

We also heard from families who had struggled to encourage their child to attend school resulting in fines and in Tameside, even leading to prosecution against the parent; absences are said to be a direct result of their child's condition, which was not being recognised:

> *Education always requesting that child/young person attend school. This is NOT possible at times. There needs to be something in place that highlights on an attendance register the reason why your child is not in school.* (Rochdale focus group)

> *My son's school attendance has significantly dropped over the last 6 months, and we have received minimal support.* (HW Stockport)

> "she's basically refusing to go to school, and all we're told is well she has to go to school otherwise you'll go to jail." (HW Salford)

Almost 20 percent of parents/carers named needing time off for appointments and time away from work as a barrier to them accessing the pathway for their child; a parent in Salford was unable to get time off work to reach support sessions.

Impact on the Family: Summary

The experiences captured document the many and varied ways in which supporting a child or young person can have a **negative impact on the health and wellbeing of the whole family unit**. Where families shared **overwhelming experiences** with us, it is evident that the understandably distressing experience of having a child who is unwell is exasperated by a lack of support and communication whilst on the pathway to care, which we know can involve long waiting times for many families. Identifying similar challenges for families, Kruger[22] makes recommendations which could combat these effects. These include calling for both parent/carers and children and young people to be more

supported whilst on the waiting list "through the delivery of support groups, self-help material, and detailed information on the assessment journey."

There is evidence of clear **negative economic impact** on both the family and the workplace, with parents citing working days lost and having to leave work altogether to support their child. This relates fittingly to findings we mention (see 'Lack of adjustments' page 45) in relation to lack of flexibility with appointment times and settings. As well as within our own recommendations, suggestions have been made elsewhere for CAMHS to consider options for more flexible appointments in order to address missed appointments[23].

Communication

Issues around communication both before accessing the pathway and at all different points along the pathway were prominent in our research. This wasn't just between professionals and families but also between professionals in different organisations.

With regards to barriers accessing the pathway, 17 percent of parent/carers and almost 30 percent of children and young people selected 'worried about communication between staff'. For Wigan 19 percent of parent/carers selected this option.

Almost 77 percent of parents/carers told us they were not kept up to date with the progress of their referral and a further 18 percent told us they were only kept partially up to date. In Wigan however, the picture was more positive with 45 percent of parent/carers reporting that they were kept fully up to date.

This section discusses our findings in relation to communication which is not directly related to waiting times. We have found this theme to be closely linked to concerns relating to waiting times and therefore have decided to include both in the following section.

Disjointed services

Many parents gave feedback in relation to a lack of cohesion between services which impacted on how well their child's care was handled. This resulted in out-

of-date and/or contradictory information being shared, missing or incorrect information being passed between professionals about a child's health and parents having to repeatedly share their child's story.

As outlined in a section above, one parent told us they had gone to the lengths of re-writing a list of local, regional, and national services provided to them by a GP as it had out of date and inaccurate information. From the HW Stockport focus group we heard there were mixed messages from GPs and schools, with poor inter-communication. Also, outdated and inaccessible information was shared and one parent reported that they had sent an email as instructed to do so but as this was the wrong place it resulted in a delay for their child accessing care.

Similarly:

> *"services do not seem to have a joined-up approach, nor liaise with each other. It is frustrating having to repeat my son's story over and over"*

> *"I feel I am forever going round and round with services, it is a never ending frustration. The disconnection is ridiculous…"* (HW Rochdale)

> *"Loads of teams they are not joined up. They don't know who is doing what when."*

> *"Seen by loads of different professionals who just saw him separately. Nothing was joined up."* (HW Tameside)

> *"There is an army of people involved but none of it is joined up"* (HW Trafford)

> *"I have no idea of what communication takes place. SENCO meetings with school, CAMHS do not attend, not sure if CAMHS get copy. They have not explained."* (HW Bury)

For the family in the HW Bolton case study, a panel of doctors discharged the child for whom it became apparent that the school had not sent the correct paperwork in relation to potential ADHD and in Tameside we heard of untrue or inaccurate statements being written in reports.

In light of their experiences, focus group participants in the HW Stockport focus group called for improvements which would ensure they would only need to tell their story once and all who needed access to it would be able to do so as and when needed. Similarly, several parents suggested that case managers or care coordinators who actively oversee and facilitate the referral process.

> *"to contact CAMHS - we now have to go through the Parent Carer Forum. They are an obstruction, and I don't want to tell a 3rd party details of our lives. The PCF are not independent, and they always choose to support the NHS or the Local Authority over parents and children. We are in a mess and nobody to support us. We are constantly signposted to the Local Offer - which is the PCF, so nothing is accessible to us"*

The significance of follow-up

We heard a lot of feedback which highlighted the importance families placed on follow-up from professionals, both in relation to communication and follow-through on actions as promised. An example of this can be found below where a parent was promised to be contact about one-to-one intervention for their child, but this hasn't happened after waiting over 2 years. They also heard:

> *"Beginning ADHD assessment and ASD referral, offer of emotional regulation work with my son, but this never came to fruition"*

From the HW Trafford case study, there was a telephone triage assessment from CAMHS the day after the referral was made and a further follow up call however, the parents says through this *"it became clear that no real support was on offer."*

HW Bury heard from a parent who has *not heard back from CAHMS and feels 'confused' by the referral process*:

> *"Unsure what has happened with the CAHMS referral for ADHD, it's just fizzled out"*

Recommendations made through the Bury case study include for CAMHS to communicate with both the parent and child directly, soon after the referral is made.

Through the Manchester case study, we heard that after making an urgent CAMHS referral, the GP rang the parents the following day to check in, which was welcomed by the family.

Lack of adjustments to meeting the needs of children/young people and parents/carers

Via the survey 14% of all parents/care respondents selected *Lack of reasonable adjustments* as a barrier to accessing or considering accessing support. Through the survey, we heard:

> *"Sadly no understanding of Asperger Syndrome and how to interact with my son."*

> *"Complete lack of understanding autism"*

Concerns around a lack of adjustments was also highlighted through the case studies and focus groups with issues including inappropriate interventions, a lack of understanding and/or failures to adapt communication to the needs of the child. HW Tameside heard via their case study that many assessments were done with their child via Zoom which was unsuitable for them and HW Salford heard from more than one a family who was provided no interim support whilst waiting for interventions but were advised to go to A&E if the child had suicidal thoughts. This was inappropriate in these cases due to high levels of anxiety. Similarly, HW Bolton heard from a family who *were given inappropriate suggestions such as encouraging a child who refused to leave the house to go to a drop-in session.*

Other parents told us:

> *"Son was referred here* [HAF provision via #Thrive/Your Trust] *but absolutely not the right provision for his needs."* (HW Rochdale)

> *"One point I'd like to make is these decisions are being made for and around our children, yet why are they not more involved in the process? The professionals don't really communicate directly to them!"*

"The first appointment was with myself and my child – I don't feel this was fair, they shouldn't have to sit there and listen to you talk about them. They have selective mutism which means they don't speak it doesn't mean they can't hear!" (HW Stockport)

A parent in the Oldham focus group mentioned an instance where it was identified that due to the child's needs, a one-to-one type of intervention would be more appropriate than the group sessions initially offered. They said:

"they would be in contact and start that soon and this never ended up happening, again, I chased it up on several occasions over the course of 2.5 years."

HW Stockport heard through their case study that During the assessment, [the child] faced a distressing fire alarm incident, and the evaluators failed to recognise his anxiety, reflecting their lack of experience with complex cases. This situation ended up causing mistrust between [the child and parent].

With a view to ensuring communication is more accessible, they heard calls for information to be provided in multiple formats (e.g., written, digital, visual) [to] help accommodate different learning styles and preferences.

Decisions made cold

Many parents felt decisions about their child's care were made by professionals who didn't fully understand their child's condition. This includes frustration with decisions being made by professionals who had never met the child and where parents felt their accounts of their child's condition wasn't considered. HW Stockport found many parents expressed frustration over not being sufficiently included in decisions about their child's care. They often felt that decisions were made by professionals without adequate consultation or consideration of the family's insights and preferences.

We heard:

"..after [S]'s initial assessment for CAMHS, we got a call saying a panel of Doctors – whom had never met my son - had [discharged] him [because]

his school had not sent the correct paperwork for an ADHD diagnosis. I put in a formal complaint about this as I felt it unfair people who had never met my son could make a decision like that." (HW Bolton)

"At least see or speak to us before you decide we don't need help" (HW Oldham)

"Professionals have tried telling me what is best for my child – I know what is best and they need to understand I know my child and their needs" (HW Rochdale)

"We are just a name and a number in the system – they don't care." (HW Salford)

Communication: Summary

We have heard from families who are concerned on accessing the pathway about **communication between professionals from different services**. We have been able to identify the effects on families given the perception of services being disjointed. For the parents we heard from, this has resulted in out-of-date and/or contradictory information being shared, missing or incorrect information being passed between professionals and parents repeatedly sharing their child's story. Findings from the 2019[3] report found similar sentiment such as **communication with families not being clear enough** and families finding it **hard to contact CAMHS** and get answers to questions they had. Our more recent findings suggest, where parents reported examples of where they had experienced **good communication**, this was often in relation to **interactions with specific individual professionals**.

The importance of **follow up from professionals** was identified by parents/carers as being key to their ongoing understanding of the process. This also applies to children and young people; Hayes, Fleming and Wolpert[19] highlight the potential of "providing a consistent lead professional" in having a positive impact on young people's satisfaction with mental health services.

Lack of adjustments were also highlighted as a key area in which some parents felt the system failed to meet the needs of their child. This in turn meant **a lack of confidence** that their child's needs had been fully understood and that any subsequent course of treatment (or referral rejection) would be appropriate for and in the best interests of their child. This extends to the **decision-making process**, where some parents felt decisions were made about their child by people that had never met them. As the assessment process should be **fair and equitable** it is essential that all possible reasonable adjustments are made, without compromising the ability to make an accurate assessment.

In terms of the established referral pathway, this highlights the gaps in consistency of approach between both individual professionals and services. For communication between all parties, the accuracy of information given and the frequency in which it is done, should be increased and entrenched within the process.

Wait Times

As touched on in previous sections, our findings reflect ongoing concerns around wait times. Of the barriers listed in the survey, this was the most common cited by both parents/carers (83%) and children and young people (67%). The charts below show the lengths of time parents/carers told us their child had waited. As these show, almost 60 percent of parents/carers told us they waited over a year between their child receiving a referral and getting an initial assessment and over 40 percent of parents/carers waited over a year following the initial assessment for their child to receive some form of intervention.

Waiting times between referral and initial assessment (n - 244)

- Longer than 1 year
- Between 4 months and 1 year
- Less than 4 months

17%
25%
58%
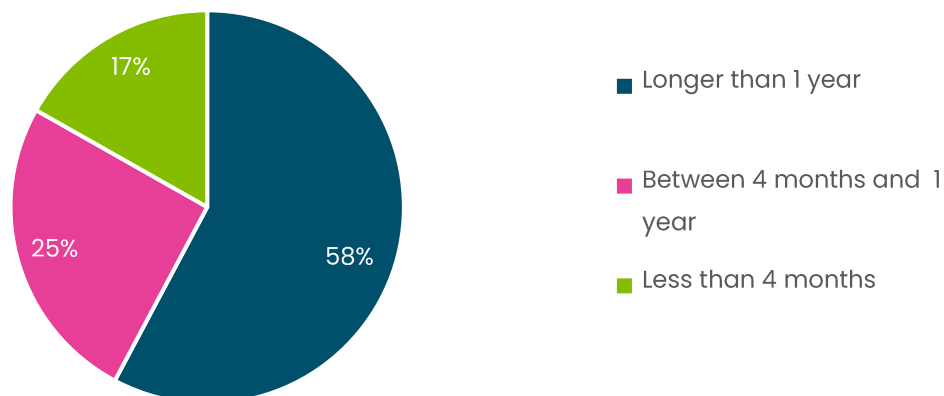
Waiting times between initial assessment and intervention (n - 214)

- Longer than 1 year
- Between 1 month and 6 months
- Between 6 months and 1 year
- Less than 1 month

6%
24%
44%
26%
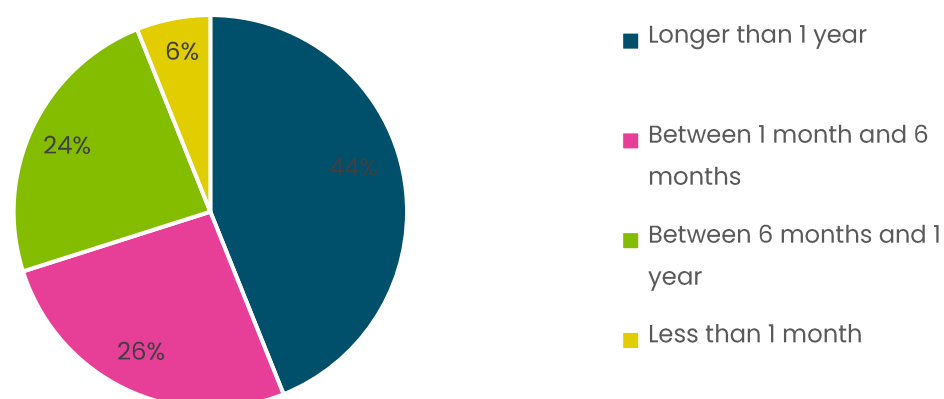
Through the survey we heard:

"I was told that the waiting list for my child was so long that they would be classed as an adult by the time it would be their turn. They were too young to be seen by adult services so we could not access any help other than me paying privately."

"We are still awaiting a full ADHD assessment which will take approximately 2 years before he's assessed. Which is appalling to say the least!!"

"Long waiting times. No communication. Inaccurate timescales given. No follow up. No consistency of worker. No interest in how we are coping or how child is doing. No insight into masking. Terrible"

On analysing the focus group and case study we heard in regard to wait times, we identified feedback in relation to how long parents told us they were waiting, their experiences of their child's condition during the wait and what we were told about support and communication during the waiting period.

The effect of wait times

Through the focus groups and case studies, many parents shared with us how their child's condition progressed during the wait time and how these further impacted aspects of the children's lives such as their education. HW Stockport found through their focus group that the lack of timely and effective communication delayed the start or adjustment of treatment plans, potentially worsening the child's condition. Parents expressed concerns that these delays and the associated lack of coordination among care providers could lead to suboptimal care outcomes. Also, wait times for assessments such as those for autism could be excessively long (up to 5 years), significantly affected the quality of life and support for families. We also heard:

"I first got referred to CAMHS and had a traumatic wait for a month to be seen. I had to ensure she didn't have access to sharp implements, however, she broke a mirror to harm herself."

"and in the time it took for him to be assessed, diagnosed and begin medication and applying for EHCP he was expelled from school because of his behaviour relating to his LD"

"I had to chase up his ADHD assessment for over a year with no updates unless I constantly left messages and in that time, he was expelled from mainstream school for behaviours related to ADHD" (HW Oldham)

"Whilst on waiting list for CAMHS assessment my son had suicidal thoughts and tried to commit suicide" (HW Rochdale)

"My concern is my daughter has lost her golden treatment time with professional therapist to learn how to tackle with her learning and social weakness." (HW Trafford)

Lack of communication and support during the wait

Further impacting on the challenges of waiting for assessments and interventions, families shared experiences of challenges with communication and a lack of support specifically during the wait time. From the survey, we found the majority of parents/carers (71%) received no advice or support during the waiting time. The chart below shows the responses we had to a question asked within the children and young people's survey.

To what extent did you understand what to expect at each stage of the process (n - 62)

- 13% I fully understood
- 40% I partially understood
- 47% I didn't understand
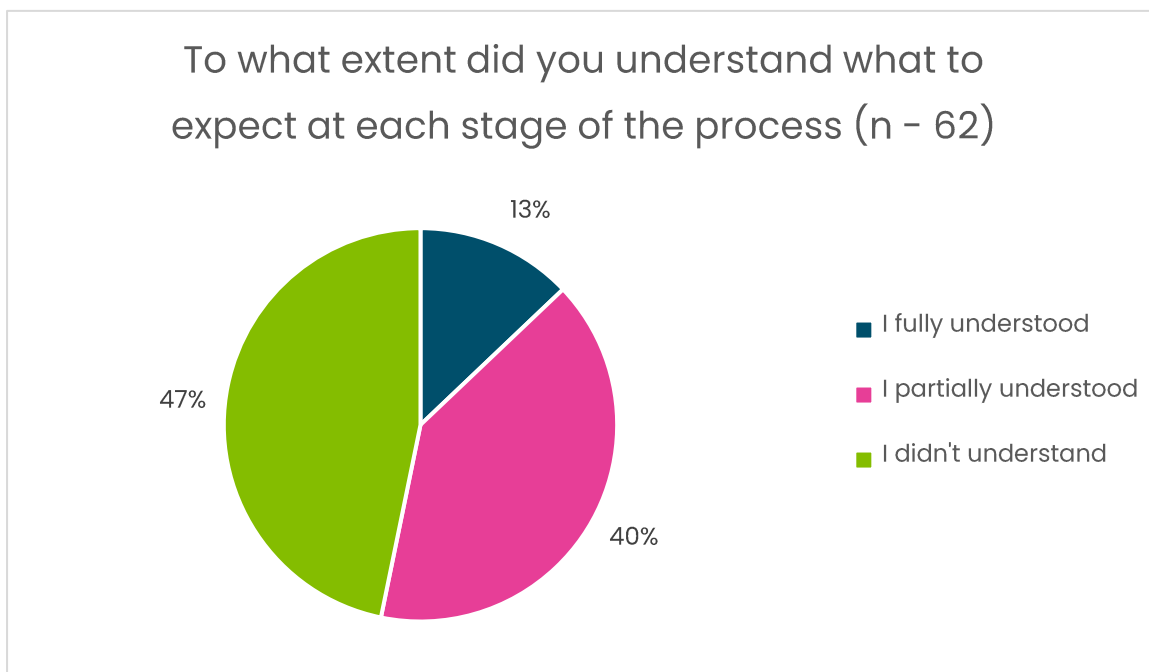
Respondents also commented:

"No one spoke to me really they talked at my mum. My mum kept saying he is there you can ask HIM There doesn't seem to be a box to say how bad I found the CAMHS service and how they totally did not help me."

"There hasn't been a process. No one has seen/spoken to parent or child, still waiting assessment after 4yrs and only receive curtesy letter every few months."

"It's difficult to say. They didn't listen to me or help in a positive way"

Experiences shared through the focus groups and case studies also help us to understand challenges faced during the wait. Many parents told us they were not made aware of the length of wait times and didn't receive interim support. HW Stockport found interim support was often characterised by minimal communication from health services. Parents expressed frustration over not having regular updates about their status in the system or what to expect next, which compounded their feelings of uncertainty and neglect. We also heard:

"I was never told of the waiting times"

"mixed messages about wait times. Told we'd hear back next month then you hear nothing so you call them and they so oh no, now it will be the month after" (HW Bolton)

"Didn't get any interim support other than what school provided. I rang CAMHS but the only information that I was given was still on the waiting list. Not told how long the waiting list is."

"There is no interim support that I know of." (HW Tameside)

"Really poor communication it was all one way. There was no effort or attempt made by the service to keep us updated, or even check in with how the YP was doing, which was bad given how long he had been on the waiting list to commence therapy"

"Leaving people in limbo on a never-ending waiting list with no advice, tips or updates is really poor and should not be how any service operates let alone one dealing with people who are vulnerable and mentally unwell"

"It would be helpful if after the person is placed on the waiting list, there is a system to initiate contact regularly with the patient/family and keep them updated, at one point we wondered if we have been removed from the list" (HW Oldham)

I'm on the waiting list and then that's it. it's silent. Nothing, absolutely nothing apart from being treated, I feel as though at school he's being treated like a naughty boy and because of the things he's getting distracted. So, you know, he's constantly being thrown out of lessons, but it's going to impact on his academic ability.

"we're on the waiting list - been on the waiting list since October 22 and the problem is you don't get any support from anywhere." (HW Salford)

"CAMHS is not able/won't tell parents how long they will need to wait for services."

"They won't refer you to another service whilst you are waiting" (HW Stockport)

"It has not been easy to navigate local help and support in the 'while you are waiting' period. I was told that we can't access anything else if waiting for the CAMHS assessment and further referral, but what do we do in the many, many long weeks that takes? What do we do and say to the services whose waiting lists we have been on for months who then say 'you are almost at the top of the list' and we have to say – sorry we are waiting for CAMHS and can't do anything else – it is so frustrating and a system that is broken..." (HW Rochdale)

One parent from Manchester commented on how "fortunate" they were to have accessed some support during their 9 months wait for intervention following and initial assessment. They said:

"While we were waiting for contact after the initial referral, my daughter was receiving CBT-style intervention from the school social worker and art therapy via the adoption support fund."

Wait times: summary

We have identified how large proportions of the families we have heard from had **long wait time**s whilst on the Pathway to CAMHS (similar findings are reflected in our 2019 report[3]). We have heard of subsequent impacts these wait times can have, including how their **child's condition progressed** during their wait and how **negative experiences of this were exacerbated** through a lack of communication and support.

In addition to the distressing waiting experiences families shared with us, external research suggests **mental health conditions in children and young people deteriorate when untreated for long periods**[24], which can increase their risk of **secondary challenges** later in life. The World Health Organisation[25] state:

The consequences of failing to address adolescent mental health conditions extend to adulthood, impairing both physical and mental health and limiting opportunities to lead fulfilling lives as adults.

Research also shows that 50% of mental illness starts before the age of 15 and that rises to 75% by the age of 18[26]. This illustrates the potential **long-lasting impact** that delays, long waiting times and conditions remaining untreated can have on an individual.

Lengthy waiting times cause a clear **blockage** in the pathway to specialist mental health support. **Improved contingency pathways** in the event of long waiting times could be better explored within the current pathway. In addition to the experiences of parents/carers, we also heard from professionals (p. 58) about the level of support they provide to families during this period and this varied, further highlighting a **need for consistency of approach** in order for the journey along the pathway to be equitable at all stages.

Private Care and Assessments

Our survey found most parents either accessed, or considered accessing, private care for their child whilst waiting for care via the Pathway to CAMHS.

Proportion of parents who accessed or considered accessing private care (n - 344)

21%

57%

22%

- Yes, I considered it but did not go ahead
- Yes, I paid privately for my child to access care
- No
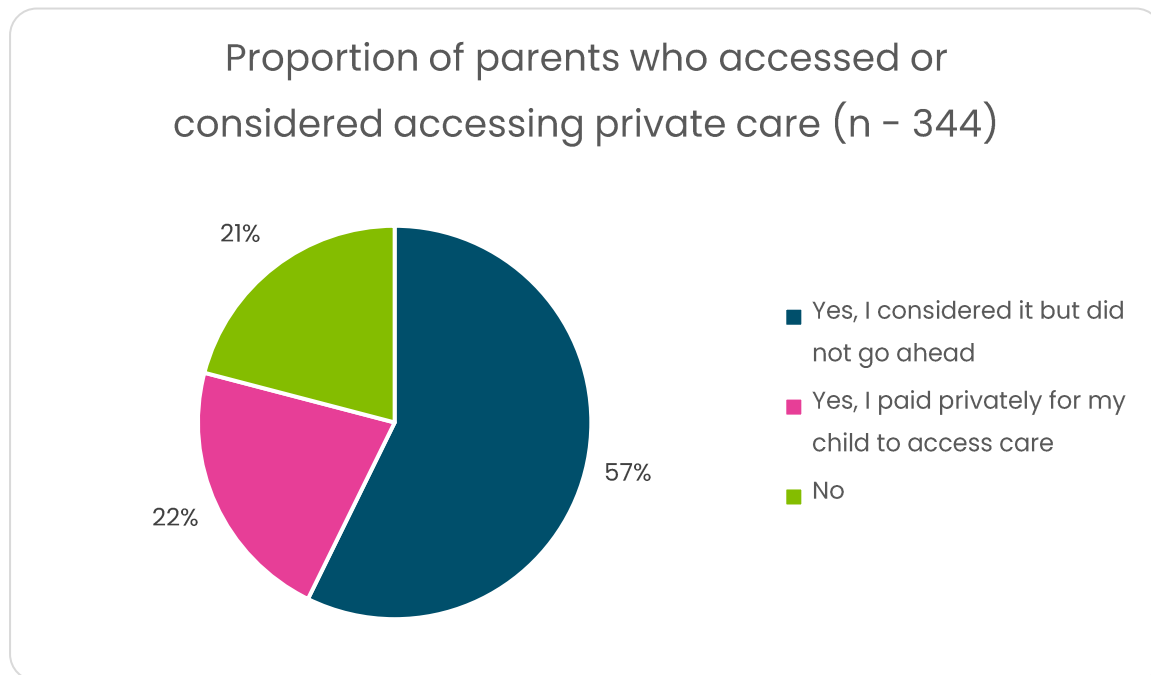
Many of those who did not go ahead with accessing private care told us they could not afford to pay and some also told us of concerns they had about re-accessing the NHS pathway when considering accessing private assessment:

> *"not sure Trafford education services would "accept" it"*

> *"I've been told it wouldn't not be accepted by the council."*

> *"I have been told [by] GPs CAMHS don't recognise it and if medication for ADHD is needed, they won't prescribe it"*

> *"Didn't go ahead as we were advised it may not be recognised by the NHS and only CAHMS could diagnose"*

> *"We looked into this and were willing to fund however we were told they a private diagnosis would not be accepted by Local Authority or NHS."*

Despite these worries, we did not hear from any families who had accessed private assessments or care and had difficulty returning to publicly funded services.

Although we didn't ask children and young people about accessing private care one told us in their survey response:

"We were left waiting for a very long time so went private as there was not enough support available for when I needed it"

Access to private care was also raised within our case studies and focus groups with parent/carers telling us they accessed private care due to wait times.

HW Stockport told us p*arents ended up going privately as they were fed up fighting the system.* From the Manchester case study, we heard from a parent who sought a private dyslexia assessment for their child due to long wait times and Rochdale found that all parent/carers in their focus group *at some point paid for support which varied from an art class to a counsellor.* We also heard:

"Due to the significant delays, we have had to pay for private assessments to ensure our son gets the support he needs – this is mainly so that the professionals around him can understand his presentation better by adding a label" (HW Stockport)

"Paid for a Private Counsellor due to long waiting lists, helped but couldn't fund for a long period of time" (HW Rochdale)

"[We waited] a year but then just sought private assessment – for the second child, we went private immediately." (HW Bolton)

Furthermore, there are many examples withing our data of professionals recommending to families that they access private care:

"Was advised for son to access this – nothing offered locally so sourced and funded as a family. On initial assessment the CBT counsellor stated not a suitable therapy due to son's autism – his presentation was typical autism burnout. I was thankful that they were honest and didn't just see him for the sake of getting paid." (HW Rochdale)

"The school SENCO advised that we should consider private assessment and shared details of some services that other parents had used and

recommended. We have also secured a private ADHD, Dyslexia and Neurodevelopmental review over the past 3-4years." (HW Stockport)

Private care assessments: summary

79% of families told us that due to difficulties accessing services, long wait times and poor communication, they had either considered or opted for private care. Although not part of the NHS pathway and whilst cost is clearly a barrier to some, for those who can afford it, the comments from parents/carers make it clear that there is **confusion around the validity** of the part that private assessments can play in expediating the pathway. In order for parents/carers to make properly **informed choices** about their child's health, **clarity around the option** to pursue private care needs to be provided; this needs to include information on whether a diagnosis obtained privately would be accepted by NHS professionals (and what the criteria for that would be) and what medication private providers can and cannot prescribe. This is also linked to the need for regular and effective communication with parents/carers (see p.47 'Communication Summary').

This has the potential to impact upon socioeconomic health inequalities. For instance, families who cannot afford to pay the cost of private assessments and/or care are faced with a further disadvantage to those who can. Given the identified levels of deprivation across the GM borough[27], this could have significant implications for the health profile of the borough and the long-term health outcomes of residents. Delgadillo et al.

…found evidence suggesting that the prevalence of mental health problems is greater in poorer areas and that these areas had lower average recovery rates[28].

What we heard from professionals

We heard from a huge variety of professionals from various jobs roles across the health and social care, and education sectors. We captured their experiences via a survey and one-to-one interviews and present our findings below in relation to the themes identified. Almost half of the professionals who responded to the survey took the opportunity to share suggestions on what they feel would improve the pathway.
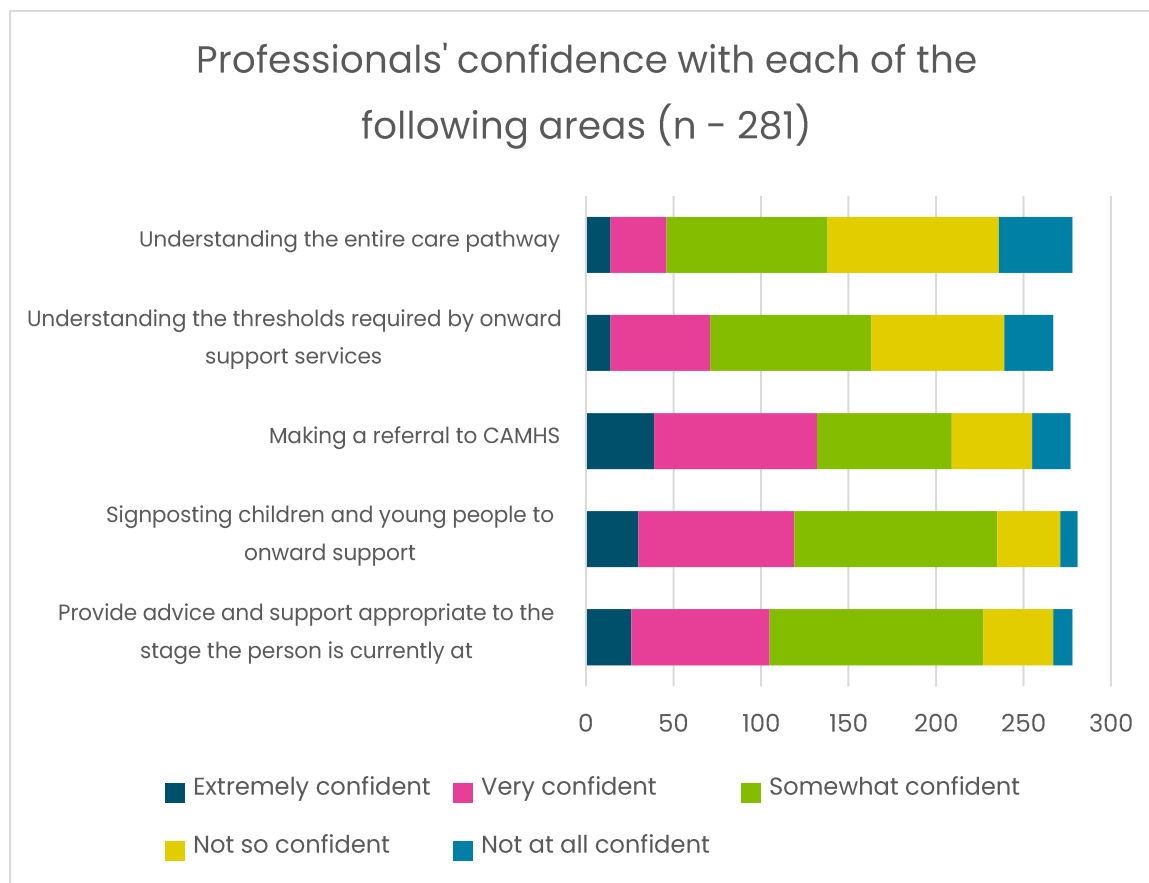
Experiences of the overall pathway

Over two thirds of respondents told us that in their experience, the referral pathway was either *'very poor'* or *'poor.'* Similar sentiment was also reflected in the responses gained via interviews, although the reasons behind this varied. One professional mentioned that once support was accessed, individuals' experiences were more positive, others gave feedback that the pathway doesn't meet families' expectations, that experiences can differ between families, there are long wait times and the pathway itself is unclear.

Overall experience of the referral pathway for children and young people accessing mental health support services (n - 278)

- Very Poor
- Poor
- Okay
- Good
- Excellent
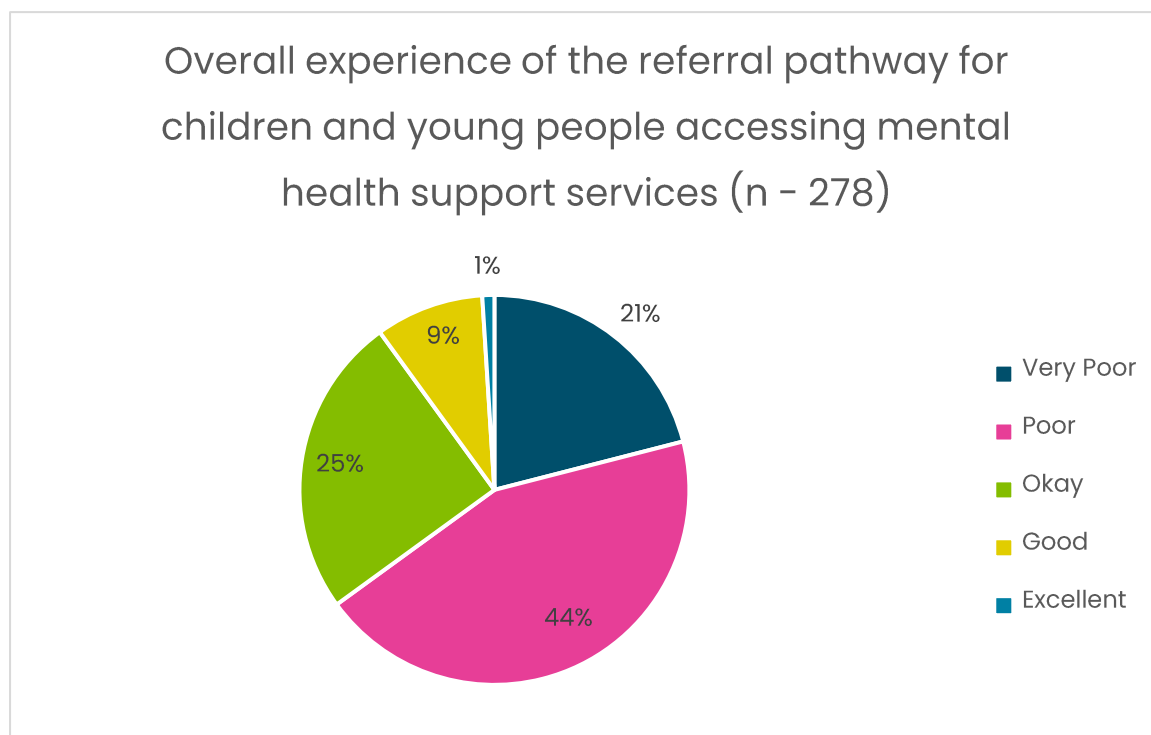
Feedback on given aspects of the Pathway

We asked professionals to rate how confident they felt with regards to various aspects of the CAMHS pathway. We received a mixed response to each of these:

Professionals' confidence with each of the following areas (n - 281)

	Extremely confident	Very confident	Somewhat confident	Not so confident	Not at all confident

The area in which professionals told us they feel the most confident was making a referral to CAMHS whereas the area in which professionals reported the least confidence was understanding the entire care pathway. This was echoed in the interviews conducted, in which a primary school head teacher (and former SENCO) told us on behalf of herself and her team, they

"don't understand why it looks different for different children and we don't understand processes. Parents come back and tell us things that don't match up with our understanding."

A community coordinator told us:

"[there is] *no clarity on what threshold is or who can refer."*

A Connexions Advisor suggested it would be beneficial for training to be available for professionals like themselves, who sit outside the pathway but who support

children and young people who are going through the process. Conversely, we also heard from an Educational Liaison Officer who told us they were *"fairly confident"* with understanding the entire care pathway.

Communication

Responses in relation to communication were prominent in both the survey and interviews. This was most evident when directly asked about communication but also within responses to the question asked about suggestions for improvements to access to CAMHS[vi].

Within the survey we asked respondents to rate the effectiveness of communication between the groups provided below. Responses are similar for each of the groups with the professionals being most likely to report communication to be either *'somewhat effective'* or *'not so effective.'*

How effective do you feel communication is (n - 280):
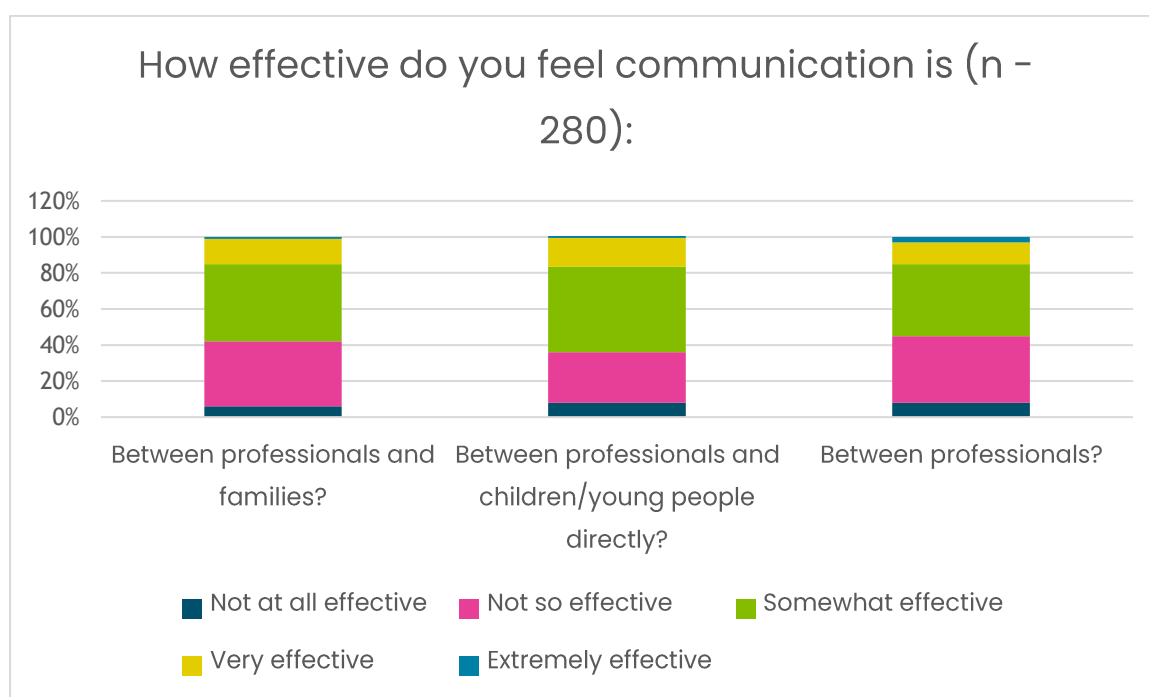
We also asked this question in the interviews. A head teacher we interviewed reported of a distinct lack of communication with CAMHS and the impact this has. They said, *"We refer into a black hole"* and told us of a lack of follow-up with referrals or when there is follow-up that the delay can be so long that the

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[vi] See call 'Calls for improvements' section below

information provided is then out-of-date. This can have a knock-on effect in terms of the workloads of school staff (attempting to catch up with families or follow-up directly with services) and also damage the relationships they have with families in relation to difficulties managing expectations[vii].

In relation to communication with families, both an educational liaison officer and head teacher made reference to the distinctiveness of the relationships school staff are able to build with families given the consistent contact they have with them on school days. The head teacher also expressed how utilisation of these relationships could be highly effective (from a partnership perspective with CAMHS, as an opportunity to communicate with families).

The community coordinator we interviewed told us of an additional communication issue they had identified through working with families. In relation to BAME communities specifically they said:

> *"It doesn't matter what my relationship is with other professionals, it's whether the public trust them. My relationship can be great but if the public don't have confidence in the service I am helping them access, then it's going to be ineffective."*

Professionals - communications: summary

With the majority of respondents stating that they felt communication between all stakeholders was either **'somewhat effective'** or **'not so effective'**, there is clear room for improvement. Improved communication arguably leads to improved relationships and improved understanding between all parties.

As outlined above through interviews with professionals a potential underlying issue relating to the perception of CAMHS within BAME communities came to light. This is also reflected in the demographics of survey respondents; we noticed a distinct lack of representation from many ethnic groups, particularly from the parents/carers survey (see page 25). Concerns with access to mental health services for minority ethnic groups have been reported elsewhere[29][30]. **More**

[vii] a challenge explored below in relation to actions taken when referrals are not accepted

targeted efforts to research perceptions of CAMHS specifically would be beneficial to ensure diverse representation. This could also lead to further work to **challenge misconceptions** and ensure more families are able to access the support they need.

Referrals that are not accepted

When referrals to CAMHS are not accepted, we asked professionals what they do in this instance and received an array of responses. This gave us an understanding of action taken in seeking alternative support and/or continuing with the referral pathway. This also gave an insight into associated concerns professionals have around the process such as feelings about the pathway, relationships with families and professional knowledge and confidence.

The prevalence of rejected referrals varies between boroughs but research in other areas for example showed that half of the children referred for mental health support in 2023 did not receive any treatment within that year[31].

Seeking alternative support

Most frequently (mentioned in 55% of comments), professionals told us they would seek alternative support for the child or young person. This includes often providing additional/continued support within existing setting and/or looking for alternatives elsewhere. We also heard from some who followed advice/signposting outlined in the rejection letter received although, this was mentioned in fewer comments. We heard:

Additional/continued support in current setting

"Usually hope that the young person will get support through school pastoral care"

"It all falls to me! It feels like there are gaps that are never filled and, when CAMHS deem that they won't or can't see a young person, there is no one else to pick them up"

"Ultimately – Explore in school interventions, however, schools are incredibly stretched, short staffed, under-funded and simply don't have capacity either. We try though!"

"School has to muddle through, with next to no resources or staffing. We lost our ELSA worker & no other staff are willing to step up to do training because they are overwhelmed with work and paid very little."

"Look at how we can support the young person and the family even more than already done. Suffer the consequences of not being able to fully meet need. School becomes the place to meet need, education, care, health (mental) which spreads resources too thinly. Despair that nothing will be done until an emergency."

"We tend to just have to try and meet the needs ourselves. The number of children refused, and their extreme level of need is just appalling."

"Support in school. Thresholds are really high and so support cannot be accessed"

"We have some therapeutic support in school (counsellor, play therapy) but we tend to use this before a referral is made to CAMHS, so not really able to offer further support if referrals are not progressed."

"Continue to help support the young person / family in primary care"

Alternative Support

"We see what other support we can access where appropriate but there isn't always much available."

"Look for alternative support but we do not really know of very much, especially for under the age of 8"

"We constantly try and find a service for the young person"

"… We can signpost to universal services/parenting groups/support groups and forums/Greater Minds Together/SENDIAS, we ask if schools can utilise their resources such as learning mentors/pastoral support and in-house counselling, we can offer some direct work with children if appropriate.

Often children and families are in crisis and awaiting professional assessment, when we are involved, children may be displaying violent behaviours, self-harm or more."

"…Signpost to other forms of support such as [Mahdlo] mentors, Youth in Mind etc as appropriate. Signpost parents to Young Minds, National Autistic Society, POINT/SENDIASS etc"

"Sometimes there is no further actions that can be completed, I regularly sign post families to #Thrive but they tend to close after a few sessions and further referrals take years to go through. I share the Kooth website information and discuss cases with the mental health practitioners, but again next steps aren't always clear or pathways haven't been followed and young people are closed to services."

"Look at what other services can support. Often these are very limited with long waiting lists, leads to a sense of frustration for professionals and families and that the young person is not getting the support they need"

Advice/signposting outlined in rejection letter

"Read to the patient the frankly generic non individualised letters that we receive back"

"I would often hope that possibly some recommendations are made on the rejection letter unless I felt very strongly about the decision and then I would challenge this"

"Follow advice and signposting outlined on rejection letter"

"If I get a referral declined, I will follow the advice, but there are times when the advice or suggested plan i.e. i-thrive is recommended but not completed [by the family]"

Challenging and re-referral

Also frequently mentioned (in 47% of responses to this question), professionals told us of actions they took to try to ensure the child remained on the care pathway. This includes ways they told us they would check information in the

referral, discuss with colleagues and/ or other professionals, escalate, challenge the outcome, and/or simply re-refer. We heard:

Checking information

> *"Review the referral document"*

> *"Check the organisation has got all the information around the young person"*

> *"try to gather further information"*

Consult colleagues

> *"Speak to other professionals involved i.e. schools"*

> *"Seek further advice from other professionals/colleagues in different settings". "Request additional advice and support from Stockport inclusion service. 99% of the time they agree that the referral to CAMHS is needed, and further intervention is needed from CAMHS"*

> *"We come together as a group and discuss options at an operational or strategic level depending on level of risk"*

> *"Discuss with my team manager*

Escalate and/or challenge

> *"Question why referral not accepted, seek to find out the reason why and what other services are available"*

> *"Challenge this and fight for the young person to get more support"*

> *"Ask why and to clarify the thresholds"*

> *"Try to phone up although nothing really changes"*

> *"If the young person's circumstances are likely to deteriorate upon refusal of referral, I seek to appropriately escalate, either through my own organisation or other services involved in the process."*

Re-refer

"Review the patient and try to refer again"

"Re-refer, resubmit, add more info to report…"

"Re-apply. Encourage the family to reach out, direct of via their GP."

Other Comments & Concerns

Alongside the above actions that professionals told us they would take, many also expressed other sentiment and associated concerns. This includes the motivation professionals express to ensure children and young people are adequately supported, discussions professionals have with families to manage expectations, the importance of knowledge and understanding of the referral criteria, feelings of frustration and powerlessness from professionals and challenges that professionals witness with accessibility.

Commitment to supporting families

"We don't really accept refusal or defeat we work together with all the people around the child or young person to ensure that they can receive the support they need, and things put in place"

"We always ensure that no child or young person is left unsupported"

"I always do my best to support the family on their journey which is sometimes all we can do"

"Attempt to support our young person and their family as best possible, with the resource available to us. However, this can often feel like we are short-changing the young person, unable to give them the level of qualified response they require. Many school staff can only scratch the surface of what that young person really needs in order to prevent an early case becoming much more deep-rooted and having a substantial and significant impact on their life and that of those around them"

Managing families' expectations

"I will spend time with the parent (and child if appropriate) to explore their feelings / managing expectations of what CAMHS can support with."

"Share this with the patient and family and figure out an alternative plan"

"Professional challenge and ask for answers as to why this has been declined so this can be fed back to the family and young person."

Knowledge/understanding of referral criteria/thresholds

"I try to understand why it has been refused or deemed ineffective. Sometimes the advice suggests things which are not appropriate or have already been done."

"Try to speak to someone in the relevant org to understand the criteria better for future referrals, but to also find out alternative options."

"Very complicated, lack of understand around thresholds"

Frustration and feelings of powerlessness

"Parents ask us what's happening and many times we are unable to say - professional communication needs to be addressed"

"Too many times the response seems to be 'no role for CAMHs'. This seems to be about managing demand rather than there not being a need to be involved."

"Nothing. What can I do if specialist services decline to get involved? I only refer if I can't manage a problem."

"To be honest I tend to hear about thresholds then look at the needs, look at the queue then despair a little."

Accessibility

"We have families with LD (learning disability) and this makes it very confusing as to where everyone is up to."

"... some parents won't challenge or are unable to because of their own mental health issues or own literacy/language issues. Parents who are good at making a fuss get more. I know what the pathway is and I know

what the thresholds are but they are applied inconsistently. Where parents are articulate and knowledgeable they get taken seriously. If parents are aggressive, or look aggressive, have a slightly alternative look it is often deemed to be parenting. Lots of professionals seem to have an idea of how parents should look and sound and if they don't this becomes a barrier to get effective support"

"Signposting may not be taken up no matter how strongly we advise it. There are all sorts of barriers: language, suspicion of services, lack of confidence on part of the parent or patient. I would revisit the reasons for referral, reassess patient, re-refer."

"This happens routinely because everyone knows that children will not get seen in a timely way, and too often when they do, there is no actual help or support provided. ...any child that does not fit neatly into their boxes is rejected leaving other services to pick up the pieces."

Referrals that are not accepted: summary

As shown above, professionals take a range of actions in light of referrals not being accepted, for various reasons. For many professionals, a CAMHS referral was said to only have been made after other routes had already been tried. Despite this, a large proportion told us **they do seek alternative options** such as continuing with support provided in school. Nonetheless, this poses challenges with **meeting the level of need** for children and young people and issues such as **limited funds and staff** were mentioned. Similar concerns have been raised by Dutton, Humphrey and Qualter[32] with regards to referral challenges, who identified that professionals working in Greater Manchester mental health crisis services face restrictions on the options they have, and this can cause **secondary barriers** to access for children and young people themselves. Their findings confirm our recommendation below in favour of a **single point of access** suggesting that this function would not only be of benefit to families accessing services but also to professionals working within.

With regards to signposting to external support we heard that there is often **limited knowledge** on what is available and where professionals are aware of support, availability can be limited.

There were also many comments made in relation to professionals supporting children and young people to continue with the pathway. This included checking information in the referral, consulting colleagues, escalating and/or challenging the decision, and many subsequently re-refer. Existing research indicates that key health[33] and education[34] professionals, likely to make CAMHS referrals, face challenges with regards to **disproportionate amounts of their time** spent on administrative tasks, including referrals.

We heard feedback in terms of professionals finding the need to manage expectations of families. Similarly, in a project conducted across 8 CAMHS sites nationally, Newman et al.[2] found that referrals being rejected led to **disparities between the expectations of families** and the reality of their experience. The effectiveness of the pathway did not always lead to subsequent support in a timely and affective manner. This could be avoided by improving service users' and referrers' understanding of the CAMHS referral process, thresholds and possible outcomes as well as making the decision-making process more transparent and communicating referral decision and outcomes more clearly.

We heard of frustration with the process and feelings of powerlessness from professionals. This is highly concerning given workplace stress within both the education[35] and health sectors is contributing to recruitment and retention issues[36,37]. Harding et al.[38] found associations between teacher wellbeing and that of students which also signals the risk of issues perpetuating if effective action isn't taken to adequately support both groups.

Although accessibility was mentioned less often than other concerns, it is pertinent given that professionals mentioned it without being directly asked – demonstrating its importance to them.

Calls for improvements

Almost half of the professionals who responded to our surveys provided suggestions on what they feel would improve the pathway which cover a wide range of different aspects. Alongside what was found through the interviews with professionals, survey responses which have been categorised into the themes below:

Communication

Regarding suggestions for improvements, communication was found to be mentioned in some way by 36% of respondents to this question. Some mentioned it in general sense with comments simply stating, *"Better communication"* and *"Improved communication following referral"* however, many professionals related their suggestions to specific types of communication.

Clarify pathways and what the CAMHS offer is

There were calls for clarification both on what CAMHS deliver and on what the overall pathway looks like. This was mentioned both for greater understanding for professionals themselves and/or for families. We were told:

> *"It is very unclear to professionals how the pathways work, how to discuss concerns with CAMHS staff and possibly we may not have the knowledge of what an appropriate referral looks like. This may mean we misunderstand rejection letters"*

> *"Really clear guidelines and information about what CAMHS can offer when children are awaiting assessment and which other services we can refer to"*

and suggested the need for

> *"Increased understanding in professionals and the general public about:*
> *-what CAMHS does and doesn't do*

-the difference between counselling and therapy and the value they both have

-the importance of readiness and willingness to work on change

-the importance of the relationships babies, children and young people have with key adults around them and the role they play in their mental health and wellbeing

-what to expect from CAMHS

-the role and value that other mental health and emotional wellbeing service play in supporting babies, children, young people and their families"

Via the interviews, a community coordinator suggested in their interview that there needs to be:

"Improved comms with the public; they don't know what the pathways are. Feedback is not representative of BAME community because they are not engaged with it properly. Perception and understanding of CAMHS service itself is poor – if they don't understand what the service is, and does, then the pathway will also be ineffective because people won't want to access it in the first place."

Improve communication with professionals

Many professionals from different roles mentioned the potential benefit of improving communication between CAMHS and themselves and called for more joined up working between services. This includes calls for *"CAMHS to communicate more with the occupational therapy team"* and a Family Help Coordinator told us:

"it would be really beneficial if we could have a named CAMHs worker that we could discuss within the Family Hub"

We also heard:

"Actually listening to the professionals who support the children day in, day out."

"More collaboration, and coordination with other community teams working with the same children. Having a staff in other community services that can access the CAMHS electronic system and that can be liaison person with CAMHS for better communication considering we use different electronic systems i.e. Parris VS EMIS."

"CAMHs frequently work in isolation from other children's services. There needs to be more collaboration and identity from the service as being part of a wider children's workforce. Co-location of this team with other health teams would be beneficial."

Furthermore, there was a strong feeling from those working in education that more collaborative working could improve interactions between families and CAMHS:

"Develop a good working relationship between schools and CAMHs to increase understanding of daily challenges in school children are facing"

"Better communications, especially between the schools who are seeing children everyday"

"For the NHS to be aware of what schools are doing already. There seems to be a perception that we are not putting things in place, but class teachers are doing an enormous amount at the expense of an academic education."

Improve communication with families

Communication with families was mentioned as an aspect requiring improvement this is in relation to understanding the process, reasons referrals aren't accepted and accessibility issues:

"Better communication with families about reasons for rejecting referrals."

"CAMHS most of the time only work with children and YP [young people] who attend their office/clinic. Many of the YP I work with are unable to attend a new strange place. It would be best if CAMHS could offer more

community-based services and did not discharge children/YP who didn't turn up, but made more effort to understand why a child has not attended and find out how best to work with that child/YP."

"More communication to parents/carers and young people about the whole process."

"Greater communication with referrer and family, GP gets letter at times rather than me as referrer."

Personalise communication

Professionals suggested more personalised communication would improve families' experiences. We heard of this both in relation to individualised review of referrals as well as families having a consistent named contact once they are referred to CAMHS.

"Avoid sending letters declining referral that seem to show no evidence that the referral has been individually reviewed."

"Personalised response letters - all we get is a generic letter saying, 'referral was considered on the day it was received' and rejected, it doesn't give specific detail why, nowhere does it reference the thresholds for what referrals are/are not accepted.

It is also never signed or even documented which clinical personal made this decision, just 'Bolton CAMHS' medicolegally this is not acceptable, and we should know who has decided [to] the reject referrals and why"

"People triaging referrals need to read the referral. For example, I referred a young person and specifically stated that there was no Mental Health Link Worker in the school. The response I received was to refer to the Mental Health Link Worker in school and the referral was closed."

"One person to contact once referred in"

Increased transparency

"Take some proper responsibility for family outcomes. Be accountable to the public. Stop hiding."

"Honesty and transparency with families"

Wait times

Suggestions in relation to wait times were mentioned in 35% percent of comments. Some of these made general calls for the reduction in waiting times with many simply stating *"reduce waiting times,"* although others mentioned this is relation to increasing capacity in order to do so. Increased communication in relation to expected wait times and updates for families was also suggested as well as more support during the waiting period.

Reduce wait times

"Waiting lists need to be shorter, making a child wait 7 years for a QB test ['Quantitative Behavioural'] for ADHD is disgusting"

Increase capacity for CAMHS

"Less waiting time would be ideal but that would mean getting more counsellors/ psychologists/ psychiatrists which I do not know is feasible."

"To increase the capacity of CAHMS, reducing waiting list time."

Communication around waiting times

"Being aware of waiting times, as this isn't always accurate so it would be helpful for us as professionals to know what the waiting time is so that we know what to advise families. For young people as well, this would help them to know what time they are expecting to be waiting."

"More effective communication while waiting"

"Regular communication with families to keep them up to date so families don't feel like they are left in the dark."

"Regular updates to professionals around wait times"

Support during the wait

"Having more early intervention in schools as I see a lot of young people disengage then but fall through the cracks or go unnoticed. Maybe each school can have a dedicated counsellor in the future."

"Support earlier in the mental health process to reduce the risk of escalation"

"Some interim support as we have lost children in the school and others have had severe problems while waiting for some support"

"Families need some support during their time on the wait list to ensure there is no worsening of the condition."

Referral process and thresholds for support

Almost one fifth of professionals made clear suggestions relating specifically to the referral process and thresholds required for access to support. These include comments on the referral process in relation to removing the perceived restrictions having specific referral bodies (i.e. GP and/or school) in place causes, simplifying the practical process of referring (i.e. referral form itself) and ensuring responses to urgent referrals are faster. With regards to thresholds, professionals call for these to be standardised, more clearly communicated and to be opened up for increased access.

Referral Process

"Have a one front door route to an initial discussion or CAF ['Common Assessment Framework'] type assessment"

"There needs to be another way for a CAMHS referral apart from through schools as many children do not display the same behaviour at home as they do in school. Girls are particularly strong at masking behaviour in school."

"Create a mental health triage front door so one referral point for families/young people, reduce duplicate referrals. Families not repeating their story to multiple partners."

"Ensure the referral form is short and to the point and that it can be SAVED and RESUMED.

"[SENCO's] do not have enough time to fill out a referral form of the length of the ND ['neurodivergent'] pathway online form, in one sitting with parents and class teacher present. I have to send home a template to parents to fill out first and then put aside a whole afternoon to complete a ND referral.

The system used to be very simple and now it's complex, lengthy, time consuming and all on school [SENCOs]."

"Having a pathway / service for those young people who are in crisis / on the edge of care who therefore can't access the talking therapies offered by CAMHS (CAMHS discharge them saying that they're too unstable - this creates a vicious circle: the child is in too unstable a position to be seen therefore the child just gets worse!"

"Ability to expedite referrals for those we are worried about."

"A thorough triage system to prioritise those most at risk of harming themselves or others and those at crisis point where universal support is failing"

Thresholds

"[provide] clear referral criteria, that can be seen by families and professionals"

"Each professional working with young people needs to be trained on the CAHMS referral process officially so all know the threshold etc."

"Make it clear what is accepted and what support is available to those who are not accepted. e.g. self-harming behaviour - we are often really worried about these young people but we get letters of rejection and we

worry that they are not getting support and something could happen to them"

"An explanation of the criteria used when making decisions about assessment."

"A clear pathway/flowchart that helps us a professional to understand the threshold and know where to signpost/refer if threshold not met."

"Provide more information around threshold for criteria to avoid making unnecessary referrals that will be rejected to reduce waiting lists."

"It's frustrating that CAMHS appear to have a lot of criteria whereby they don't work with young people."

"Move away from adherence to diagnostic criteria and focus on giving people actual help."

"Improve equitability across services in GM boroughs (acceptance criteria, service offers)"

Alternative support

In relation to what professionals shared with us regarding the difficulties for families trying to access CAMHS (whether that be waiting times, referrals not being accepted etc.), many (14%) also made suggestions in relation to access to alternatives. This was mainly regarding increased clarity on what is available, although some called for increased funding for alternatives.

Clarity of alternative support

"Better communication about different services available"

"Clear alternative support."

"Provide info to GPs on other services/support services can use prior to/ instead of CAMHS referral."

"Advice on alternative measures if referral is cancelled."

"Expansion of access to MHP [mental health professionals] *in schools. Any other form of low-level support that is easily accessible."*

Increases to funding for alternative support

"Investment in partner agencies such as early help, education, school health, SEN, housing"

"More funding available for early intervention support for YP, ASC [autism spectrum condition] *pathways, mental health input in schools/colleges for high-risk cases"*

"To increase the scope of fully funded alternative provision within communities, specific to supporting positive mental health - pre and post referral."

Recruitment and training

Several professionals (17%) mentioned that further recruitment and training would improve experiences of families on the Pathway. We heard:

"Encourage recruitment into roles but putting more young people on the pathways to this vocation"

"More people within the roles and a fair wage to reflect the work done"

"CAMHS needs to dramatically increase the number of professionals working in the service - sadly not likely to happen."

"Need more staff Mental health is horrendous and they do not have the capacity to address everything, they try but referral and children needing urgent help are slipping through the net and lives are being lost!"

"Issues currently around workforce recruitment and retention, Vacant posts due to competitive workforce market, less staff training"

"There needs to be consistency in roles and pay rates to stop the movement of staff across the GM area. Each area is trying to recruit staff from the same pool. Investment nationally in mental health roles."

Funding

Several respondents to this question (10%) suggested increasing funding would improve service delivery, both in a general sense and more specifically, such as greater recruitment and increasing capacity of the CAMHS service overall to ensure increased access for children and young people[viii]. We heard:

> *"I think there needs to be more money, more people within the roles and a fair wage to reflect the work done"*

> *"More funding into the service and more of a draw into the workforce"*

> *"Additional funding to broaden service capacity/staffing"*

> *"[…] more CAMHS staff available to manage the workload, but this obviously relies on funding which no one seems to have."*

Accessibility

A small section of professionals (5%) made suggestions in relation to improving accessibility for families. This includes improving the accessibility of communication as well as having more flexibility for the times and locations of appointments. We heard:

> *"The service should be equitable for all children and their families. It often feels that the children whose parents have good English and can push for their child to be seen get seen quicker. Families where they can't often seem to fall off the radar"*

> *"Give them chance to engage and think out the box children and young people will be feeling a certain way already and you're asking them to come and speak about their most personal thoughts at a strange place with a complete stranger. Home visits are needed and visits in school in their familiar surroundings."*

[viii] Increased funding for alternatives to CAMHS was also suggested above. This is presented in the 'Alternative Support' section.

"Flexible appointments, evening, weekends, in the community and family homes."

"CAMHS most of the time only work with children and YP [young people] who attend their office/clinic. Many of the YP I work with are unable to attend a new strange place. It would be best if CAMHS could offer more community-based services and did not discharge children/YP who didn't turn up, but made more effort to understand why a child has not attended and find out how best to work with that child/YP."

"Have appointments in the evenings and at weekends."

Calls for improvement: summary

As seen above, the suggestions for improvement professionals shared with us cover multiple aspects of the Pathway with issues reported around communication, wait times, referral process and thresholds, alternative support, recruitment and training, funding, and accessibility.

Findings above relate to the perceived need for increased funding of services, increased staff numbers and a general need to increase capacity echo findings from our 2019 report[3]. Not only does this highlight a lack of improvement in this area but other evidence suggests there is now an intensified need for these (as outlined in the 'Project background' section on p.10).

Borough Profiles

We collected data from residents in each Greater Manchester borough, as well as professionals from each area. These capture the overall sentiment and feeling expressed through the surveys, focus groups and case studies. Data resulting from focus groups has been summarised.[ix]

We have used letters in place of children's names. These are not associated with the subjects' real names. The case studies have been shared with parental consent.

PLEASE NOTE THAT THESE ARE FOUND IN A SEPARATE FILE.

[ix] The profile for Wigan and Leigh is slightly different given that the data was collected in a different format as part of their own project.

Signposting

42nd Street	42nd Street is a young people's mental health charity with 40 years' experience of providing free and confidential services to young people who are experiencing difficulties with their mental health and emotional wellbeing. www.42ndstreet.org.uk/
Action For Children	Ther mission is to protect and support children and young people, providing practical and emotional care and support. www.actionforchildren.org.uk
ADHD Foundation	The ADHD Foundation is the UK's leading neurodiversity charity, offering a strength-based, lifespan service for the 1 in 5 of us who live with ADHD, Autism, Dyslexia, DCD, Dyscalculia, OCD, Tourette's Syndrome and more. www.adhdfoundation.org.uk
Alumina	Free online self-harm support for 10–17-year-olds. www.selfharm.co.uk
Anna Freud Centre	Supporting children and young people's mental health for over 70 years, combining science with lived experience to changes lives. www.annafreud.org
Anxiety UK	Anxiety UK is a national charity, helping to support people living with anxiety, stress, and anxiety-based depression. www.anxietyuk.org.uk
BEAT	The UK's eating disorder charity. www.beateatingdisorders.org.uk
Brave Online	BRAVE is a program designed for children and teens who want to learn how to reduce stress and anxiety and improve their mood—and there's help for parents too. www.brave-online.com
Bridge The Gap	An Emotional Literacy based service, combining healthcare and education, helping children to explore and understand their emotions, how they feel in their body and why they might be feeling different emotions. www.jwbridgethegap.com
Changing Faces	Providing support and promoting respect for everyone with a visible difference. www.changingfaces.org.uk
Child Bereavement UK	Helping children, young people, parents, and families to rebuild their lives when a child grieves or when a child dies. www.childbereavementuk.org

Childline	Childline is a free, private, and confidential service where children can talk about anything. They are here online, on the phone, anytime. www.childline.org.uk/
Family Lives	Family Lives provides targeted early intervention and crisis support to families. www.familylives.org.uk
Frank	Honest information about drugs. www.talktofrank.com
Gingerbread	Gingerbread provide expert advice and information to support single parents so that they have the tools to support their children and themselves. www.gingerbread.org.uk
Happy Maps	A one-stop hub of information on young people's mental health. www.happymaps.co.uk
Harmless	Harmless is the national centre of excellence for self-harm and suicide prevention. https://harmless.org.uk/
Head Meds	HeadMeds gives young people in the United Kingdom general information about mental health medication. www.headmeds.org.uk
Kidscape	Kidscape is an award-winning bullying prevention charity. Established in 1985, we support children and their families across England and Wales to challenge bullying and to have happy, healthy relationships. www.kidscape.org.uk
Kooth	an on-line counselling and emotional well-being platform for children and young people up to 25 years old. www.kooth.com
LGBT Foundation	A national charity with LGBTQ+ health and wellbeing at the heart of everything they do. https://lgbt.foundation/
Lucy Faithful Foundation	The Lucy Faithfull Foundation is a UK-wide charity that exists to prevent child sexual abuse and exploitation. www.lucyfaithfull.org.uk
Mind	A mental health support charity offering free support across the country. www.mind.org.uk
MindEd	MindEd is a free educational resource on children, young people, adults, and older people's mental health. www.minded.org.uk
National Autistic Society	Here to transform lives and change attitudes to help create a society that works for autistic people. www.autism.org.uk
National Self-Harm Network	Supporting individuals who self-harm and family and carers of those who self-harm to reduce emotional distress and improve their quality of life. www.nshn.co.uk
NSPCC	The UK's leading children's charity. www.nspcc.org.uk

OCD-UK	OCD-UK educate, offer hope and support people through the difficult times, right through to recovery and everything in between. www.ocduk.org
Parent Carer Forum	Forums who work in partnership with their local area partners as well as working across the region collaboratively. https://nnpcf.org.uk/blog/get-involved/find-join-your-local-forum/north-west/
Papyrus	PAPYRUS is the national charity dedicated to the prevention of young suicide. www.papyrus-uk.org
Place 2 Be	Providing mental health services in schools for almost 30 years. www.place2be.org.uk
Rethink Mental Illness	Information, services (including mental health services and peer support), and campaigns improving the lives of people living with mental illness. www.rethink.org
Samaritans	If you need to speak to someone, call the Samaritans day or night. They're always open and here to listen. They are available on 116 123. www.samaritans.org
Self Injury Support	Helpline and support groups. www.selfinjurysupport.org.uk
SilverCloud by Amwell	SilverCloud offers online programmes for those aged 16 years+ to help ease your levels of stress, sleep better or to build resilience. https://gm.silvercloudhealth.com/signup/
SupportLine	Offering confidential emotional support to children, young adults and adults by telephone, email, and post. www.supportline.org.uk
Teen Sleep Hub	A one stop shop for all teens need to know about sleep. https://teensleephub.org.uk/
The Proud Trust	The Proud Trust supports lesbian, gay, bisexual, and trans young people in Manchester, Greater Manchester and the North West. www.theproudtrust.org
Tourettes Actions	Tourettes Action works in England, Wales and Northern Ireland and is the leading support and research charity for people with Tourette Syndrome and their families. www.tourettes-action.org.uk
Wee Seeds	A platform and app that provides grownups with mental health resources to teach wellbeing skills through simple, easy to follow videos, audio, and activities. www.weeseeds.co.uk

Winstons Wish	Winston's Wish is a charity that helps children, teenagers, and young adults (up to the age of 25) find their feet when their worlds are turned upside down by grief. www.winstonswish.org
Women's Aid	Women's Aid is the national charity working to end domestic abuse against women and children. www.womensaid.org.uk
Young Minds	Young Minds is a mental health charity for children and young people. www.youngminds.org.uk/

Appendix: comments from care providers and commissioners

We have included a number of responses from organisations across Greater Manchester with regards to this report. They can be found as follows:

Greater Manchester Integrated Care Partnership

Care Pathway to Child and Adolescent Mental Health Services (CAMHS) – Response

Background:

Healthwatch, Greater Manchester have produced a report entitled *Care Pathway to Child and Adolescent Mental Health Services (CAMHS) – "I'm currently fighting to get back in, fighting – Why do we have to fight".*

NHS GM would like to thank Healthwatch for producing such a powerful report that captures the experiences of our Children and Young People, their parents and carers and the staff that work in the community CAMHS services. Our thanks are also extended to all of the people who took the time to feedback their stories and experience with honesty to our colleagues at Healthwatch, enabling them to capture the experiences within our services supporting the GM system to drive meaningful improvements.

NHS GM have reviewed the report and welcomes the opportunity to provide comment and feedback.

Response

The report is extremely helpful and provides good insight into Greater Manchester CAMHS services. Childrens and Young people's mental health is a key priority for NHS GM and this report, and its recommendations will be used to inform the Mental Health transformation work which is shaping Mental Health services to ensure they meet the needs of the population in line with the NHS Long Term Plan, [x]The NHS operational planning guidance [xi]and the NHS GM Integrated Care strategy. [xii]

[x] [NHS Long Term Plan » Overview and summary](#)

[xi] [NHS England » Priorities and operational planning guidance 2024/25](#)

[xii] [ICP Strategy | Greater Manchester Integrated Care Partnership](#)

Limitations

Children and Young people and Parent and Carer responses are predominantly from those who are predominantly in the White Caucasian group, as displayed in figure 1 and 2 below;

Figure 1

Parents and carers

90% respondents described themselves as White – British, 1% as White – Irish, and 1% as White – other. A further 1% told us they were Asian or Asian British – Pakistani, and 0.3% as Asian or Asian British – Chinese. 1% respondents told us they were mixed race.
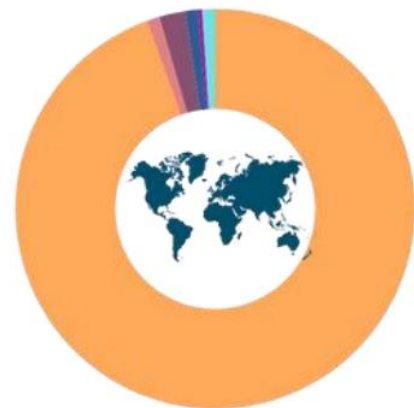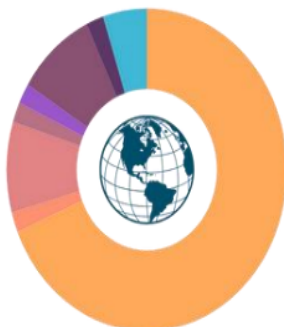
Figure 2

79% of respondents identified their ethnicity as White British, Irish, or White other. 2% told us they were Black Caribbean. 2% said they were Indian, 9% Pakistani, and 2% said they were Asian or Asian British other.

Figure 3 below is taken from the Greater Manchester Combined Authority Report – "Census 2021 Briefing – Ethnicity"[xiii] It shows the scale of the diversity in each of our localities.

[xiii] census-2021-briefing_ethnicity_final-v6.pdf

Figure 3

Percentage of the population from an ethnic minority group, 2021
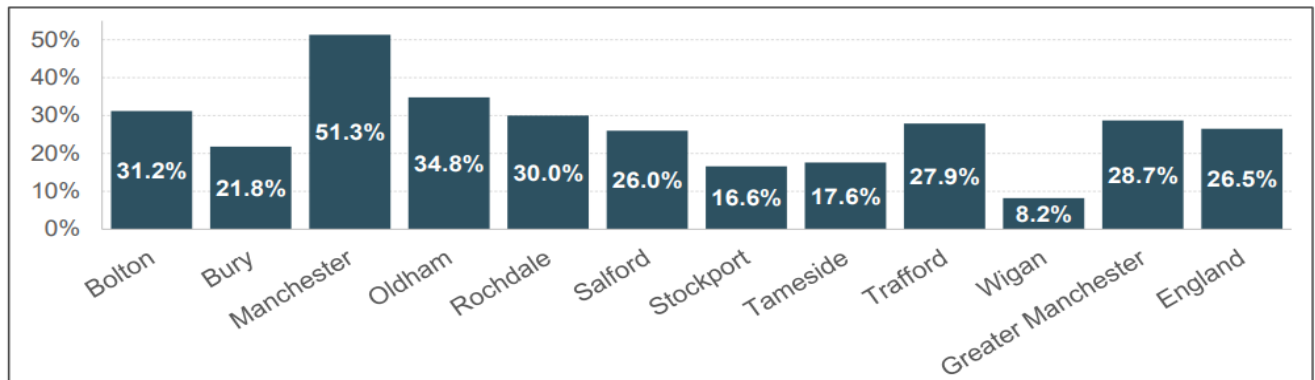
Source: ONS, Census 2021, TS021 – Ethnic group - Nomis

Given this disparity in the report it will be important to gather views from a wider range of Ethnic minority populations to ensure service transformation is addressing the needs of the entire population.

There is a significantly higher response rate from professionals working in Stockport locality, as displayed in figure 4 below;

Figure 4

Professionals

When asked where they worked, the professionals who took part in our survey responded as follows:
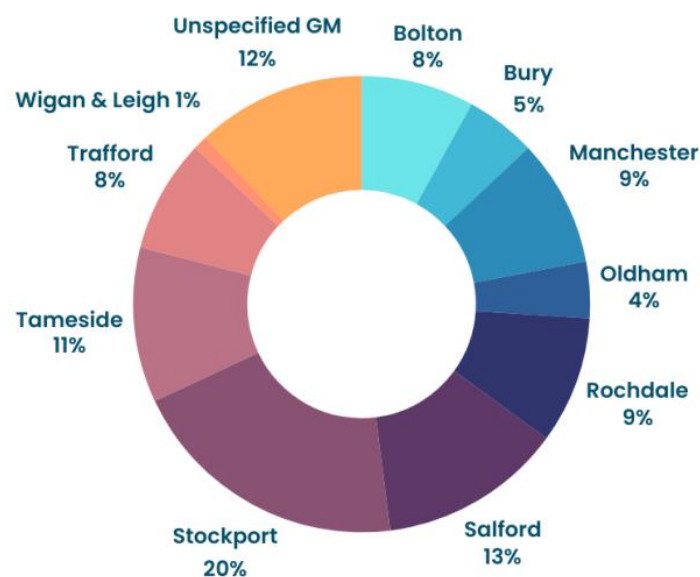
Addressing Health inequalities is a key priority for GM, figure 5 below shows percentage of children (aged 0-16) in relative poverty (after housing costs) in each GM locality over time (resolve poverty. Org)[xiv]

Figure 5
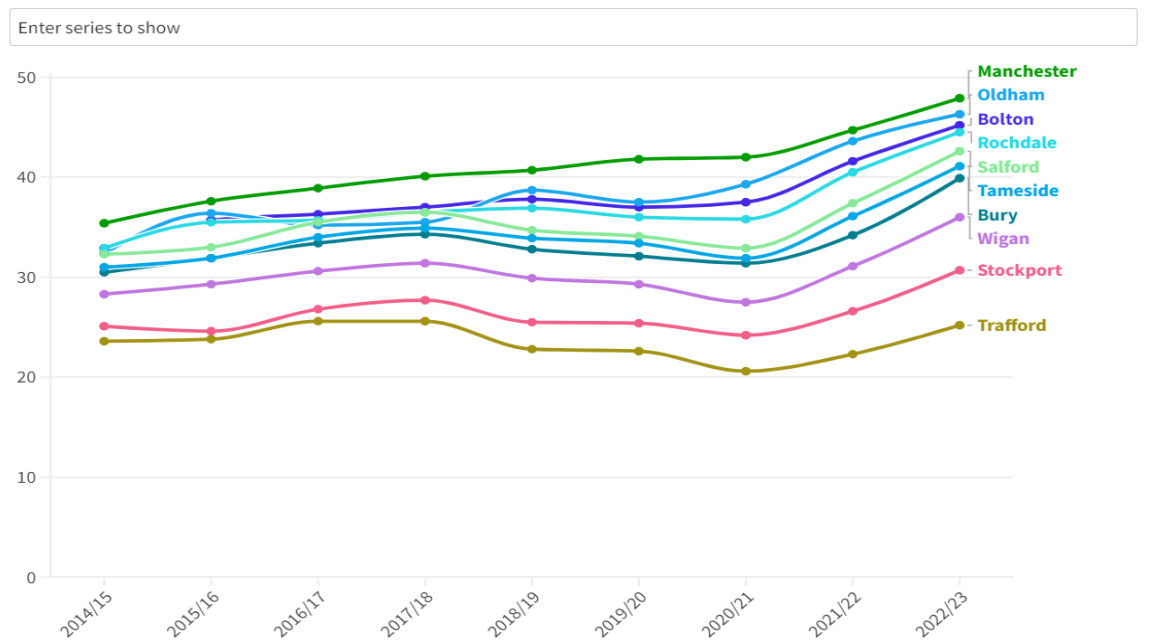
We know that deprivation and child poverty is more prominent in some boroughs than others and so ensuring the views of these families are considered so services can respond to the most vulnerable in GM is important.

The report covers views from service users of Community CAMHS, other elements of the specialist pathway are not included.

We know that when people transition between services it can correlate with an increased risk, service redesign must consider how to improve effective transition and so gathering views from those who have used other CAMHS services is important, not only to understand and address the gaps in transition but to ensure improvements are made across the whole pathway.

[xiv] Poverty and deprivation - Resolve Poverty

The report does not differentiate between presentations and clinical need of service users.

This is particularly important when considering the neurodevelopment pathways. Autism and ADHD are neurodevelopmental conditions. There is an increased risk of developing a range of mental illnesses with a neurodevelopmental condition, but this is in a much smaller percentage of young people .Over the years, CAMHS has been increasingly relied upon to diagnose and assess neurodevelopmental conditions, which has resulted in increased wait times and additional pressure on resources intended for Mental Health treatment. It is crucial therefore that developing these pathways is a priority (see table 1 below)

Key Headlines from the report to inform the GM Mental Health transformation Agenda (see table 1 below)

The requirement to eliminate the difficulties faced by service users, their families and carers when navigating pathways.

The need to develop a shared understanding of available support across the system

Address the variable experience of Children and Young people when using services.

Consider the need for more streamlined / single point of access services.

Improving the support provision to ensure service users are "waiting well"

Using the information to further strengthen the understanding of the impact the Neurodevelopmental pathways are having on Mental Health provision.

Summary of transformation work

Table 1 is a summary of ongoing work in Greater Manchester which is addressing the recommendations within this report.

As stated in the report overall performance in GM is in decline, however current access targets are being achieved. This highlights the importance of the

qualitative data within the report and how it can help to transform services so that all aspects of services are meeting the needs of the population.

Table 1

Programme	Description
Neurodiversity Transformation Programme	NHS GM in collaboration with key stakeholders is leading a large-scale ND transformation programme to address the issues and challenges faced by CYP and their families. The strategic aim is to develop and implement and evidence-based needs led model for ND pathways.
CYP Voice	We value the voices of children and young people (CYP) and are committed to ensuring their perspectives are included in service design and transformation through a dedicated programme to develop an all-ages lived experience strategy, designed to integrate lived and living experiences our work—from co-production to service design and delivery. Our collaboration with Youth Focus North West, plays an instrumental role in embedding the voices of CYP within our mental health programme, via their BeeHeard monthly fourms and Bee Counted Inspection programme. Involving young people in the inspection of our mental health services has proven to be an incredibly successful and impactful.

Mental Health Support Teams	The MHST deliver vital services in education settings, as part of ongoing expansion MHSTs will reach more schools and colleges
Core CAMHS	A system wide group is currently working to refresh and implement a consistent and evidence-based offer to improve the offer and address the needs of CYP across Greater Manchester.
	THRIVE was always intended to be a needs led conceptual model / framework to aid in the commissioning of evidence based clinical care pathways for CYP MH and a shift away from tiers (Future in mind, 2015[xv]) , however it's often been misunderstood and its quadrants almost a replacement for tiers rather than connecting them.
	Due consideration should be given to one GM CAMHS within which we have x 3 hubs (east , central and west) with one pathway that is a thrive aligned pathway - this very much speaks to this report calling for a single place for parents , YP and professionals to go to / refer to / get advice and signposting from and where our digitally commissioned services and VCSE services can sit in a more connected

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[xv] Future in mind - Promoting, protecting and improving our children and young people's mental health and wellbeing

	way with their data captured as part of a single dashboard .
CYP Crisis Pathway	A significant amount of work has been carried out to combine the offer of CYP Crisis services across GM. This has resulted in a cohesive way of working across crisis services, more support for service users in paediatric wards, a consistent offer, and a single point of access.
Expansion of VCSE led safe zones	There is a safe zone in each locality, these are services to support young people in crisis by providing an alternative option and a more complementary services. The expansion has provided a 7 day per week service, a step up / step down from other crisis services
Children and Young people Silver Cloud	A digital mental health programme for children and young people aged 11 and above, specifically to support anxiety and low mood. This is only offered only in conjunction with other interventions, such as MHST, CAMHS and VCSE Wellbeing Hubs. It has been commissioned for use across all areas in Greater Manchester.
Kooth	Is an online counselling and emotional well being platform for CYP ages 10-25 who are experiencing difficulties with their mental health and emotional wellbeing, this is commissioned for all areas in GM.

GM Creative Health Strategy [xvi]	This GM strategy covers a number of priority areas, two of which are CYP and Neurodiversity. This gives us a different way to engage with Children, Young people, and their families.

Next Steps

NHS GM system leaders and programme managers should consider the data, analysis and recommendations within the Healthwatch report and apply this to transformation, service redesign and commissioning intentions.

Considerations to be given to the limitations within the report and how to address the gaps to ensure that health inequalities across GM are embedded into current and future transformation.

Ensure that Healthwatch is represented with other appropriate GM service user and carer groups throughout our transformation work.

Part of Greater Manchester
Integrated Care Partnership

[xvi] Greater Manchester Creative Health Strategy

Manchester NHS Foundation Trust

Manchester University NHS Foundation Trust (MFT) welcome the report provided by Healthwatch Manchester (HWM) and the opportunity to comment on the draft report provided on 7th October 2024 ahead of its formal publication on 28th October 2024.

It is noted that the report highlights the significant pressures on Greater Manchester (GM) CAMHS, as result of rapid increased demand, complexity and acuity, that has been seen across the service since the COVID-19 pandemic. This has led to challenges between capacity and demand, leading to increased waiting lists and/or waiting times. The report recognises that these pressures are more acute within neurodevelopmental conditions, such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism.

The report also acknowledges the pressures are not isolated to within GM but reflects the national picture and context, and it is clear this will require collaboration with system partners such as local authorities.

MFT CAMHS also sees the report as an opportunity to utilise the patient experience feedback about the pathways to inform the development of MFT CAMHS communication strategy and seeks to share the service improvement work that is already underway which will support addressing the recommendations. These are identified in the section below.

MFT CAMHS Delivery Plan

MFT CAMHS are currently reviewing and updating the Single Point of Access, duty and assessment: standard operating process (SOP), in order to improve access and support at the front door and ensure that a consistent approach is taken across Manchester, Salford and Trafford. This will be completed by December 2024.

MFT CAMHS have started working with community colleagues in the Manchester, Salford, and Trafford Local Care Organisations to develop new shared pathways for children and young people with suspected Neurodiversity. The service aims to have developed these shared pathways, by the end of Q4 2024/25.

MFT CAMHS are currently developing a CAMHS communication strategy and action plan led by the Senior Leadership Team. This work has already seen a refresh of the MFT website and the CAMHS pages and introduced the development of waiting well offer (https://mft.nhs.uk/rmch/services/camhs/). This work is underway and will continue throughout 2024/25, with monitoring against the action plan commitments, taking place via the CAMHS Divisional Quality and Safety meeting. Additional oversight and assurance will be provided through the Royal Manchester Children's Hospital (RMCH) Quality and Safety Sub Committee meeting which reports into the Specialist Hospital Clinical Group Quality and Safety Committee.

The MFT CAMHS webpages are currently being updated to improve communication, understanding and navigation of pathways. This work is underway and will be ongoing throughout 2024/25, with action tracking via RMCH Transformation meeting, with oversight from Specialist Hospital Clinical Group Performance Committee.

As part of this approach, a 'whilst you wait' offer has been developed and implemented focusing on Neurodevelopmental conditions to ensure that patients' needs are met as a soon as possible. This includes providing a range of resources which patients can access whilst waiting for mental health services and this information is published on the MFT website. This important piece of quality improvement work will continue to be evaluated quarterly through the CAMHS Senior Leadership team, to ensure that the 'while you wait' offer meets the needs of the targeted population by gaining patient and family feedback as the available support offer grows.

MFT CAMHS recognise that demand and capacity remains a challenge for the service, despite growth of its workforce and will require a GM system-based approach and significant investment and workforce expansion.

MFT is a key partner in supporting the ICB programme that is updating the GM CAMHS service specification for 2025/26, which seeks to bring improved clarity on the role and function of GM's NHS CAMHS and ensure equity and address post code lottery of care.

In addition, MFT is also an active partner in the ICB programme reviewing and developing neurodevelopment actions plan and recovery. As part of this programme, MFT is implementing the ICB Neurodevelopmental risk stratification systems that seeks to target resources to those most in need.

MFT will be launching the GM Autism Centre (previously known as the GM Hub) once the development works to the building are completed which is expected by Q1 2025/2026.

MFT will participate in the national Demand, Capacity and Flow (DCF) quality improvement collaborative, run by the National Collaborating Centre for Mental Health, to develop more efficient neurodiversity pathways across the system. This workstream will commence in January 2025 and will be fully completed by January 2027.

Finally, MFT, under the NHS Long Term Plan (2019-2029), is committed to growing its CAMHS workforce year on year, and also support programmes, such as workforce wellbeing to ensure it looks after those delivering care and treatment.

I hope the information shared demonstrates MFT's commitment to continue to make improvements to the care pathways to CAMHS.

Yours Sincerely,

Ian Lurcock

Interim Chief Executive Officer

Specialist Hospitals Clinical Grouping

Pennine Care NHS Foundation Trust

Introduction

This purpose of this paper is firstly, Pennine Care NHS Foundation Trust (PCFT) to extend our sincere thanks to Healthwatch in Greater Manchester for sharing the above report. As a Trust, we acknowledge it is unacceptable that children and young people are not receiving access to timely support and the impact this is having on families.

Secondly, PCFT would like to assure Healthwatch in Greater Manchester that it is working closely with system partners, place-based partnerships and health and social care to deliver improvements, transform care and manage system performance to deliver safe, timely and effective care. The breadth and depth of subsequent challenges such as financial pressures, lack of resources and the aftereffects of Covid-19 pandemic are still being felt throughout our services.

This report outlines our current position and provides a breakdown of current initiatives in progress to reduce wait times and provide assurance against recommendations set out in the Healthwatch report. PCFT's Locality Board chairs have together with us set out a strong commitment, identified ownership, governance arrangements and assurance that a structured approach at local and Greater Manchester level is to be adopted to respond to barriers to accessing services for children and young people and their families.

Current Position

Waiting Times Data Refresh

A recent analysis has been conducted on available Child and Adolescent Mental Health Services (CAMHS) waiting list data, including the overall waiting lists, individual data, and examination of historical trends to understand the dynamic and changes over time. Since January 2024, PCFT has seen an 18% waiting list growth for CAMHS services. As of mid-October 2024, there are a total of 8266 children and young people waiting for assessment or treatment of which 7468 are within the Neurodevelopmental Pathway. This is significant growth compared to January 2023 baseline figure of 6785. Figure 1 below provides data concerning CAMHS waits across all Pennine Care CAMHS services.

Figure 1-Waiting List Growth
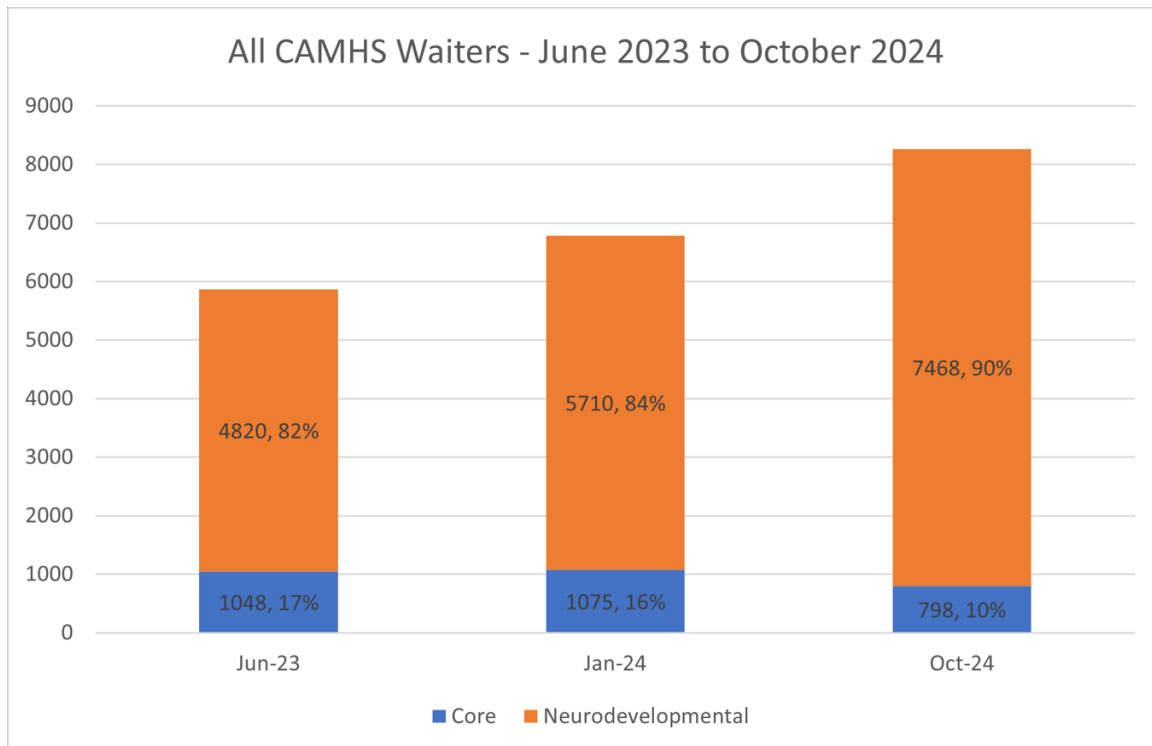
Referral Data Refresh

Looking at data refresh on referrals over time since 2020 across all CAMHS services in figure 2 below, the data shows there is a substantial spike in referrals, with referrals in July 2024 the highest month overall, with a reduction in recent months likely accounted for by seasonal variation and school holidays.

Figure 2-Referrals
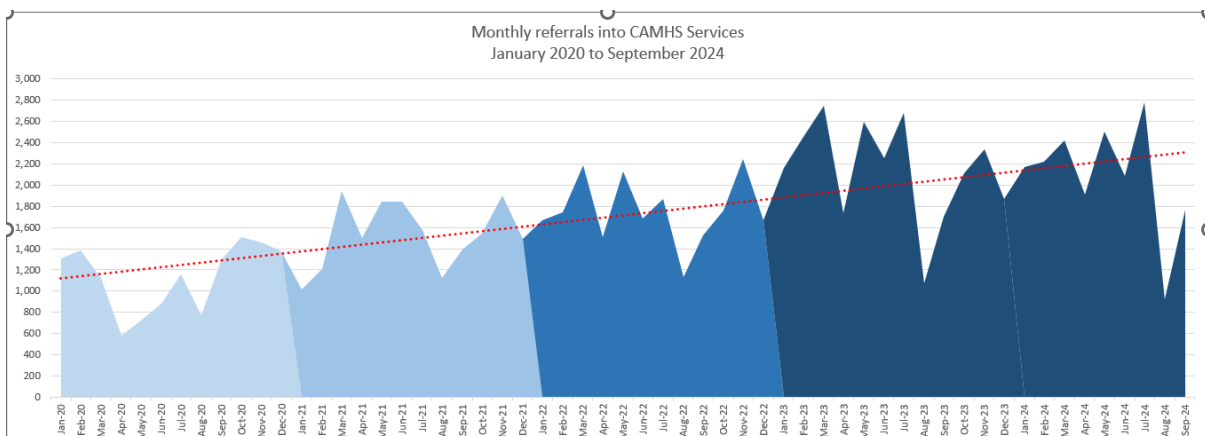
Consistent with the data trends highlighted in original findings, the data refresh indicates a substantial increase and growing challenges in respect of CAMHS waits. This position impacts the ability to provide a responsive service across all pathways.

Capacity and Demand notable gaps

Among children and young people that have been referred to mental health services there has been a slight decrease in number of referrals for core CAMHS, likely impacted by expansion of Mental Health Support Teams however, even considering those children who receive support and treatment in other settings, such as primary care, there remains a notable gap. There are deep seated worries about a growing mismatch between capacity and demand and how funding pressures are intensifying, this echoes significant resource and capacity challenges identified in your report. Over last few years, PCFT CAMHS budget setting has been allocated by the ICB based on pre pandemic capacity and demand data. A recent gap analysis across PCFT identified significant underinvestment across all five Core CAMHS localities. This is comparative to recent NHS Benchmarking findings. Whilst work is underway to refresh CAMHS capacity and demand. It is important, that a continued focus on these broader issues is essential for achieving long-term reduction in waiting times.

Locality Position

Place-based Neuro-developmental Developments.

Significant challenges being experienced by children, young people and their families has been noted by chairs of locality boards together with, recognition of Trust's approach to bringing together system partners to address this important priority. The ICB has acknowledged openness and transparency in sharing detailed analysis provided by PCFT with other mental health providers across GM.

In Stockport, a formal response has been received from Mark Fisher Chair of Stockport Locality Board recognising the breadth and depth of work along with a strong commitment, identified ownership, governance arrangements and

assurance that a structured approach at local and GM level will be adopted. In Tameside, a joint multi-agency action plan has been developed in collaboration with partners setting out agreed objectives to develop an accessible needs-led multi-agency offer. Similarly, in Rochdale and Bury, trials of Pathway Transformation using Portsmouth Needs-Based Profile Tool and Neurodevelopment Supports Hubs adopt a multi-agency approach to needs-led assessments.

Whilst there is a strong commitment from locality boards to work in partnership and move towards a needs-led model harnessing learning and success in other ICBs. It seems there is a degree of variance and levels of maturity in local development and multi-agency approach to development of pathways to address neuro-diverse needs set within parameters of the recommendations.

Neurodevelopmental Legacy Waits Initiative

The Mental Health Partnership Board agreed to support exploring options for prioritising children and young people currently waiting for assessment and treatment. PCFT has developed a proposal setting out options to management of current neuro-developmental waiting lists, including increased capacity within current diagnostic pathways to support reduction in number of young people waiting for an assessment. This optimum opportunity has been shared with the ICB and is currently awaiting a funding decision.

PCFT is also engaged in GM Mental Health Partnership programme endorsed by Commissioning Oversight Group in relation to neurodevelopmental pathway and in particular attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD)noting although mental health has a role to play in the autism pathway it isn't a mental health responsibility to manage that pathway. Nominated clinicians and medical colleagues' representative of PCFT are engaged in relevant forums to contribute and shape the GM offer.

GM CAMHS Service Specification

The current CAMHS specification, which covers all NHS providers has been refreshed by GM CAMHS commissioners and ICB. This will inform service delivery and commissioning decisions for core CAMHS from April 2025 with a renewed

focus on ensuring that children and young people will receive timely specialist services ensuring clarity on interventions offered consistent with a clinical model.

PCFT Measures in place to Support Young People Waiting

To help address challenges also echoed in the Healthwatch report to ensure that children and young people are managed safely, additional measures have been implemented across our services as set out below. Whilst these initiatives aim to improve operational efficiency and manage waiting lists, they do not directly address underlying underinvestment and capacity and demand issues.

Young People Prioritisation Criteria

On receipt of referrals into CAMHS, regardless of referral reason, all information provided is reviewed and clinically assessed to determine required response and prioritisation. Factors such as evidence of mental disorder, identified risk issues, placement or school breakdown and periods of transition inform response required. In accordance with recent Greater Manchester Children and Young People Prioritisation Criteria approved by Greater Manchester Clinical Effectiveness Group for people on the Autism and ADHD waiting lists, PCFT has been improving ways to systematically work through all new referrals to prioritise young people deemed to be at highest need and risk for assessment and access into CAMHS pathways. Additional information is provided about how to access support from CAMHS if their situation changes or deteriorates.

Monitoring and resource

For the core CAMHS mental health pathway, well-being checks are being conducted for young people experiencing long waits. Whilst these checks are intended to occur every 12 weeks, the frequency may vary depending on clinical capacity.

To enhance service availability during evening and weekends, bank staff are deployed to support services with significant operational pressures and management of waits.

Caseload Cleansing and Understanding Waiting Lists

To enable movement of children and young people from waiting lists, approximately every quarter services are reviewing caseloads to ensure that only active and necessary cases remain open. This process enables identification and addressing of delayed discharges, incomplete clinical discharge processes and improved communication flow and pathway allocation.

Work has also commenced in Stockport to cross reference children and young people on waiting lists who are also known to local authority and health agencies to ensure these children and young people with no additional active support are identified and targeted needs led timely interventions or support is provided. This initiative is expected to be implemented across all localities by March 2025.

Maximising potential

www.penninecare.nhs.uk

Stockport Integrated Care System

In Stockport we are passionate about transforming our offer for local children and young people and their families and we know that we have rising demand for our services, and challenges that this brings to children and their families. We are working hard to meet these challenges.

It is for this reason that health and care system leaders, in Stockport, welcome this very important report highlighting the concerns of families about the challenges they have in accessing child and adolescent mental health services (CAMHS).

Improving the mental health and wellbeing for children and young people in Stockport is a key priority for us all. This priority is reflected in both our All-Age Mental Health and Wellbeing Strategy (October 2023) and our refreshed Special Education Needs and Disabilities (SEND) Strategy (September 2024). These strategies were co-produced with parents and young people and they therefore reflect already the themes that this report highlight including:

- Access to services, waiting times and finding the right support at the right time.
- The need for mental health support in schools
- Communication from services and between services – difficulties in communication and having to re-tell stories.
- The importance of family and friends in supporting around mental health
- Limitations in services for young people after age 16
- Waiting times for diagnostic assessments, particularly for neurodevelopmental conditions, and the support following diagnosis
- Communication available to families during the process
- Mental health treatment

Recognising the high demand for neurodevelopment assessments our SEND Strategy has a particular focus on early intervention, providing support to both children and young people and families while they are waiting for assessments and implementing the evidence based approach for a needs-led model.

In addition, we are committed to taking the following additional steps to address the recommendations set out in the report:

- With respect to the specific case study presented we will work with the family and services to ensure that the family and young people are receiving the right care and support.

- Share and discuss the report within our existing governance processes, in the first instance this will be both the Stockport SEND Board and Children and Young People Mental Health and Wellbeing Partnership, where all system partners, including parent carer representatives and Healthwatch are present.

- Review our Single Point of Access/Early Help Pathway for Children and Young People Mental Health Service to ensure that parents, families and health and care professionals understand that this is the point of referral for all CYP mental health services. We will do this in partnership with parents and carers and in line with the Stockport Co-production Charter. This inevitably will involve promotion and publication of the offer on a regular basis.

- The SEND Local Offer has recently been updated, we will work collectively to ensure that all our services and offers of support, and how to access them are widely publicised.

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