The Strategy Unit.

# Inequities in Access to Children and Young Peoples Mental Health Services in the Midlands

Report for the Midlands Decision Support Network

**July 2021**

NHS
Midlands and Lancashire
Commissioning Support Unit

# Document control

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| **Document Title** | Inequities in Access to Children and Young People Mental Health Services in the Midlands |
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# Foreword

The full impact of the pandemic will not be known for many years to come. Overall, it will be negative. But the pandemic may also offer a breakpoint in history. It may be an opportunity to see things more clearly and in a different light. It may be a time when we decide that previous problems cannot now be tolerated, and that new priorities and new efforts are needed.

As both a parent of a young child who is growing up in a society distorted by the pandemic, and as a citizen concerned about my country, I hope that this is true for the way we think about both inequities and inequalities in children and young people's mental health. If it isn't, then we are storing up wide-ranging and profound problems.

This report was commissioned by all eleven Integrated Care Systems (ICSs) in the Midlands Region as part of the work programme of their Decision Support Network. The ICSs in the Midlands are to be commended for wanting to see the questions addressed in this report examined openly and for making children and young people's mental health a priority for improvement.

The report reinforces the need for data and analysis to see things in a new light. None of it makes for easy reading. The analysis draws on many sources, contains much important data and provides several essential recommendations. It also shows the need to hold full and extensive conversations with children and young people themselves about how they want to be helped.

The factors that lead to poor mental health are complex, but one thing is clear: we need to build upon the areas where we have recorded success to address these areas of ongoing health inequities and inequalities. And one encouraging factor is that the poor mental health among our children and young people is, in large part, amenable to preventative approaches. More needs to be done to understand how these preventative approaches can be achieved. We need to work with children and young people and the many partners who are involved, and we need to work together to bring our collective insights and creativity to bear.

We also need a response that matches the scale and long-lasting nature of the problems we face. The Decision Support Network that the Midlands ICSs are building together provides just the vehicle, perhaps, for addressing the challenges that will be faced in doing this by acting as a 'learning system' focussed on common problems.

We then need robust, high quality evaluation of all promising initiatives. We need deliberate and coordinated continuous improvement cycles. We need excellent and effective sharing of knowledge to support wider adoption of effective innovations.

In the words of author and activist Arundhati Roy **"Once you see it, you can't unsee it. And once you've seen it, keeping quiet, saying nothing, becomes as political an act as speaking out**." This report contains compelling insight into the health inequities that we know exist. It provides us with a frame of reference for accelerating efforts to deliver equitable access to our services -

ensuring that our children and young people have an excellent experience and enjoy optimal outcomes.

There is a great opportunity here for transformational change. We must seize the moment and use the impetus created by the pandemic to drive the change and improvement that this report shows is needed.

**Peter Spilsbury**

**Director - Strategy Unit**

# 1. Executive Summary

The population of the Midlands region is diverse in the ethnicity, identity and culture of the people who live here. Within this richness of diversity, there is much variation in social and material deprivation and in the provision of health and care services. Given that it is well established that exposure to adversity in childhood can determine the long-term wellbeing and mental health needs of the adult population, the Midlands region wanted to understand the reason for having the lowest percentage of children and young people (CYP) aged 0-25 accessing mental health (MH) services (across the seven English regions) and why as a region it did not meet the 35% access target.

As part of its regional analytics programme, The Midlands Decision Support Network (MDSN) prioritised the Strategy Unit to undertake a mixed methods analysis of primary and secondary data relating to access of CYP to MH services in the Midlands. Of particular interest to the MDSN was an exploration of whether access to CYP MH services varies by factors of demography or need and the potential reasons underpinning any difference.

The mixed methods data collection included an evidence review, a service user survey, interviews with clinicians, commissioners and providers of CYP MH services and a high-level analysis of current performance data. Through triangulation of the findings, we highlight three key messages below, which are expanded in the findings' chapters (4-6) of this report. Based on these findings we have made recommendations as to actions the Midlands region and individual systems might take in response. In the conclusions chapter (7) of this report, we suggest additional activities related more specifically to improvements in data quality and their use.

We would advocate that both the recommendations here, and our conclusions in chapter 7, are formally considered within the MDSN. Our expectation is that the Midlands region will come to a consensus of how to adopt these recommendations into routine practice, considering also the regional funding of activities. The recommendations at a regional level would also require the involvement of other regional structures such as NHSEI and relevant clinical networks. One approach to locally actioning these recommendations is that systems build awareness of the specific challenges for their own ICS and then work together via the mechanism of the MDSN to deliver them.

There is clearly a moral case for improving access to CYP MH support; there is also a powerful economic case too. Our previous work has illustrated and quantified the implications of adults with MH conditions in terms of their life expectancy and usage of both mental and physical health services. If the findings described in this report are left unaddressed then this previous work shows all too clearly what the consequences will be for CYP with worsening MH issues as they become adults.

## Key findings and recommendations

There are numerous routes into CYP MH services and a wide array of services to choose from – this can be confusing for all attempting to use these services. Those able to persist in their attempts to access relevant services are likely to be more successful in accessing the support they need. Of the 350,000 CYP in the Midlands predicted to have a diagnosable MH condition, only 12.5% are able to access them.

The navigation of MH services is an easier experience for those CYP who have support from an adult (usually parent) who can advocate or navigate on their behalf (when they wish to involve them). Conversely, services are more inaccessible, unsuitable or ineffective for those that are already disadvantaged. For example, poorer (as classified by Indices of Multiple Deprivation) CYP are more likely to have a referral deemed 'unsuitable', have shorter contact time during an appointment and are more likely to be re-referred back into services within a year, despite a higher percentage completing their treatment plans.

CYP from minority ethnic groups access, experience and use services differently, based on a combination of differing cultural attitudes to mental health and societal discrimination. Black CYP have more frequent contact but shorter contact time with services, the highest re-referral rates and are the most likely of all ethnic groups to have prolonged service needs. The poorer experience of MH services for CYP identified as Black is compounded when they are male, socio-economically disadvantaged and/or social workers are involved in their care.

Older CYP (18-25 years of age) are more disadvantaged than their younger peers, mainly as a result of their having to transition to adult MH services. These 18+ CYP find their experience of adult MH services to be poorer, as the services are not well-matched to their needs. 18-25 year olds are less likely to receive support after referral and more likely to be re-referred back to MH services within a year of discharge.

CYP with a learning disability, autism or other neurodevelopmental condition also face additional challenges to accessing the MH services most appropriate to them – frequently, the lack of diagnosis for one condition affects the ability to get a diagnosis or treatment for the other.

**Key Finding 1**

The Midlands, as a region, has complicated processes for children and young people accessing mental health services. This disadvantages some children and young people more than others.

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| **RECOMMENDATION 1: Promote access to all** | ***Regional stakeholders should*** do more to support services user involvement in designing CYP MH services. Some examples of local good practice are evident in this report. These should be collated, shared and built upon to co-produce equitable CYP MH services. |
| | ***Local systems should*** simplify access. They should proactively learn from other areas where access is working well and invest in communication and engagement activity via involvement of the voluntary and community sector to outreach as appropriate to target groups of CYP. |
| **RECOMMENDATION 2: Increase support and access for deprived groups** | ***Regional stakeholders should*** develop a 'psychological profile' of deprived populations in order to develop preventative strategies in education and primary care settings. NHSEI or PHE are well-placed to do this. |
| | ***Local systems should*** move the narrative away from assumptions that certain populations are less likely to access services, to a stated ambition to do more to provide improved access to these populations. Multi-disciplinary teams supporting the mental health of CYP should include social care and education colleagues. |
| **RECOMMENDATION 3: Dedicate resource to improve access for minority ethnic CYP** | ***Regional stakeholders should*** support *w*ork with relevant service user groups to share understanding of wider needs (both social and cultural) to inform the service provision of MH and partner agencies. The MDSN is well placed to lead these activities in a collaborative and coordinated way. |
| | ***Local systems should*** consider investment in a digital offer (e.g. Kooth) where this is not already offered and undertake work to understand whether this offer is more accessible to ethnic minority service users, particularly those identified as Black. |
| **RECOMMENDATION 4: Provide better support to those with ongoing MH needs as they reach adulthood** | ***Regional stakeholders should*** provide service design principles and benchmarks for young adults' MH service provision using evidence-based guidelines, best practice and expert opinion which includes service users. |
| | ***Local systems should*** incorporate quality improvement approaches to improve equity of access for young adults with a focus on discharge and transition between services. This includes holding providers accountable for the quality of this provision. |
| **RECOMMENDATION 5: Provide additional support for CYP with neurodevelopmental conditions** | ***Regional stakeholders should*** provide a regional clinical view on managing the dual support and treatment needs of CYP with neurodevelopmental conditions (such as learning disability, autism, dyspraxia) and MH need. Access to MH support should not be dependent on having a diagnosis of another health condition. |
| | ***Local systems should*** provide training across the health and care system to support a neurodevelopmental condition 'sensitive' workforce. Services should be sensitive to specific needs and not offer generic psychological interventions. |

**Key Finding 2**

There is system inertia with regards to improving equity in access to CYP MH services; lack of regional and national accountability means systems do not prioritise improvements.

The collection and analysis of data related to equity of access to CYP MH services is not common practice in the Midlands. On the whole, activity data was perceived by the system representatives to be inadequately recorded and submitted, resulting in much variation in the quality of submitted data by system and provider. Adding to this issue is the limited awareness on how to appropriately record demographic data in local systems.

The national requirement to report on general access rates maintains focus on that measure, that is a low performance 'ambition' of 35% with a diagnosable condition receiving two or more contacts after referral. In the absence of provider requirement to report on inequity of access, there is no dedicated resource for data collection and analysis of inequities to inform service improvement, there is no investment in engagement to involve children and young people to co-design services, there is no system accountability for improving access.

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| **RECOMMENDATION 6: Prioritise data collection, analysis and use.** | ***Regional stakeholders should*** centralise reporting of access and outcomes measures by population groups and continue to push for data quality improvement from providers.<br>They should then systematically evaluate the service models in use across the Midlands, exploring the associations with demographics, funding and workforce on access measures and health outcomes. |
| | ***Local Systems should*** facilitate data exchange and linkage so local planning can account for population sub-group and geographical variation. |

**Key Finding 3**

The need and demand for some mental health services, such as eating disorders, far exceeds the supply across the Midlands. Demand is expected to rise further as a result of the pandemic.

The conditions of self-harm, emotional disorders, hyperkinetic disorders, conduct disorders and eating disorder have high levels of unmet need across the Midlands. Most notable is the low provision of services specialising in the treatment of eating disorders: of the 160,000+ estimated CYP requiring help for an eating disorder, only 2% are receiving support. There is a variation across the Midlands with some systems having a greater level of unmet need for eating disorders than others.

The average time to treatment nationally for CYP diagnosed with an eating disorders, was more than three years pre-pandemic. This very delayed time to access the right support is understood to be caused by capacity limitations with 30% of urgent referrals not seen within a week. In addition to the previously known factors of some CYP - such as minority ethnic and male - delaying seeking support, CYP MH professionals also recognised that there were primary care challenges in referring. The pandemic was likely to not just increase demand, but increase demand from much younger children.

The many different CYP MH service options in the face of the high levels of unmet need is suggestive of a mismatch in supply and demand. Qualitative accounts suggest an over reliance on Child and Adolescent Mental Health Services (CAMHS) and reactive investment in services. National workforce challenges, with high competition for qualified clinical MH practitioners further exacerbate the inability to match supply with need.

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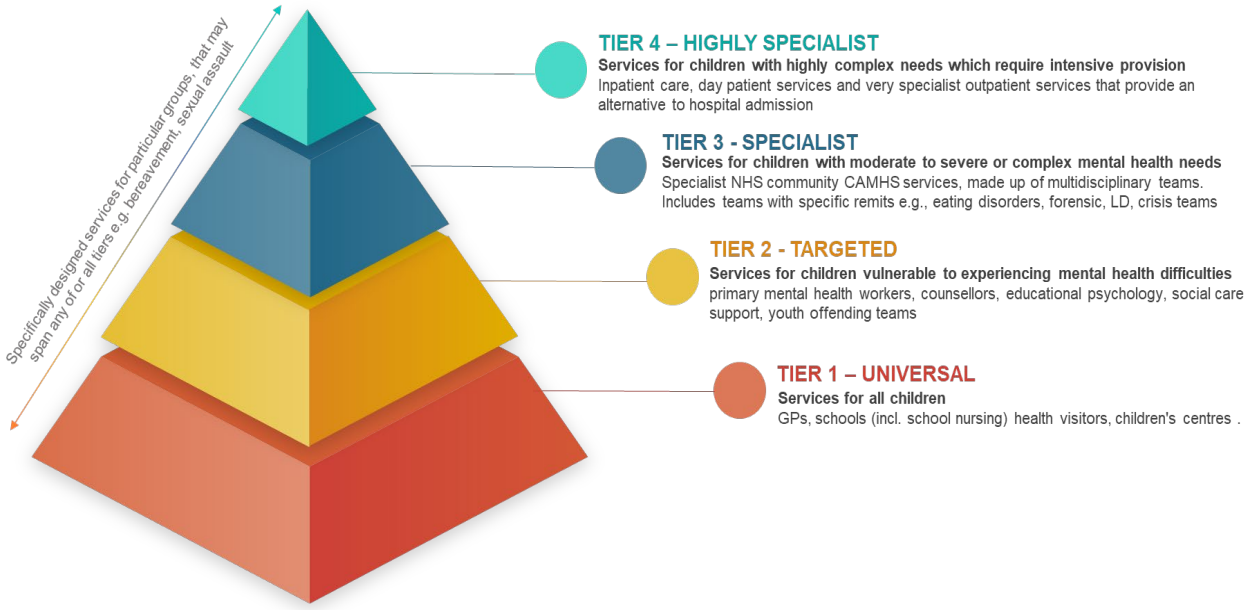
| **RECOMMENDATION 7: Build capacity to support those with eating disorders** | ***Regional stakeholders should*** develop a workforce strategy for eating disorder services and build the case for additional funding for implementing interventions to support those with eating disorders. |
| | ***Local Systems should*** carry out full health needs assessments of eating disorders and review referral pathways and the service model in response. |
| **RECOMMENDATION 8: Distribute resource according to need** | ***Regional stakeholders should*** fully assess the extent of regional inequity and inequality, for example, in admissions and detentions, self-harm, mortality and system-wide service use. |
| | ***Local Systems should*** – before designing and implementing improvements in access<br>• Assess the mental health needs of their CYP population<br>• Review service and workforce suitability<br>• Engage, involve and coproduce service improvements with relevant CYP |

# 2. Introduction

## 2.1 Current Structures

Until recently, mental health (MH) services for children and young people (CYP) have followed a tiered approach, with four tiers providing escalating levels of support dependent on need. Figure 1 below describes this model:

*Figure 1: The four tiers of children and young peoples' mental health services* as mandated prior to 2017




Health and care systems have been increasingly moving away from this model, to 'tier-less' approaches, following the *Transforming Children and Young People's Mental Health Provision* Green Paper (2017), although this transition is not complete and some services are still organised in this way. The aspiration is for 'boundary-less' services with more joined-up working between the NHS, local government, education and the voluntary and community (VCS) sector. Investment is also increasing in targeted early intervention and preventative services traditionally viewed as part of tier 2.

There are many access routes into these services, some of which are described in more detail for the Midlands in section 5.1.

## 2.2 Inequities and inequalities

Health inequalities have been an increasing concern to health and care professionals and policy makers for some time, with the 2010 *Marmot Review* acting as a catalyst. In 2019 the *NHS Long Term Plan* (LTP) called for 'stronger NHS action on health inequalities' and committed to providing those areas with high health inequalities with a greater share of funding to address this. Targeted interventions have sought to improve the health outcomes of: vulnerable mothers and babies;

people with severe mental illness; people with a learning disability; people who sleep rough; and carers; amongst others.

In 2019 the National Collaborating Centre for Mental Health (NCCMH) produced guidance on commissioning and delivering equality in mental health care. In it they argued that:

> "*Mental health inequalities are varied and pervasive, affecting the access, treatment and outcomes that people can expect to receive.*" (NCCMH, 2019)

This guidance recognises that inequalities emerge because certain groups are less able to access the mental health care they need, that is they are subject to inequities in access, because they are not enabled or supported to access appropriate care. The guidance required commissioners to *identify* where inequities exist, *design* services to address these inequities, *evaluate* these designs and then *deliver* them.

Given limited understanding of these inequities in access and inequalities in outcomes from which to base the design, delivery and evaluation of interventions in CYP MH services, senior health and care leaders across the Midlands region – through the Midlands Decision Support Network (MDSN) - asked the Strategy Unit to undertake an analysis of these inequities and consequences on health use later in life. The main findings of this work, as described in this report, provides the region with baseline intelligence to start to reduce inequities in access with the potential to then reduce inequalities in outcomes.

## 2.3 CYP MH service provision in the Midlands region

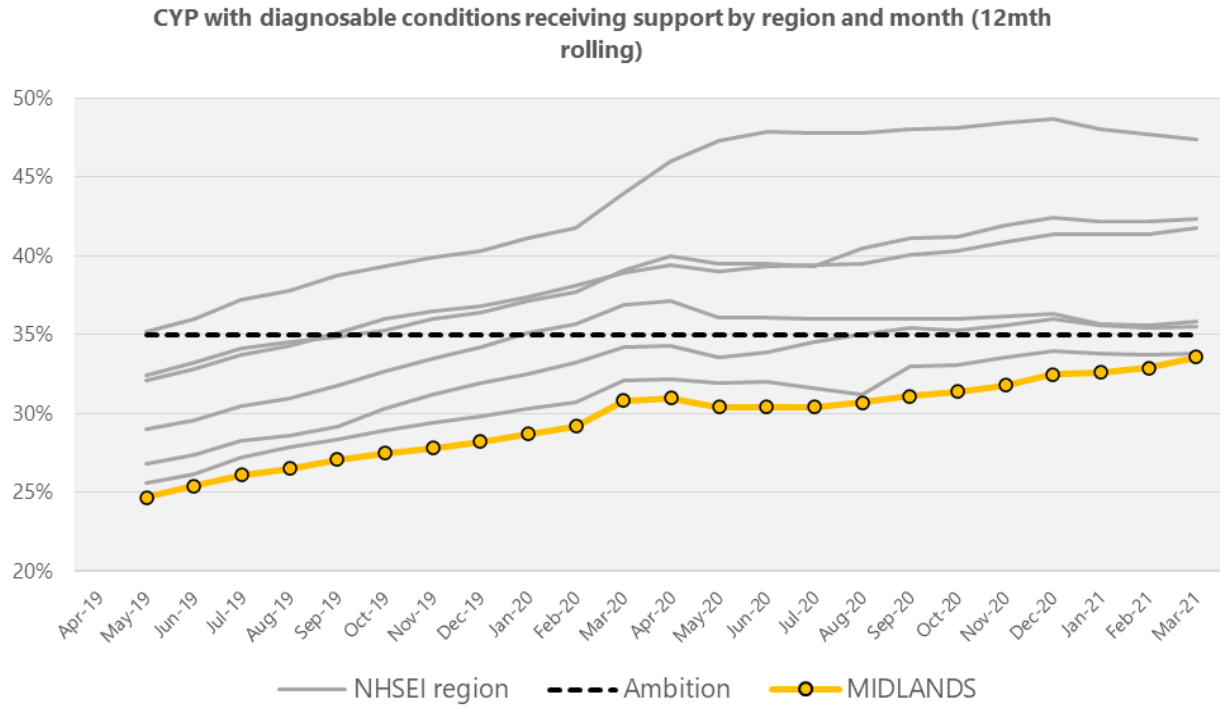
The Midlands is home to eleven health and care systems. These are:

- Birmingham and Solihull (BSol)
- Black Country and West Birmingham (BCWB)
- Coventry and Warwickshire (C&W)
- Derbyshire (Derbs)
- Herefordshire and Worcestershire (H&W)
- Leicester, Leicestershire and Rutland (LLR)
- Lincolnshire (Lincs)
- Northamptonshire (Northants)
- Nottingham and Nottinghamshire (N&N)
- Shropshire, Telford and Wrekin (STW)
- Staffordshire and Stoke-on-Trent (SST)

NHS Digital report the performance against the 35% access ambition for CYP that forms part of the NHS LTP and *Next steps on the Five Year Forward View* (2017). Since May 2019, the Midlands has

continued to have the lowest coverage of MH support for this group of any region in England, although is now approaching the 'ambition'. This trend is shown in Figure 2.

*Figure 2: Percentage access to CYP MH services by region and month to March 2021*




## 2.4 Aims and Objectives

The aim of this mixed methods analysis (triangulating quantitative, qualitative and evidence data) was to describe the current state of inequities in access to mental health services for children and young people in the Midlands region in order to inform better decision-making for investment and priority setting in improving access to these services.

The objectives of this study were as follows:

- To undertake a descriptive assessment of the need, access and demand for CYP MH services in the Midlands, breaking it down by systems and protected characteristics to explore the factors associated with longer-term support needs.
- Provide a qualitative understanding of any differential rates of access, through interviews with individual system leads for CYP MH services and a survey of CYP living in the Midlands and using MH services.
- Contextualise the findings with evidence, by reviewing the literature for known inequities and barriers in accessing CYP MH services and any approaches to mitigating these.

The key findings of this work are reported in this document. The subsequent chapters are structured as: summary methods; three 'findings' chapters (4-6) which are set out to provide the evidence relating to the three main messages from the study and a final conclusions chapter.

The appendices provide some further detail as follows:

- Appendix A: Research methodology
- Appendix B: CYP MH professionals interview topic guide
- Appendix C: CYP service user survey
- Appendix D: CYP evidence map
- Appendix E: Presentation of regional report

# 3. Methods

## 3.1 Summary of data collection methods

This study employed a mixed-methods approach, designed to source data from existing literature as well as gather new data through the means described below. This has inevitably led to a deep and broad range of information on this topic and the core task of the project team has been to collate and distil this to form actionable content for the eleven health and care systems in the Midlands that are members of the MDSN. As a result, there is much that has not been reported in the main body of this report as it goes beyond the remit of inequities in *access*. Some of this additional material can be pursued in follow on discussions with the Strategy Unit for individual ICSs.

The following mechanisms have been employed to gather and analyse relevant data. A fuller explanation of these methods has been included as appendix A.

1. **A review of relevant academic literature**

Academic literature from the international evidence base was consulted to review what is *already known* about the subject of this report. This focused on:

- Known causes of inequities/barriers to access
- Known consequences of these inequities
- Interventions to enhance access

2. **Semi-structured interviews with stakeholders**

At the outset of this research the project team conducted thirty-eight interviews with MH service commissioners, providers and clinicians to inform the study. These were carried out under conditions of anonymity but included representatives from each of the eleven stakeholder systems.

3. **A survey of users of MH services for CYP**

In order to understand the experience of accessing mental health services on the part of CYP themselves, the project team designed and conducted a service user survey. This received eighty-five responses.

4. **Quantitative data collection and analysis**

Three types of quantitative data analysis were undertaken to inform this study. These were:

- An analysis of unmet need to evaluate the ratio of observed demand to estimated needs for a sub-set of common mental health disorders;
- An analysis of pathway inequities that draws on completed spell discharge data to demonstrate the variation in referral pathways, suitability of referrals, intensity of treatment, completion of treatment and re-referrals for different population sub-groups;

- A logistic regression analysis to explore the nature and extent of exposure to demographic, social, health and care factors and their relationship to future mental health support needs.

## 3.2 Presentation of data in this report

All four methods have been employed and triangulated to formulate the key messages for CYP MH services that form the subsequent chapters of this report.

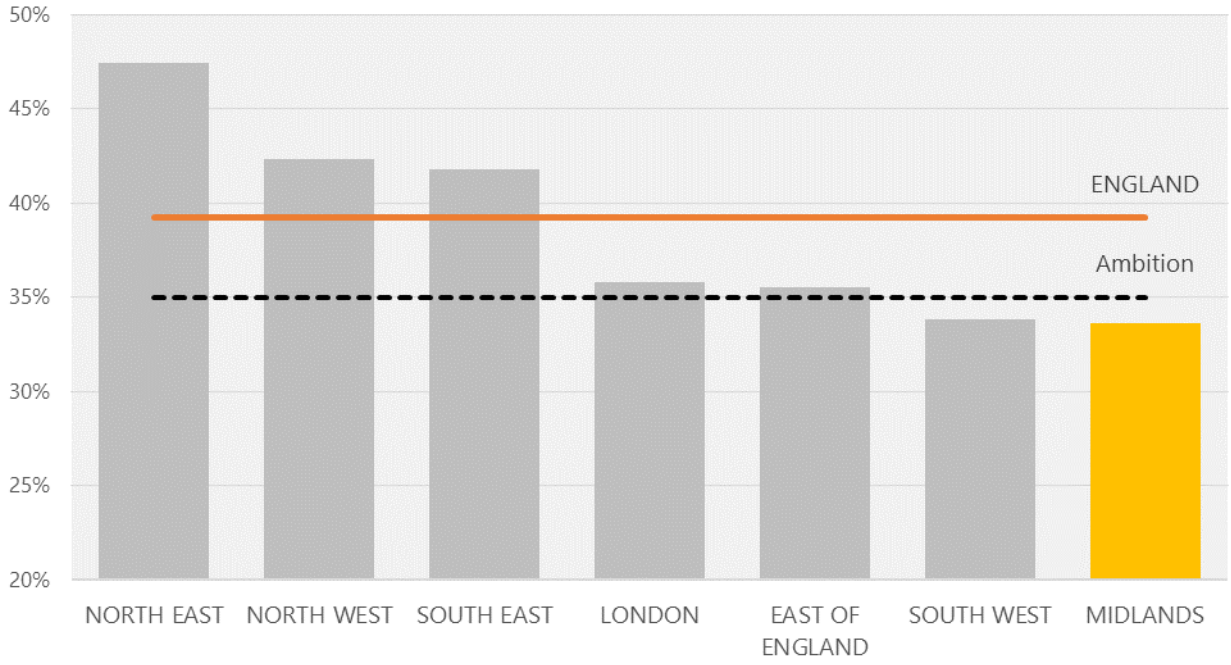
Where quotations from the interviews and survey are used, these have been anonymised to ensure the confidentiality of the source. Clear labelling as to whether quotations are from the survey or interviews (attributed as 'CYP MH professional') is used throughout.

# 4. Accessing services is complicated and inequitable

## 4.1 Access in the Midlands

Official statistics suggest less than 40% of children and young people across England who need specialist support receive it. The Midlands region currently has the lowest levels of 'access' and, along with the South West, has not yet reached that interim ambition of 35%. The North East region by contrast has, by some margin, the highest level of access according to this performance metric.

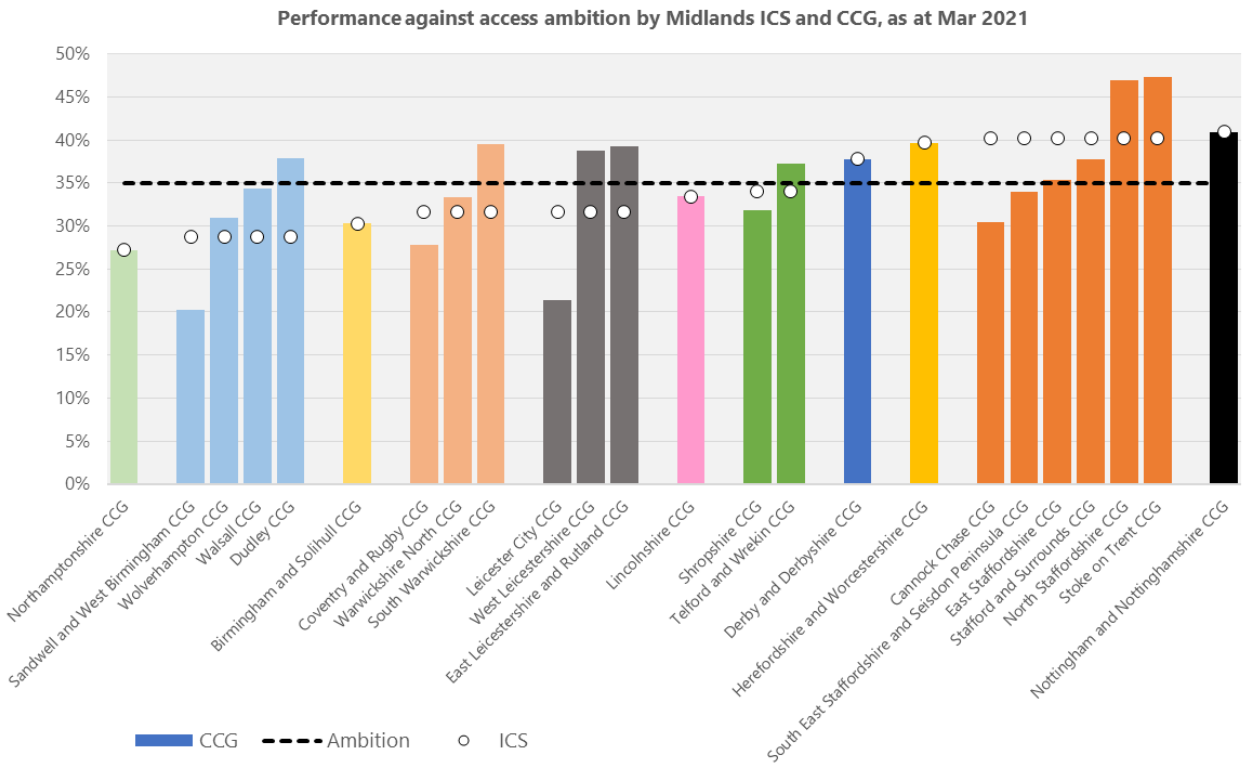
*Figure 3: CYP access target and performance by English region, as at March 2021*




There is significant variation by health economies in the Midlands. Only four of the 11 Midlands Integrated Care Systems (ICSs) have currently reached the 35% 'ambition' and only half of the twenty-four Clinical Commissioning Groups (CCGs). Despite having broadly similar demographic and socio-economic profiles, Sandwell and West Birmingham CCG area has the lowest access rates – only 1 in 5 children – and Stoke-on-Trent the highest – almost 1 in 2 children supported. This suggests there are systematic differences in the provision and delivery of services and/or the reporting against this particular target.

There is no common rural-urban split. Some city areas within ICSs such as Coventry and Leicester have lower access while their rural neighbours have higher access. Inversely, areas like Telford and Stoke appear to have better access whilst neighbouring rural areas have poorer access.

*Figure 4: Access to specialist mental health support by CCG and ICS in the Midlands, as at March 2021. Source: NHS England & Improvement, CYP access dashboard.*




Whilst out of the scope of this study, it would be prudent to explore the associations between funding, workforce, pathways and service models on this particular access measure to better understand the underlying mechanisms that are supportive of, or a hindrance to, access for CYP.

## 4.2 Persistence is required to navigate services

CYP in the Midlands who completed the survey confirmed that they experience difficulties in finding the right information in accessing MH services with almost 50% of respondents stating that it was 'very difficult' or 'difficult'. For example, one respondent stated:

> *"It was possible to find information, but the information itself wasn't very accessible. The language used wasn't easy to understand. I came across different organisations and didn't know which one I should be using, this made it overwhelming, they just kept telling me to refer myself instead of answering my questions, which I felt I needed the answers to before I could make the decision whether to refer myself or not."*
>
> **CYP Survey Respondent**

Survey respondents also expressed some frustration in not being able to access services directly without the knowledge of parents or other adults.

*"There aren't many specifics online and everything points to call[ing] your GP or refer[ring] yourself but it's not that easy for young people who don't want to involve parents/ guardians."*

**CYP Survey Respondent**

Some services were chosen because of the ability to directly access them via a preferred route of communication.

*"[I] liked being able to just email the service; not having to speak to anyone on the phone which I hate doing. That's what made me choose this particular service."*

**CYP Survey Respondent**

CYP also described the lack of information available to them for the services they were trying to access, what they were, how and if they work and how they interact with other support services.

*"There needs to be more services on offer, there needs to be [a] clear description of what these are e.g. counselling or art therapy. There needs to be more sessions offered - there needs to be a review point to see if it's helping. The services need to interact with my school to help there too - none of it flows together or actually helped."*

**CYP Survey Respondent**

Survey respondents also reported that sometimes they did not seek help for a mental health concern because a professional they had spoken to advised that they were unlikely to be seen. Interview accounts of MH professionals were also suggestive of this, furthermore there was some acceptance that CYP MH services were designed to provide a selective access advantage to some over others.

*"I think there's inequalities there because those that know how to access [services] will and those that don't never seem to be successful."*

**CYP MH Professional**

Stakeholders reported the difficulties of being these gatekeepers to CYP MH services when there were expectations of a referral being accepted. This created tension between the different professionals as to whose role it was to inform the CYP or parent that the referral was unlikely to be successful, and added to the confusion felt by those being referred.

*"What wasn't happening is that then the referrer was having that conversation with the parents, so we would always put at the bottom 'please have this conversation with whoever's parents', because you do get a lot of comeback - especially if you're a duty clinician - of a parent ringing you up the next day, the next week, 'I can't believe you've done this', but actually that should be the role of the GP to say, or the, I don't know, the paediatrician, the social worker, whoever's referred, to have that conversation with the parent. And I think that they do shy away from that."*

**CYP MH Professional**

It was acknowledged by MH professionals that parents, carers and CYP who were able to navigate the complicated processes for accessing services, through persistence and an ability to quickly familiarise themselves with the options, were more successful in getting a referral.

*"So yes, I think we're very good as services predominantly run and driven by middle class people in professional roles, at developing systems that are right to help people who are middle class, [.....but] we're not necessarily very good at thinking outside of that without it being paternalistic and a little bit pejorative and condescending."*

**CYP MH Professional**

In the absence of parental or other adult advocating on behalf of the child or young person, it fell to the MH practitioner to play that role, and whilst there might be a desire to fulfil this, there was not always the capacity to do this.

*"It's a tricky one isn't it, because I know if it was my children I'd be as vocal as I needed to be just to make sure things happened, but often people don't understand systems and processes, they don't know our waiting times… I think we're pretty good.., [we have a] really dedicated team, people bust their gut to make sure that they do see young people, but we do have some often at times very vocal people, but that's the nature of the work isn't it?"*

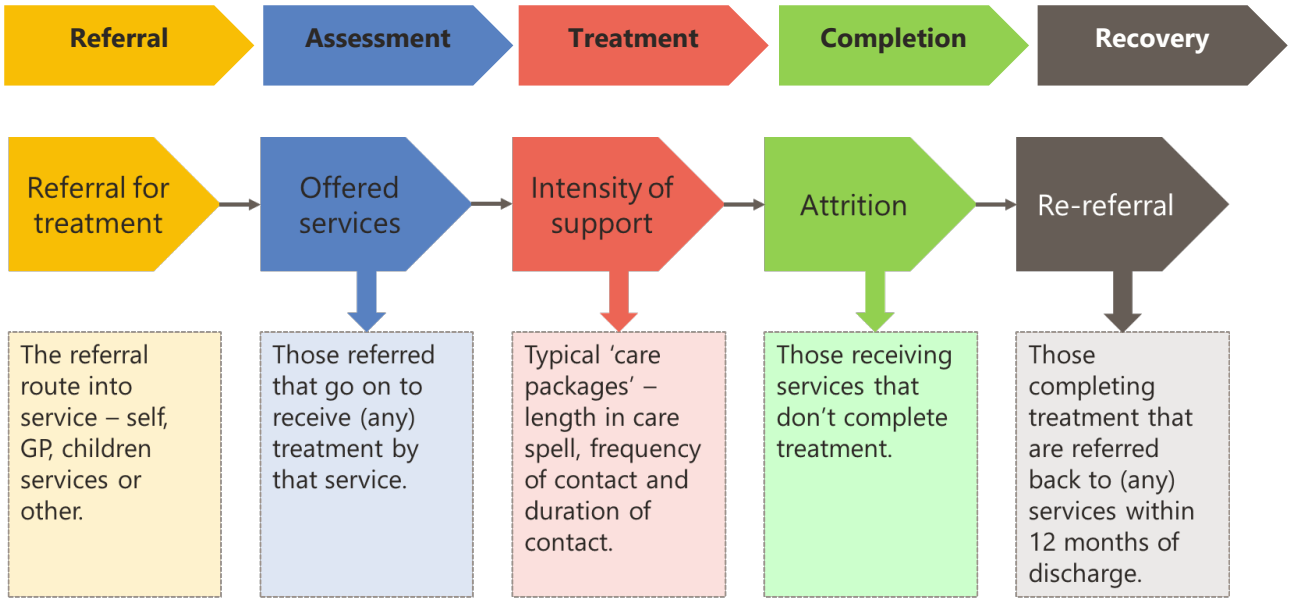
**CYP MH Professional**

## 4.3 Inequities in access to the pathway

The journey of CYP through services once a need has been recognised can be distilled down to five steps of: referral, assessment, treatment, completion and recovery. These steps are not necessarily linear and the concept of recovery is often a temporal one. Figure 5 shows our approach to assessing the variation in these stages. Note:

- A metric/s has been assigned to each of these five steps of the journey;
- The journey of five population sub-groups of: age, gender, ethnic group, Index of Multiple Deprivation (IMD) decile, disability group, are described here as a series of bar charts;
- For these five population groups, quantitative data is triangulated with findings from the literature review, CYP MH survey data and qualitative analysis of MH professionals interview accounts where relevant data is available.

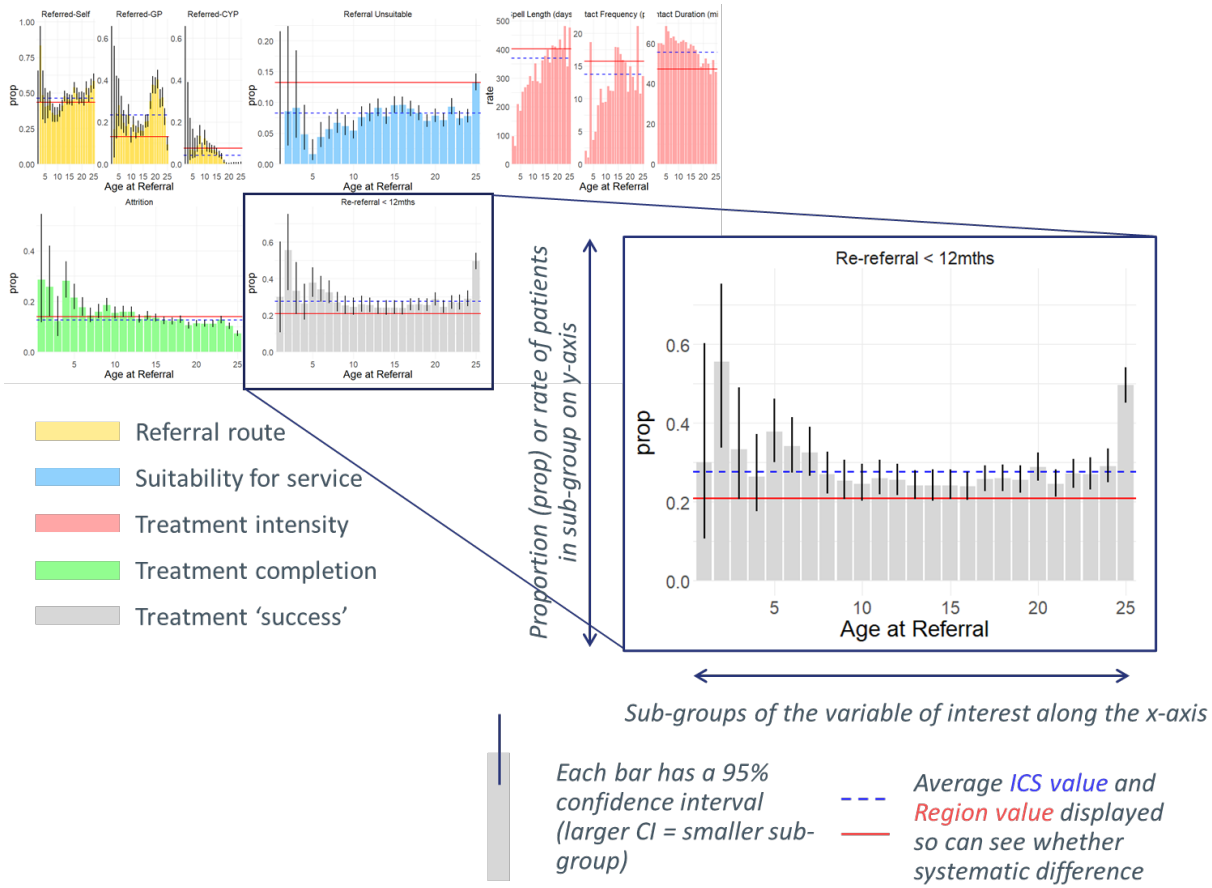
*Figure* 5: Five steps of the CYP MH access pathway with associated metrics.




**Reading and interpreting pathway charts:**

There are several standardised chart clusters in this chapter that represent the data for different population sub-groups for each component of the above pathway concept. The annotated diagram below describes each element of the charts and how they should be interpreted. More information on the data used, methods and descriptions of each metric can be found in the ICS area packs provided in support of this report.

*Figure 6: Pathway diagram explained and key to chart headings*




| Pathway part | Component name | Description & Derivation |
|---|---|---|
| Referral route | Referral-Self | Patient referred themselves – referral source code = B* |
| | Referral-GP | Patient referred from primary care – referral source code = A* |
| | Referral-CYP | Patient referred from other formal CYP service – referral source code = C2,E6,F* |
| Suitability | Referral Unsuitable | Unsuitable referral as determined by the service – Referral Rejection – **OR** the patient – closure reason = DNA, request discharge or refusal to be seen (05,07,09) |
| Treatment intensity | Spell length (days) | Total (avg.) time from date of referral to date of discharge (completed spells). |
| | Contact frequency p/y | Average number of annualised clinical contacts |
| | Contact time (mins) | Average time of clinical contacts |
| Treatment completion | Attrition | % of patients leaving before treatment is complete (DNA, treatment refusal or self-discharge) |
| Treatment 'success' | Re-referral | % of patients with referral (any reason, any service) within 12 months of discharge date |

### 4.3.1 Pathway variation by Age

Analysis of the quantitative data by age (Figure 7) highlights the following:

**Referral** — CYP of secondary school age (11-17 years) are the most likely to self-refer themselves to MH services.

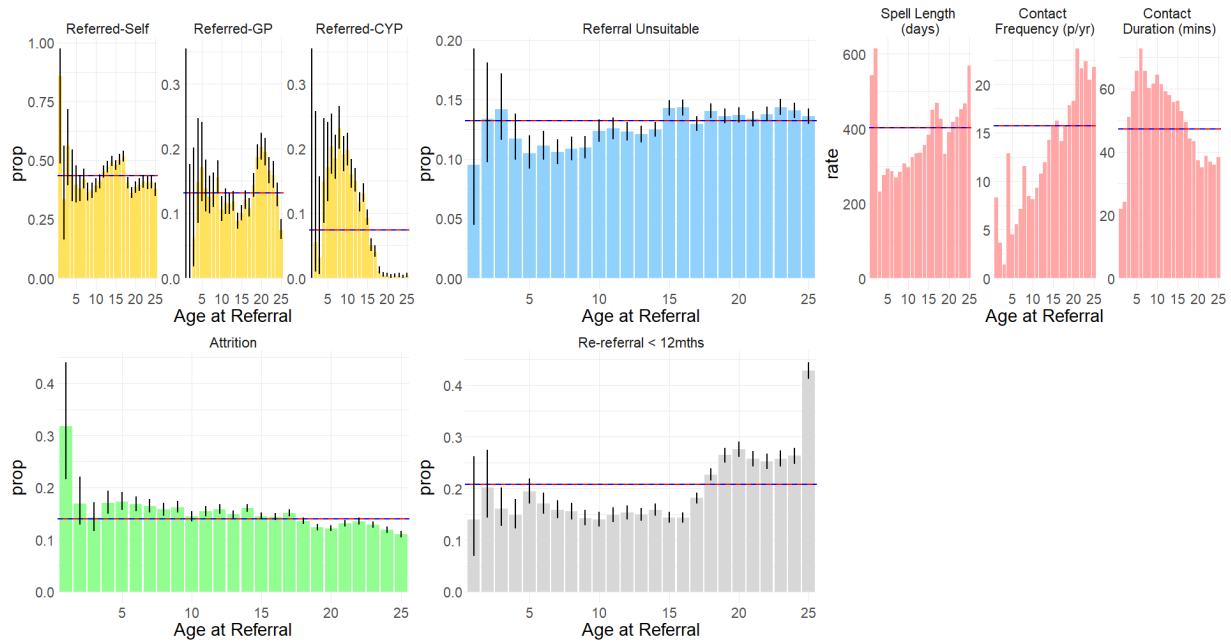
**Assessment** — Young adults (18-25) are the least likely age group to receive MH support after referral.

**Treatment** — Total time spent in treatment and contact frequency increases with age. The opposite is true for clinical contact time per appointment.

**Completion** — The likelihood of CYP completing their treatment decreases as they get older.

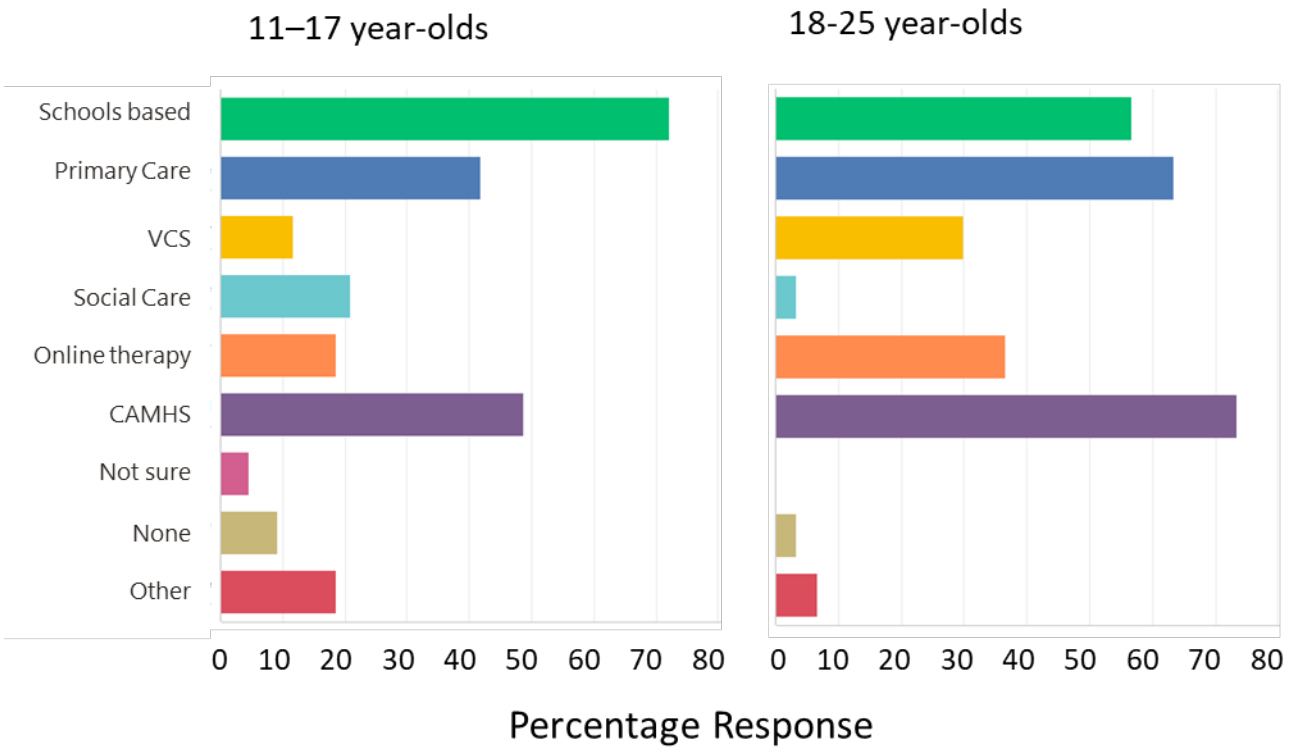
**Recovery** — Adolescents and young adults much more likely to need recurrent support demonstrated by high rates of re-referral after discharge.

*Figure 7: Difference in pathway measures by patient age. Completed care spells 2019.*




Survey responses showed a difference in the services accessed, or attempted to access, by different age groups. Figure 8 demonstrates that whilst the three main routes to access to MH services were via schools, primary care, and Child and Adolescent Mental Health Services (CAMHS), there is an age-based difference within these modes of access. 11–17 year-olds are more likely to attempt to access through their school, whilst 18-25 year olds are most likely to access CAMHS.

*Figure 8: CYP responses to survey question 'what services have you accessed or tried to access support from.'*




The open text survey responses from older young people confirmed the additional barriers to access observed in the quantitative findings above. For example, some stated that they had been told they no longer qualified for the CAMHS MH support they had been in receipt of when they reached 18 and that they often had no option but to take up this offer of adult MH service support despite perceiving that adult service did not meet their needs.

> *"Although [the service] is 0-25, when I was 18 I had to move to an adult psychiatrist in the same building. I wasn't told until my birthday."*
>
> **CYP Survey Respondent**

CYP also described the poor experiences of using MH services as they got older, in terms of accessing, getting diagnoses and treatment.

> *"I got to 25 years of age, I saw counsellors, I saw doctors and I saw specialists and not one person was able to identify that I have ADHD [Attention Deficit Hyperactivity Disorder] and ASC [Autism Spectrum Disorder]. I feel very let down by the limited services available to me… They tried to medicate me which made me very ill because I didn't need antidepressants and the whole experience was very traumatic."*
>
> **CYP Survey Respondent**

Stakeholder accounts confirmed this additional challenge faced by those who are 18+ in the Midlands and the inappropriateness of adult services to meet the support needs of young adults.

*"Under the guidelines we're supposed to be able to treat children, at least for educational purposes and ongoing mental health support, up until the age of twenty five. But all too often when somebody gets to eighteen or seventeen even, they're discharged from CAMHS specialist supervision and they end up hitting adult services, if they need any help, and the adult services are not geared up particularly well for that first five years – eighteen to twenty five sorry, seven years. So I think that that's an area where things can go wrong."*

**CYP MH Professional**

The literature review suggests that the reasons that adolescents and young adults (aged 18-25) feel that adult MH services are inappropriate to their needs include the inability of adult MH services to include accommodation or employment support or routinely involve parents in the process, given they are designed to manage the chronic MH of adults (Paul et al., 2015; Abidi, 2017; MacDonald et al., 2018). This is more problematic for CYP with specific conditions or multiple diagnoses (Swift et al., 2014; Young et al., 2011; Whittle et al., 2018).

This was confirmed by our MH professionals' accounts which highlighted that for those CYP with multiple diagnoses, who transitioned to adult services, they needed to meet more stringent adult criteria for referral. There was awareness that in the absence of adequate support in the transition process there was a risk of disengagement from services (Figure 5) or a cycle of discharge and re-referral.

*"Yes, there are big issues, because a lot of the children and young people that may well have even got through the door and are being supported by the CAMHS type services don't meet the criteria for adult mental health services and you do get more of that holistic view within children's services whereas it's definitely much more separated, you've either got to meet the criteria for the learning disabled team or you've got to meet the criteria for the community mental health service and so you get young people that are sort of discharged into the care of their GP and sometimes that's not sufficient for these young people moving into adulthood. "*

**CYP MH Professional**

A specific challenge faced by those seeking to improve the transition process are hampered by lack of knowledge as to what works. This was raised in interviews and has been reported in the literature: very few interventions of CYP transitioning to older age services have been evaluated (Embrett et al., 2016).

### 4.3.2 Pathway variation by gender

The analysis of the quantitative data by gender (Figure 9) highlights the following:

**Referral** Girls are more likely than boys to seek support via their GP and boys picked up by other statutory services more often than girls.

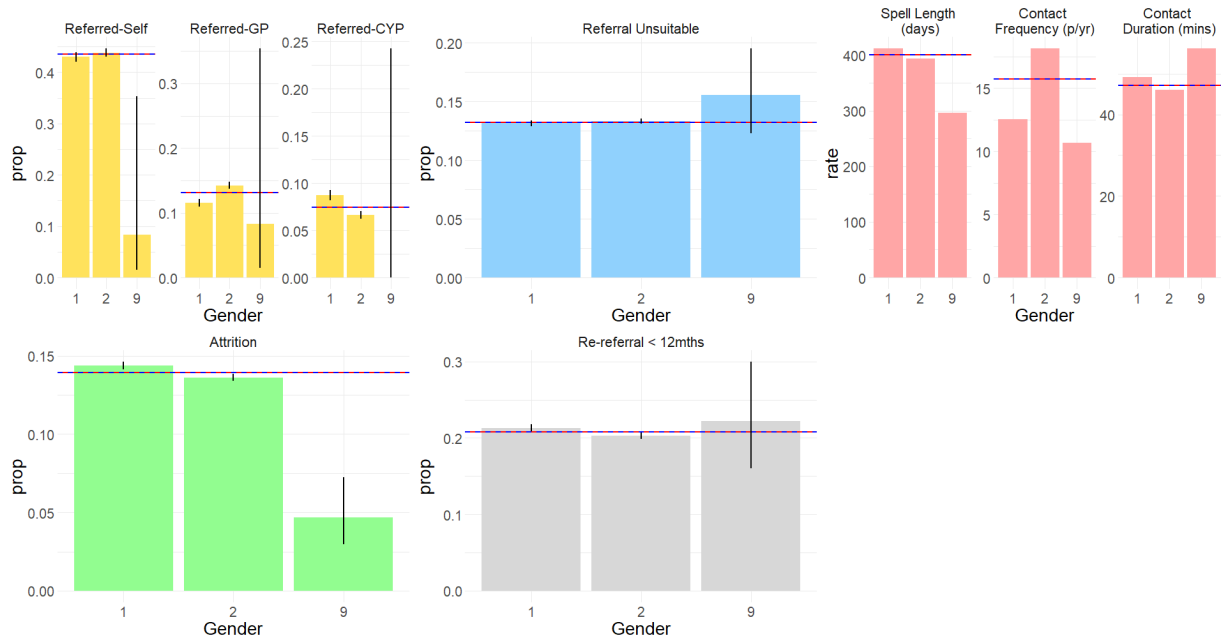
**Assessment** Those with no specific gender are less likely to receive a service after referral.

**Treatment** Care spells are longer on average for girls, contact frequency is highest for boys and those with no specific gender have the longest appointments.

**Completion** The likelihood of 'drop-out' (not completing treatment) is slightly higher for boys than girls.

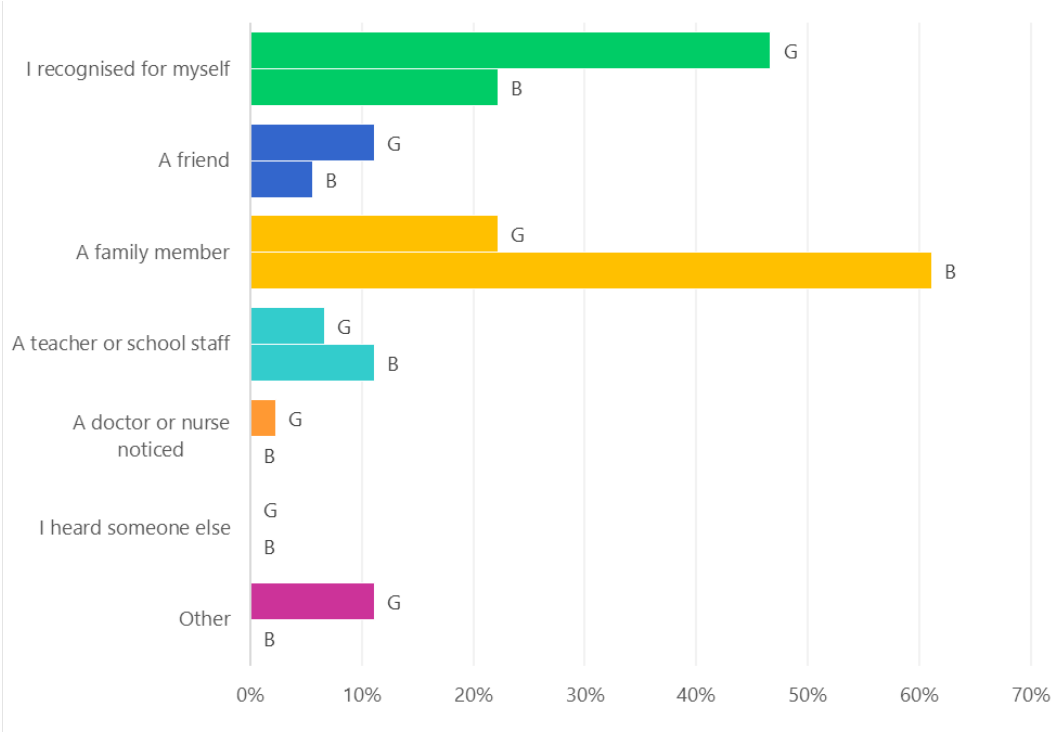
**Recovery** Boys and CYP with no specific gender are more likely to need recurrent support as measured by referral within 12 months of discharge.

*Figure 9: Difference in pathway measures by gender. Completed care spells 2019.*




The survey also surfaced some experiences relating to gender. Figure 10 shows differences by gender even before seeking help: girls are more likely to recognise a need for themselves and boys are more likely to be made aware of a need by a family member.

*Figure 10: Survey response of girls (G) and boys (B) asked 'how did you first recognise that you needed support for your mental health?'*




Another access issue related to gender as described by one survey respondent was the lower recognition of some conditions in girls and young women which may mask their mental health conditions.

> *"There is a huge lack of support for young women with autism or ADHD and more should be done to educate mental health workers on spotting the symptoms of masking behaviour in girls and teens. I was denied all the support I needed as a teen and suffered because of it. More girls need to be identified and supported so they don't slip through the net and struggle later in life. I just think more support and aftercare could have been better."*
>
> **CYP Survey Respondent**

This was corroborated by MH professional accounts, who suggested that some MH issues in girls were more likely to be hidden until a later age as a result of awareness of specific need being lower in society.

> *"We're seeing them [girls] at 15, 16 quite often and we do obviously see them younger, but we see a higher proportion being referred at a later teenage year because some of their symptoms can be hidden earlier on by the schools and parents approaches, if you like."*
>
> **CYP MH Professional**

Similarly, in eating disorder services specifically, there was a concern that poor recognition of the condition in boys meant that they presented to MH services later when support needs became more significant.

*"Our eating disorder service is massively more female rather than male and actually when we do see a young person who is male they're often much more poorly, like, they're often, you know, we're kind of in crisis. Yeah, we see a much more predominantly female cohort of young people coming through. I think it goes down to the stigma really."*

**CYP MH Professional**

There is limited evidence from the literature around gender disparity in accessing mental health services. A study from the US found that a combination of inadequate provision and a lack of knowledge of services prevent young men from seeking professional MH support and suggested this to be a factor of the perceived stigma related to accessing MH services in young men (Lynch et al., 2018). MH professionals interviewed in the Midlands recognised this issue of stigma in boys and young men and some ICS had intervened to provide more gender-based support. For example, Lincolnshire described a service for boys and young men called *Men Talk* designed to get this group thinking more about their emotional health and wellbeing.

Another study from Canada found that girls were more likely to make repeat visits to emergency departments presenting with mental ill health (Leon et al., 2017) and this was corroborated in an interview account discussing emergency department attendance in Northamptonshire.

### 4.3.3 Pathway variation by ethnic group

Recording and coding of ethnicity in the Mental Health Services Dataset (MHSDS) is poor and as such inferences about the ethnicity-based inequities are uncertain. However, the quantitative findings by ethnic group as illustrated in Figure 11 do show a variation in access to CYP MH services across the pathway that may be systematic:

**Referral** — Asian CYP are more likely to self-refer to services. Those who identify as ethnically white are more often referred by children's services (includes education, social care and youth offending teams).

**Assessment** — Those that are identified as 'other' with regards to their ethnicity are more likely to have their referral deemed unsuitable. This group covers Arab populations and those not commonly identified in other ethnic groups.

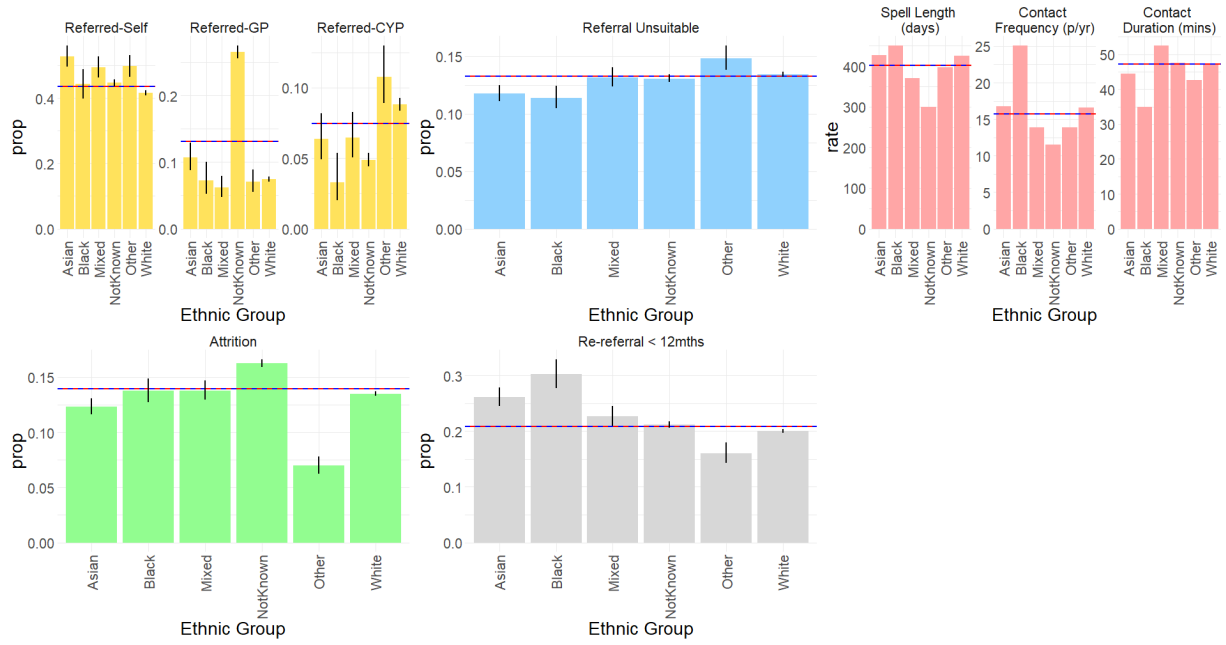
**Treatment** — Black CYP have a different experience of MH services with longer spells of care, more frequent contact and less contact time.

**Completion** — The likelihood of 'dropping-out' of treatment is lower for white CYP than most other ethnicities and significantly higher for those with unrecorded ethnic group.

**Recovery**

Black and Asian CYP are more likely to need a re-referral for MH support within a year.

*Figure 11: Difference in pathway measures by high-level ethnic sub-group. Completed care spells 2019.*




The literature review suggests that the South Asian young people with learning disabilities and/or diagnosed mental health issues face access barriers to MH services for a number of reasons which include: a lack of knowledge and awareness of services; lack of a single point of contact with services; language difficulties; and low understanding of cultural and religious sensitivities on the part of services (Durà-Vilà and Hodes, 2012; Robertson et al., 2019). However, given that in the Midlands (as shown in Figure 11) Asian CYP are the most likely to self-refer, it suggests other reasons as to why their experience, alongside those who identify as Black are markedly different when accessing MH services.

Stakeholder accounts raised the possibility of bias and discrimination based on racial profiling, albeit unconscious, and lack of cultural competence within mental health professionals as factors contributing to poorer experiences of treatment especially in Black CYP.

> *"I mean, I think the Afro Caribbean, Sudanese group have challenges because I think there is inadvertent discrimination. Just the way that those children and families tend to deal with things and present – often they are maligned I think – and that's just a problem of lack of experience dealing with that particular group of people. And certainly, a large young Afro Caribbean male who can look quite threatening is often treated very differently*

*from a similar age Caucasian female, even though their mental health problems may be very similar."*

**CYP MH Professional**

Many MH professionals interviewed, especially those working in areas of high ethnic diversity, perceived that there were differences in access to CYP by ethnicity. However, they could only evidence this by 'soft intelligence' and speculated that lower rates of access were due to poor uptake and lower referrals.

*"But we also, for such a multi-cultural city, don't see a fair representation of ethnic minorities either, which is, yeah. We don't need to jump to conclusions meaning that it's not being met, but I would be curious why there isn't a need there if there's a need in the rest of the population."*

**CYP MH Professional**

CYP responses in the survey confirmed that cultural aspects, in particular the taboos and stigma relating to mental health in specific groups were a contributing factor to their lower rates of accessing MH services.

*"I live in a very tight knit Indian community where mental health is never discussed, and when it is it's always portrayed negatively and passed off as being crazy. I found it incredibly hard to talk to my parents about it. I found it hard to even talk about it with my siblings and close friends around me."*

**CYP Survey Respondent**

### 4.3.4 Pathway variation by socioeconomic status

The findings of analyses by socio-economic group in Figure 12 show a variation in access to CYP MH services across the pathway:

**Referral**

CYP who live in more affluent areas are more likely to self-refer, those living in deprived areas are more likely to be referred by primary care.

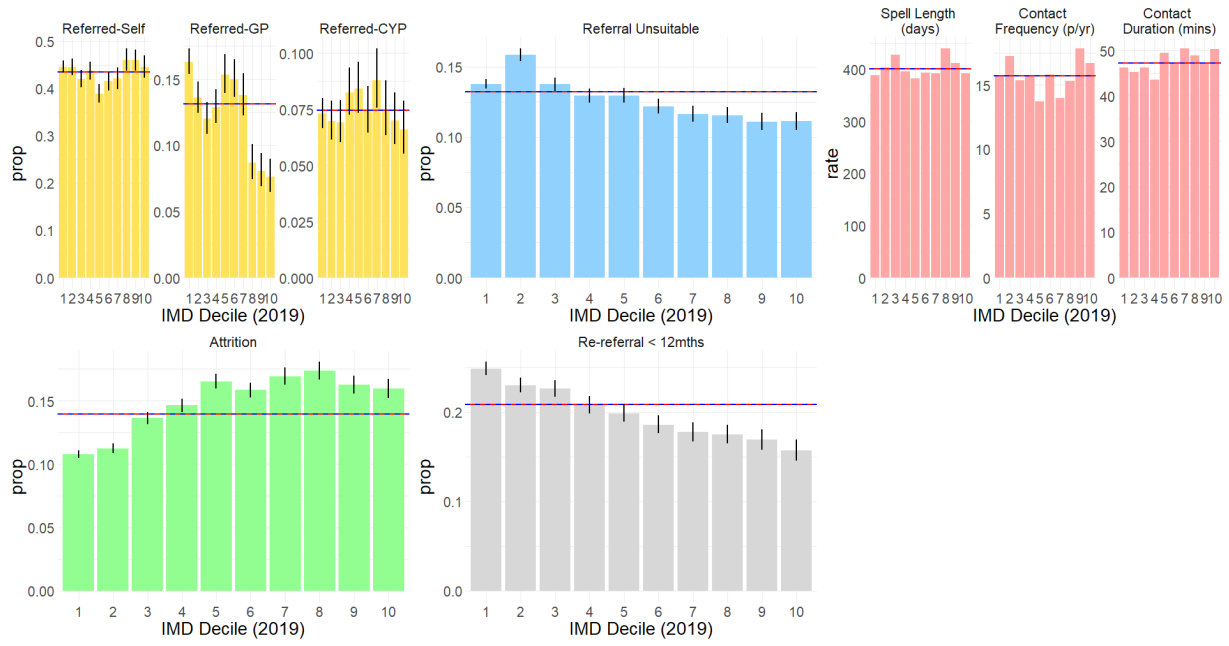
**Assessment** Poorer CYP are more likely to have their referral to MH services deemed unsuitable and rejected.

**Treatment** Poorer CYP have less contact time with MH services once accessed for treatment.

**Completion** The likelihood of 'dropping-out' is lower in CYP who are considered more deprived.

**Recovery** There is a clear gradient in recurrent support needs: CYP who are more socio-economically deprived are more likely to need re-referral.

*Figure 12: Difference in pathway measures by socio-economic status (IMD decile). Completed care spells 2019.*




MH professionals interviewed were aware that CYP from poorer backgrounds were more disadvantaged when accessing support for their MH needs and that there were poor referral rates from areas that were considered socio-economically disadvantaged.

> *"So I can absolutely tell you now that the highest demand for referrals do not come from the areas that I would expect there to be the most predominant mental health problems…I know that some of our wards and postcodes that have got the highest levels of deprivation so they're going to have the highest levels of safeguarding, neglect, highest levels of children's deaths, mortality for example, and we will see the lowest rates of referrals from those areas."*
>
> **CYP MH Professional**

The lower demand for CYP MH services in areas that would be expected to have high need due to socio-economic deprivation was in part understood to be due to lower self-recognition of support needs. Other more basic needs such as housing were seen to take priority before mental wellbeing.

> *"The more deprived populations find it much more difficult to engage. That's for so many different reasons. I think it's not just about them trying to engage. It's about probably their understanding of the causation of their mental health so you know if you sit there and go well, of course I'm going to feel rubbish because this is happening and that's happening, and I can't see any way around it, then you don't identify that necessarily as a mental health issue and that's why it's so important to start a narrative with the early help offer."*
>
> **CYP MH Professional**

The daily stressors and demands of living in poverty that can keep families from prioritising mental health needs has been reported in the literature as well. For example, poverty when combined with rurality, inflexible employment, and ability to travel to appointments can worsen the ability to access support or treatment as well (Hodgkinson et al., 2017; Smalley et al., 2010; Gulliver et al., 2010). MH professionals' accounts from interviews confirmed these additional challenges for CYP and their families when physically accessing MH services.

> *A number of parents who weren't able to get their child into clinic, they couldn't drive, or it was too far away for buses and things like that, we had awful difficulty booking some patient transport to go and pick those young people up and bring them to us. So actually, something that you take for granted that you thought I just thought it would be there, actually really isn't or it was really painful trying to get something. And there are young people, you know, there were single parent families, four or five kids, and they just needed to get one to us in clinic and it would be like a proper day trip out for the whole family trying to get them on the bus to get to us. It was crazy."*
>
> **CYP MH Professional**

Whilst the pandemic, and the new ways of remote consultation provided an alternative to face-to-face consultations, interviewees stated that there was a risk of digital inequities widening societal inequities for CYP that were already poor.

> *"At the beginning [of the COVID pandemic], most services moved to online provision only – that's fantastic if you have the resource in order to be able to access such services – but given the levels of deprivation in the local area and that's now playing out with the online schooling – actually that has had a massive impact on poorer families."*
>
> **CYP MH Professional**

As Figure 12 shows, children who live in more affluent areas are more able to self-refer and have their referral accepted. Interviewees stated that a main reason for this was the ability of parents acting on behalf of their child to seek help and persist in accessing treatment (see section 4.2).

> *"It's a very deprived place, kind of, social status and class and the education levels, they're not as high as other places in the country – actually that is a real disadvantage for some of our parents because quite often as we all know with any walk of life, whether it's CAMHS or not, it's you being forceful and you pushing and you saying 'I really need this' gets you somewhere."*
>
> **CYP MH Professional**

One ICS highlighted that there was still a stigma associated with mental health in less deprived communities which could prove to be a barrier to access for CYP. This could explain the lower referral by GPs or relevant services shown in Figure 12 and has implications for meeting MH needs in children given that the main mode of access to support is through schools-based initiatives as indicated by CYP responses in the survey (as shown in Figure 8).

> *"We know a lot of the private schools and the girls' schools where there is issues, we've tried to offer support and help but they've declined that they've even got an issue… There is a school.., that we knew there was a group of girls self-harming there and we tried to get in and offer them help and 'no, no, no, it doesn't happen here, we don't have any mental health in our school', 'well actually you do', but they would not let us in for love nor money, we could not get in to support any of those kids and they just point blank refused to allow us. There's been a couple of attempts like that, some schools just don't want to admit that they've got mental health needs in them."*
>
> **CYP MH Professional**

### 4.3.5 Pathway variation by disability group

Figure 13 shows the CYP MH access journey for those that have an existing disability. It should be noted that the analysis of this data was limited by the poor recording of disability data. Key quantitative findings for this group are:

**Referral** — Those with a pre-existing disability are less likely to self-refer for mental health support.

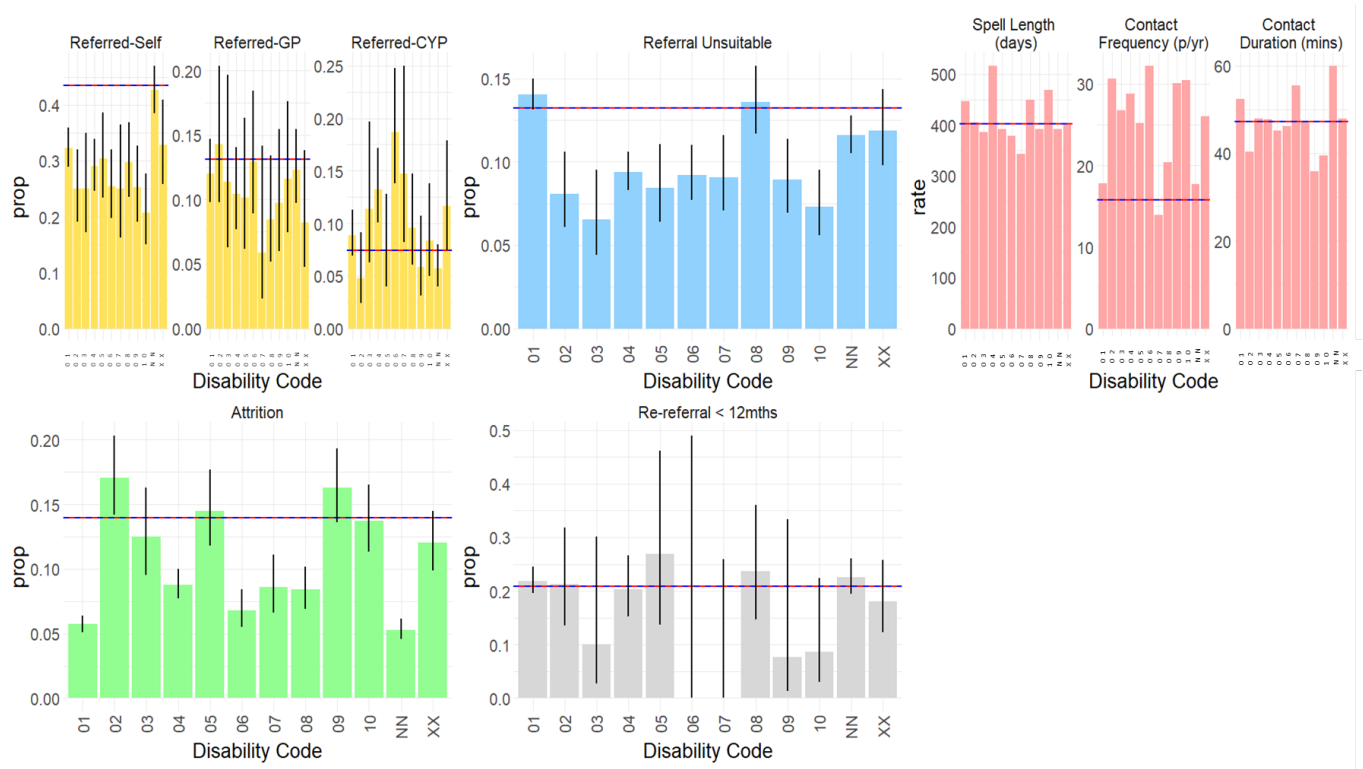
**Assessment** — CYP with existing emotional or behavioural disorders (01) and progressive health conditions (08) are less likely to have a successful referral.

| | |
|---|---|
| **Treatment** | Patients with learning disabilities (04) tend to have longer spells of care and more frequent contact with MH services |
| Completion | Patients with Hearing (02) and Sight (09) difficulties are less likely to complete their treatment plan than those with other disabilities. |
| **Recovery** | There is no significant variation in re-referral within 12 months for CYP who have a health disability recorded. |

The full list of disability codes for Figure 13 are as follows:

| | |
|---|---|
| 01 | Behaviour and Emotional |
| 02 | Hearing |
| 03 | Manual Dexterity |
| 04 | Memory or ability to concentrate, learn or understand (Learning Disability) |
| 05 | Mobility and Gross Motor |
| 06 | Perception of Physical Danger |
| 07 | Personal, Self Care and Continence |
| 08 | Progressive Conditions and Physical Health (such as HIV, cancer, multiple sclerosis) |
| 09 | Sight |
| 10 | Speech |
| XX | Other (not listed) |
| NN | No DISABILITY |

*Figure 13: Difference in pathway measures by existing disability sub-group. Completed care spells 2019*




Qualitative accounts, both through the survey and interviews reveal that CYP with a learning disability, autism or other neurodevelopmental condition, experience unique barriers to accessing MH services, mainly because there is a dependency on having obtained a diagnosis for their condition first. This was more challenging for those who had autism and identified as girls.

> *"[My] GP wouldn't refer me - said school had to do it.... school wouldn't do it, said education had to do it - no one helped - my parents had to push to get me help. Help only came once I got [my] Autism diagnosis."*
>
> **CYP Survey Respondent**

> *"It's a bit tricky because you might have someone that's got strong autistic tendencies and that they've been through – they're on the track – pathway of a neurodevelopmental assessment and pathway but they can't get into CAMHS to get the holy grail of a diagnosis, until they get the diagnosis they can't access other services such as [Autism Services], resources for autism, Barnardo's, because they haven't got the magic diagnosis. Even if they get the diagnosis, there's nothing else from a pathway perspective."*
>
> **CYP MH Professional**

It was clear from these accounts that poor understanding of dual and complex support needs on the part of professionals and the services offered put the onus and burden on CYP with neurodevelopmental conditions to access support for their mental health needs.

*"I wish they would understand why I couldn't 'engage'. They just don't understand autism especially the demand avoidant profile."*

**CYP Survey Respondent**

*"One of the things that can go wrong is that finding a bed for somebody whose needs can be met when they're complicated, because they've not just got a pure mental illness - they've also got either a learning disability or autism as well - can be challenging in terms of getting the marketplace to offer a support to place these people, because their needs are so complicated. So that's an issue that I am aware of and that's around the whole of the Midlands. It's very easy for providers to decide "we're only going to deal with x and y" but the patients that are coming through the system are always going to have x, y and z, and so the provider will say 'oh we don't deal with that' and then you've got nowhere to put them."*

**CYP MH Professional**

### 4.3.6 Pathway variation for other groups

There were several other notable findings from the pathway analysis, that weren't necessarily supported by evidence from the qualitative study. As such, these should be treated with caution or subject to local stakeholder engagement to corroborate.

**CYP engaged with the Criminal Justice System (CSJ)**

**Referral** — CYP engaged with the Criminal Justice System are much less likely to self-refer for mental health support.

**Assessment** — Those from a CJS background are slightly less likely to receive a service than others.

**Treatment** — Patients with CJS background tend to have less frequent contact but more contact time.

**Completion** — Patients with CJS history are significantly less likely to complete their treatment plan than others.

**Recovery** — They are also significantly less likely to re-refer back to services within 12 months of discharge.

**CYP with looked after child (LAC) status**


Those with a LAC status are much more likely to be referred by statutory agencies than other children.

LAC are more likely to receive a service than others.

Patients that are LAC tend to have longer care spells, less frequent contact but more contact time.

Patients with LAC status are significantly more likely to drop out before completing treatment.

They are also significantly less likely to re-refer back to services within 12 months of discharge.

### 4.3.7 Chapter Conclusion

The findings in this chapter highlight that there is a dependency on understanding the user pathways and referral mechanisms on the part of the CYP or their parent/carer, to stand the best chance of entering into services and receiving appropriate and effective support and treatment. It is unlikely that this understanding will be equal across factors such as socio-economic status, making these challenges unequally experienced.

It is also unlikely that the varied experiences of access will be understood by MH professionals without the involvement of the CYP who are likely users of the services. As one interviewee from a service that had involved CYP in co-design of MH services put it:

> *"I would say that what we've delivered in the mind of children and young people is hope that you can shift services and you can tell us about your experience of services, and you can expect there to be an improvement or transformational change based on the feedback that you provide for us."*
>
> ***CYP MH Professional***

# 5. Equity in access is not a system priority

## 5.1 Access routes into CYP MH services in the Midlands

MH professionals described the myriad of MH services available to CYP, some of which aim to meet the specific needs of a specific group of CYP. Those described have been collated in Table 1 and in the section below. Given that the table and descriptions are based on interviewee accounts, they are not exhaustive, but provide an indication of where CYP MH resources have been prioritised to support access.

Some access routes to CYP MH services are ubiquitous across the Midlands, although their scale of implementation varies. For example, all systems have a single point of access (SPA), or are working towards one, but who can refer to this access point varies. It is clear from these descriptions that the focus of resource has been on streamlining access routes and preventative and early intervention services such as Mental Health Support Teams and online MH provision. These, and other types of provision, are described in more detail below. There is a need for systematically evaluating the models currently in use and their effectiveness in terms of equity in access and health outcomes.

**Online access - Kooth**

Kooth provide an online platform where CYP can access mental health support and resources anonymously. This includes information, messaging services, online forums, activity centres and live counselling. CYP do not have to be referred to Kooth and can access its services themselves 24/7. Nine of the eleven Midlands systems commission Kooth to deliver its services in their area.

**Online access – system-dedicated website**

Some systems have established their own dedicated webpages to support CYP to access their MH services. Staffordshire, for example, have a site providing details of local services delivered by Action for Children. CYP, parents and carers, and professionals can all refer a CYP via this site. BSol's Forward Thinking Birmingham also caters for direct referrals as well as signposting to local services.

C&W have developed their Dimensions Tool. This is a free online tool providing personalised information to support an individual's wellbeing and mental health. The Dimensions report it creates provides information that is relevant to the ratings made on each of the Dimensions. It can be used to find self care, local support groups and telephone help lines, and services offered through the NHS and various other organisations.

**Online access - Healios**

At least two of the Midlands systems commission Healios, an online mental health treatment service. Healios provide direct support to CYP who may not require a CAMHS intervention. It provides mental health assessments, therapies and interventions, and mental wellness self-care.

Feedback obtained by Healios identified that 76% of CYP liked being able to have a session within their own home and 93% felt the services fitted well with their daily routine (C&W CAMHS, 2019).

**NHS 111 for crisis care**

As set out in the NHS LTP, through NHS 111, all CYP experiencing a mental health crisis can access crisis care 24/7.

**Single point of access**

A SPA is a single point for all mental health referrals, which are then passed to the most appropriate service or signposted to other support. Models vary in terms of who can refer to the SPA, but the mechanism is widely used across the Midlands. Coventry and Warwickshire's RISE service, for example, operates a navigation hub where professionals can make referrals on behalf of a CYP up to the age of 17. In Nottinghamshire, parents and carers, as well as CYP themselves, can refer into their service.

**Schools provision: Mental Health Support Teams (MHST)**

As set out in the government *Green Paper* on CYP MH, these teams are linked to groups of primary and secondary schools, and to colleges. They provide interventions to support those with mild to moderate needs and support the promotion of good mental health and wellbeing. Most systems provide this service, or are in the process of establishing it.

**Self-referral**

Just over half of the Midlands systems allow self-referral into at least some of their services. This includes CYP referring themselves as well as parents or carers doing so on their behalf. Some systems only provide partial self-referral where it is only available for some of their services.

**24/7 crisis resolution and liaison mental health services**

The *FYFV for Mental Health* required CCGs to commission improved access to these services for CYP by 20/21, although not all systems in the Midlands have been able to offer this at the time of this study. This service is most commonly a freephone number to a crisis team who will provide advice and arrange an urgent appointment with a mental health professional if required.

**Initial Assessment Teams**

An Initial Assessment Team (IAT) has been established in BCWB. Following an initial triage from the SPA, the IAT would assess patients that were not passed to specialist core CAMHS clinicians. The IAT is staffed by psychologists and senior nurses and would take on approximately half of initial assessments required, freeing up core CAMHS clinicians. The IAT also provide solution focused interventions to patients that don't require specialist interventions. The purpose of this team is to try and reduce the waiting times for these patients.

**Emergency department mental health triage**

In LLR, they have an all-age mental health initial triage service within their emergency department. If a child presents in the department with a mental health issue, they are reviewed and risk assessed, before being directed to the appropriate intervention.

**CAMHS liaison in primary care**

In BCWB, GP surgeries can subscribe to having a CAMHS liaison, who can carry out an initial appointment with a CYP if they are attending due to a mental health concern. This role provides support to GPs around appropriate referrals into mental health services.

**Social prescribing**

In BSol, they are creating Community Connectors, whose role will be to support families who have children at risk of developing mental health issues to access non-medical support in the community.

**Wellbeing cafés**

In Northants, they have begun a pilot for a wellbeing café where CYP can drop-in to receive support ranging from advice and guidance around their mental health to crisis management. This is called *Espresso Yourself*.

*Table 1: Access routes CYP mental health services by system*

| *Intervention type* | SPA | MHST | NHS 111 | Online offer - Kooth | Online offer - other | Self-referral | ED triage | CAMHS liaison | Social prescribing | Crisis café (drop-in) | Initial Assessment Team | 24/7 crisis resolution |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***BCWB*** | ✔ | ✔ | ✔ | ✔ | ✔ | **Partial** | | ✔ | | ✔ | ✔ | ✔ |
| ***BSol*** | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | | ✔ | ✔ | | |
| ***C&W*** | ✔ | ✔ | ✔ | ✔ | ✔ | **Partial** | | | | | | ✔ |
| ***Derbyshire*** | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | ✔ | | | | |
| ***H&W*** | ✔ | ✔ | ✔ | ✔ | | ✔ | | **Partial** | | | | ✔ |
| ***Leics*** | ✔ | ✔ | ✔ | ✔ | | | ✔ | | | | | |
| ***Lincs*** | ✔ | ✔ | ✔ | ✔ | | ✔ | | | | | | |
| ***Northants*** | ✔ | ✔ | ✔ | | | | | | | ✔ | | |
| ***Notts*** | ✔ | ✔ | ✔ | ✔ | | ✔ | | | | | | |
| ***STW*** | ✔ | ✔ | ✔ | ✔ | ✔ | | | | | | | ✔ |
| ***Staffs*** | In train | ✔ | ✔ | | ✔ | **Partial** | | | | | | |

Required in *Transforming Children and Young People's Mental Health Provision*

Required in *Five Year Forward View for Mental Health*

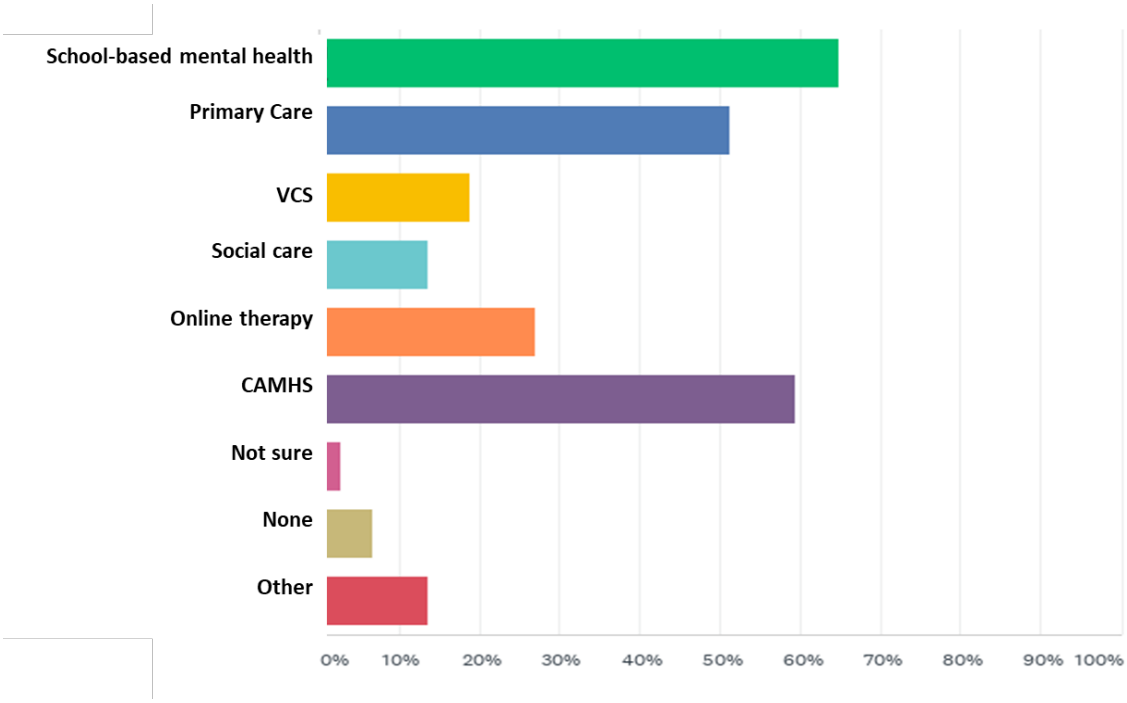
Required in *NHS Long Term Plan*

## 5.2 The experience of the main routes of access

### 5.2.1 CYP experience of the routes to accessing MH services

CYP who responded to the survey identified the three main routes of accessing MH services (Figure 14; see also Figure 9 for breakdown by gender) as being: schools-based services, primary care and CAMHS.

*Figure 14: Survey responses showing the main routes of access into CYP MH services attempted by CYP.*




There was some frustration expressed through the service user survey of a lack of coordination between these access routes. For example, one respondent described a situation where they were referred by their GP to a mental health service but were also told to self-refer themselves. The purpose of each MH appointment was also not made clear to them; with the CYP not made aware that their first appointment was an initial assessment and not treatment. The same respondent, and others, stated they had to repeat their symptoms to multiple healthcare professionals and communication between services was poor. They concluded that:

> *"I know that especially now there are so many people trying to access the services so the wait times can't be helped, but a bit of communication about them and about what to expect at each appointment would have been really helpful and reassuring."*
>
> **CYP Survey Respondent**

This view was not universal however, with another respondent feeling that services in their area did liaise well with each other. Although the long waiting times to access CAMHS came up persistently in the survey, there were some positive experiences reported once a CYP had been seen. For example:

> *"I used CAMHS when I was younger and I feel that this specific help was useful"*
>
> **CYP Survey Respondent**

More than half of survey respondents found information about mental health support available to them through their school/college or through their GP suggesting that these are key sources of information to CYP along with family members and seeking out information themselves online.

Digital and telephone appointments have also been used increasingly by service providers due to the pandemic. Some of the survey responses however, demonstrate that these do not work for everyone as it requires the involvement of parents or is not the CYP's preferred method of communication.

> *"All online or limited appointments, [so I'm] reliant on parents and [I have] little independence to seek help."*
>
> **CYP Survey Respondent**

> *"Everything is online or phone. It's harder for me to use this... I won't even talk to family this way."*
>
> **CYP Survey Respondent**

> *"[There] should have been virtual meetings but the camera never worked for them... so ended up on [the] phone and I don't like talking on phone."*
>
> **CYP Survey Respondent**

These responses suggest that MH services need to provide different choices, that are more in keeping with the age and circumstances of a CYP, in order to improve access to services and complete treatment.

### 5.2.2 MH professionals' perspectives on access routes

MH professionals interviewed observed the same three preferred routes of access and in particular highlighted the over-reliance on CAMHS, including by other health care providers. This was argued to be a result of medicalising MH support needs, in part due to the belief that a MH diagnosis was required for entry into MH services and CAMHS in particular. The system dependency on a

diagnosis meant that CYP who could benefit from an earlier lower tier service were missing out on timely support.

> *"One of the reasons for that additional pressure on referrals is because the parents and everyone think that the only way to get any help from education services is to actually have a diagnosis of one of these conditions. So without the diagnosis they feel there's no help available. That's why everyone's on the waiting list for a diagnosis. And during that time they might not be getting any help, which could be a year, could be longer than a year which is a long time for a kid at school to be struggling with whatever.*
>
> *So the question is, well why do they think they need a diagnosis when in fact that's not actually strictly speaking true. It should be done on need, and there's a lot of either myths or misunderstandings within the system about the need for a diagnosis in order to get access to help. So we have had a problem with people not maybe using those early services when they could, in preference they want to be referred."*
>
> **CYP MH Professional**

A number of reasons were provided for maintaining the status quo of dependency on particular services. One reason was poor communication of the types of services available to CYP that matched their need and the providers of these services. In particular the ability of third sector agencies to be able to provide preventative and targeted early intervention support in a timely and high-quality way was not always shared with CYP and their parents. This was more problematic for those already disadvantaged by poor access, for example as a result of language barriers.

> *"I think people feel fobbed off because we don't manage expectations and because I think we sell them this line of 'oh, you can come into mental health services and we're going to meet all of your needs and that's going to include you having a mental health nurse as a care coordinator, a child psychiatrist and child psychologist'. We've fostered these outcomes based on those conditions being there… I think then when people go away and they go 'blimey, I've just been signposted to the Children's Society to speak to somebody there about my mental health problems' and we haven't necessarily described that actually the Children's Society have been given a million pounds to run an absolute professional service and have to have a quality kite-mark and they have to jump through hoops through my quality assurance and governance to make sure that they deliver high quality services. So I just don't think we've got the culture of that right yet."*
>
> **CYP MH Professional**

Despite the uncertainties of increasing demand for higher tier services and the ability of systems to cope, there was a degree of confidence that a school-based resource would improve access to CYP MH support in a timely way. In some systems this was based on prior work which had identified the need for emotional wellbeing support in CYP that could be provided by trained school-based staff.

*"Our offer is going to be as a completely integrated school resource with an education and mental health practitioner who's a band 4 post in each school and they've just completed the first wave of their training and they're doing digital placements in schools at the moment, so we would expect that that programme will really improve access more broadly - not just CAMHS – and it's not – that really isn't what it's about – it's about being able to improve access and early intervention and work with other partners so we don't duplicate other people's work."*

**CYP MH Professional**

Similarly, there was confidence in the ability of other preventative and early intervention services to support CYP to access the right support in a timely manner.

*"I think that's where, you know, we're seeing that we have made that improvement because we have been able to put in additional resource, particularly at that earlier end of the pathway and that's been the strategy. It's obviously a really tricky time with COVID to access for children and to get the referrals but yeah, we have seen that improvement."*

**CYP MH Professional**

## 5.3 Collection and analysis of data related to equity

Interview accounts of CYP MH professionals revealed many inconsistencies and inadequacies around data collection for CYP MH services; equity of access and impact on equalities is poorly recognised and understood across the Midlands. Three overarching themes related to this point were identified.

### 5.3.1 Activity data is inadequately and variably recorded and submitted.

CYP MH professionals pointed out the numerous challenges in collecting and recording activity data accurately and consistently, which could frustrate commissioners and providers alike. For example:

*"I do think that we have an issue with data recording. I think it was March and April or quarter 1 of last year – they leapt out of nowhere by a significant proportion and it was noticeable. So I spoke to them and asked what had happened here, how did you do all of this – and essentially they have done a huge data analysis audit; they went through everything with every one of their providers and identified where providers believed they were putting activity in, but it wasn't being drawn through to the system."*

**CYP MH Professional**

A key challenge for obtaining good quality CYP MH data is the inevitable inconsistencies that arise from multiple providers recording activity on multiple datasets, some with more experience than

others.

> *"I think anybody who's involved in the mental health services dataset will know that it's torture and we always have issues, whether it's counting the right beans or not, and we're an NHS organisation which is completely orientated towards the datasets. If you're a different sort of provider, let's say a voluntary organisation or a charitable organisation, I would be worried about the alignment of their data, so in terms of what it represents. So whether it represents the truth or not, I'm not certain."*
>
> **CYP MH Professional**

As CYP MH services could be commissioned and contract managed through a number of commissioning arrangements, relevant decision-makers may not have access to all the data they require, nor have the ability to hold providers accountable for data recording or performance against contracts or standards expected.

> *"There's also the potential issue of other providers not submitting data to the mental health service dataset that we don't commission, because I commission [one] contract and then there's the other bits we've described that, you know, additional investment into crisis, additional investment into eating disorders, we don't have involvement in that contract management or of commissioning those contracts. So we don't necessarily know [the data], however, as commissioners, we're expected to be updated and reporting and explaining why that access rate isn't met even though we may not commission all the services responsible for the datasets."*
>
> **CYP MH Professional**

These challenges around data collection and quality mean that confidence in reported access rates is not always high, although recent improvements in this area were reported in a number of systems.

### 5.3.2 Reporting on inequity of access.

Even where confidence in data quality is higher, the national target around access is focused on the number of contacts made with services, and not who is making those contacts. The pressure felt by systems to meet this target means that they are not incentivised to collect and analyse data relating to equity of access.

> *"I don't think we get specific data around 'this many proportion are accessing it and really it should be that' – so I think probably in terms of our data and comparing it in that way we're probably a bit light in terms of understanding that differential between if there's specific populations that aren't accessing it."*
>
> **CYP MH Professional**

This has meant that, despite a shift in focus nationally to understanding better issues relating to health inequities and inequalities, the understanding, data and evidence relating to it for CYP MH services, both regionally and system-wise was still expected to play catch-up.

> *"Every discussion that we've had with NHSE recently has always included a conversation about inequalities and that just simply wasn't the case about a year ago.., it's a shame that it's taken a pandemic for us to get to that stage but in those discussions that we had.., people just don't have any real – anything quantifiable [to contribute]. They've got a lot of anecdotal perspectives on things, so I don't think there's enough evidence to understand where those inequities and those inequalities exist."*
>
> **CYP MH Professional**

There was also some scepticism from MH professionals as to whether the focus on improving performance against the access target improved the experience and outcomes of the CYP who are accessing these services. Or whether the national requirement to report on general access rates maintains focus on activities relating to improving the recording of that measure rather than quality improving the services that underpin that performance.

> *"And the reality is a lot of the performance has also come through improved reporting and data-flow so we've had a lot of services that haven't historically kind of reported all the data or had challenges so there's a scepticism in me and I'm accountable for this area. So I'm conscious of how this comes across but actually we've hit the target and actually maybe things haven't changed on the ground for children and young people."*
>
> **CYP MH Professional**

### 5.3.3 Resource for data collection and analysis

It was clear from interviewee accounts that most systems did not have dedicated resource collecting and analysing data relating to access and equity, which resulted in the extent of the problem being poorly understood in individual systems.

> *"It's [demographic data] not something that's routinely collated, I don't think, but it's certainly something that is missing. I haven't seen that data so in relation to [inequity of access] - each of the key [protected] characteristics - I haven't seen that data. I'm not sure we collect [that] data. Now there's probably some of that available in the JSNA work I was referring to, but that's something that we have do more work on. I think one of our challenges with data is that our system is quite poor at data collection and some of its ability to pull out data."*
>
> **CYP MH Professional**

CYP MH professionals, however, see the value in directing analytical resource to this issue in order to meaningfully address suspected inequities. They recognised that this will require a shift in thinking from access according to the supply-side (provider), to access according to the demand-side (service user), that is not currently catered for by access targets.

> *"I think it would be helpful, because we know that BAME communities in particular don't necessarily access mental health services, there's a stigma around that I think, but I think understanding our local population, understanding percentages of ethnic origins who are accessing services would be useful I think, particularly health inequalities, etc, I think it would be really useful to see that data but, yeah, I don't think we have that currently."*
>
> **CYP MH Professional**

> *"No we don't have it [that data]. I think it would be useful. I think it would be good to understand. We talked about barriers earlier, didn't we, so it's difficult to understand some of the barriers without some of that information. So, yes, having that demographic information, ethnicity, age groups, you know, all those different indictors would be really useful. But, no, we don't have a breakdown of data that tells us who's accessing it [CYP MH services] in terms of ethnicity, religion, etc."*
>
> **CYP MH Professional**

## 5.4 Chapter Conclusions

This chapter describes the numerous access routes to CYP MH services in the Midlands, providing a view of where effort and resource is currently being concentrated within the region to support CYP to access services. There is a broad focus on simplifying access routes through increased use of a SPA, as well as providing more preventative and targeted early intervention services. However, survey and interview respondent accounts reveal that the current focus does not consider the problem of inequity: in attempts to improve access for all, there is little consideration of who accesses the service and who needs the services more.

The findings in this chapter also suggest that the issue of equity in access to CYP MH services is not a system priority. MH professionals are frustrated that their efforts to support proportionate access to services is encumbered by a lack of data and intelligence to help them to understand or improve the issue of inequity. Lack of prioritisation of the problem persists also because systems are only encouraged to report data related to the national access target, which focuses on the number of contacts, rather than the type or need of the contacts.

# 6. Mismatch in supply, demand and unmet need

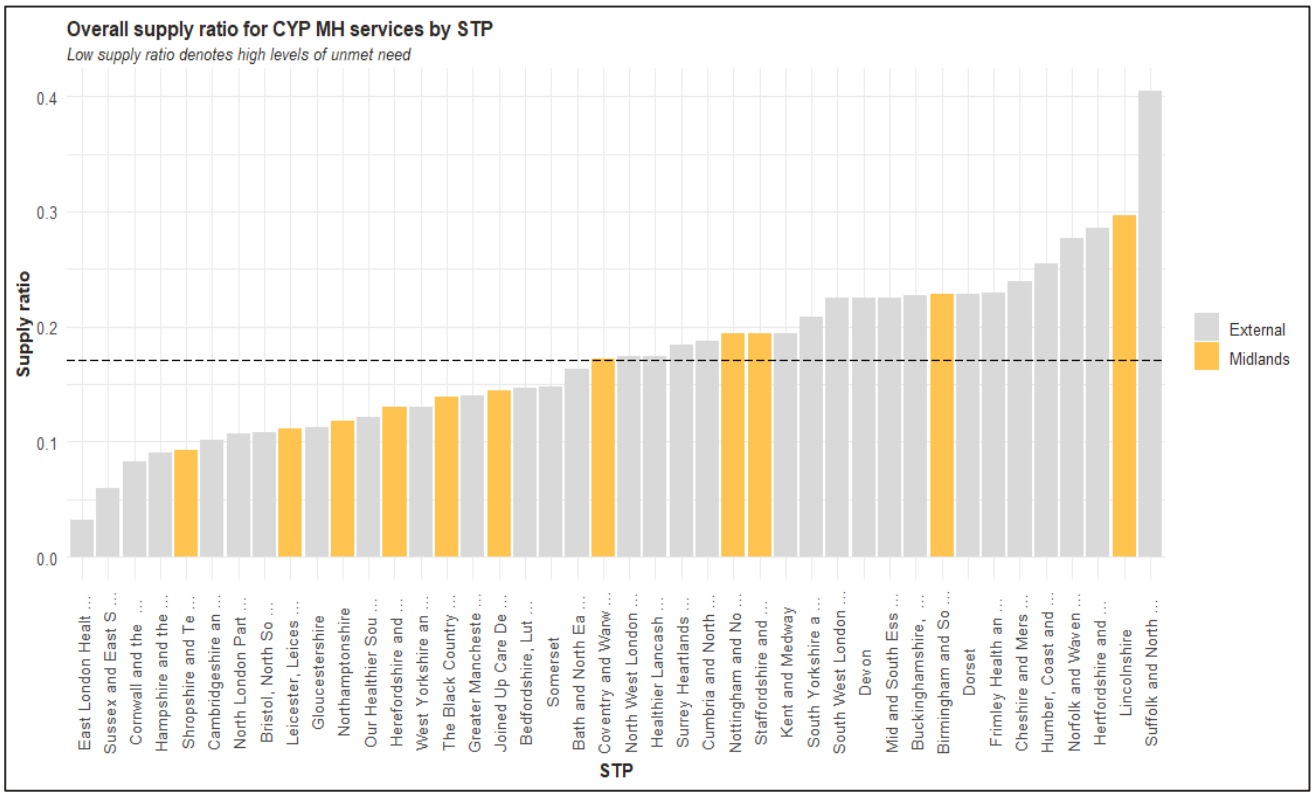
## 6.1 The supply of mental health services for CYP

Ideally in health and care the provision of services (supply) should be set in response to the need and/or demand for them. Unmet need can be described for any given population as the gap between what is needed and supplied. This concept assumes good knowledge of both need/demand and supply, however this isn't necessarily the case for MH services which are often commissioned with block contract arrangements.

Our analysis takes published data on estimated needs for ICS populations and then compares this to record-level data on patients in specialist services to quantify the potential levels of unmet needs. Across a range of common mental health disorders and diagnoses and areas across England, there is large variation in unmet need.

Figure 15 shows the variation in the supply ratio (demand : need) for the 41 ICS areas in England. In East London fewer than 5% of children with diagnosable conditions have received (some) specialist support whereas Suffolk and North East Essex have around 40% of CYP with specific needs in touch with services. Within the Midlands, Shropshire has the lowest supply ratio (9%) and Lincolnshire the highest (30%).

*Figure 15: Supply ratio across all conditions, all ICS areas in England*



MH professionals interviewed for this project described that whilst there had been investment in aspects of MH services, often the decisions on which services to fund, were made independent of the understanding of how services are accessed and used in practice, with no follow-up or rectification when inefficiencies or poor investment decisions were recognised.

> *"So there has been huge investment already in children's mental health, but it's been more, a lot of it's been at the preventive end, and I think the problem with the preventative end is that it may not always be easy for people to use. So it's not always access is it? That's where people end up coming to the doctor and saying 'nothing's happening. What can we do?' and the doctor's job then.., seems to be.., to write a letter to CAMHS to say 'can you make this case urgent because things are getting worse?' And that's how it goes."*
>
> **CYP MH Professional**

A linked supply challenge, borne out of lack of knowledge informed decision-making, was one of capacity, and having the right skills available in the right place to meet local demand or need. Some systems were already aware that there was an unintended consequence of increasing the supply of lower tier services: it increased demand on higher tier services which did not benefit from a similar investment.

> *"It [additional finance] has been used to strengthen perhaps, you know, the getting help, the tier 2 services, because of this kind of logic, well if we address it earlier then we'll reduce the amount that escalate up, that to me takes me back to the days of primary mental health workers when we introduced those into CAMHS and actually what you do when you increase the getting help or the tier 2 provisions is it identifies more that need to escalate up to specialist CAMHS, so it doesn't really solve that problem."*
>
> **CYP MH Professional**

This reinforced the view of some interviewees that workforce related supply challenges for CYP MH services were made worse in systems that did not have a clear commissioning strategy. This could be either due to a lack of data and analysis to inform commissioning decisions or as a result of having commissioning teams in flux, for example due to CCG mergers or ICS development, that could impact on relationships and awarding of appropriate contracts.

Better and more informed-decision making did not have to be limited to the quantitative data, for example where experiential knowledge had been prioritised as a means of service improvement there was some benefit described to be realised over time. One system had formalised improvements by the use of 'Experts by Experience'. These Experts now had the potential to be incorporated into the workforce, in a way that was rewarding for all concerned and ultimately beneficial to MH services.

*"We're starting to recognise the diverse talent of our experts by experience 5 years ago who are now coming into the workforce and are part of our staffing mix if you like to meet that local need. So I think it's just a signal of that shift in that transformational leadership isn't just about having a document with the model on a page and a long term plan, it's about the leadership that you need to really turn that into an operational delivery plan but also kind of a true sense of inspiring ambition and change for young people to flourish."*

**CYP MH Professional**

## 6.2 The variation in unmet needs

The quantitative analysis revealed further variation in supply, demand and need across areas in the Midlands and by mental health sub-group. Table 2 provides the estimated need, that is expected number of CYP likely to have a diagnosable MH condition versus the number of CYP in contact with services, expressing this as a supply ratio. This ratio reveals a three-fold difference in the supply of CYP MH services across the Midlands. CYP living in Lincs are three times more likely to receive the MH support that they need than those living in STW (approximate supply ratio: 3:10 versus 1:10, respectively).

Table 3 shows variation in supply across the Midlands as a whole by MH condition, comparing need and demand to provide a supply ratio. It highlights a number of conditions with a low supply ratio such as emotional, hyperkinetic and conduct disorders. LAC appear to be reasonably well served by specialist services with 60% of MH needs supported in some way.

Eating disorders has by far the lowest supply ratio, with only 2% of CYP expected to need support for this condition across the Midlands receiving it. It is worth noting here that some areas in the Midlands have both high prevalence and high levels of unmet need for some of the conditions below and there is expected to be much variation within individual systems as described in chapter 4.

Focusing on the unmet needs for eating disorders (Figure 16), it is clear that the Midlands region has a particular problem. Derbs ICS area has the largest relative volume of unmet need in England and only two other areas support more eating disorder patients than the national average. The 'best' at meeting needs in the Midlands region – Northants – still only identifies and supports 1 in 33 children or young people that might need it.

It is likely, given the huge gap in provision, that only the most severe patients tend to receive treatment and there are therefore significant opportunities for prevention and early intervention.

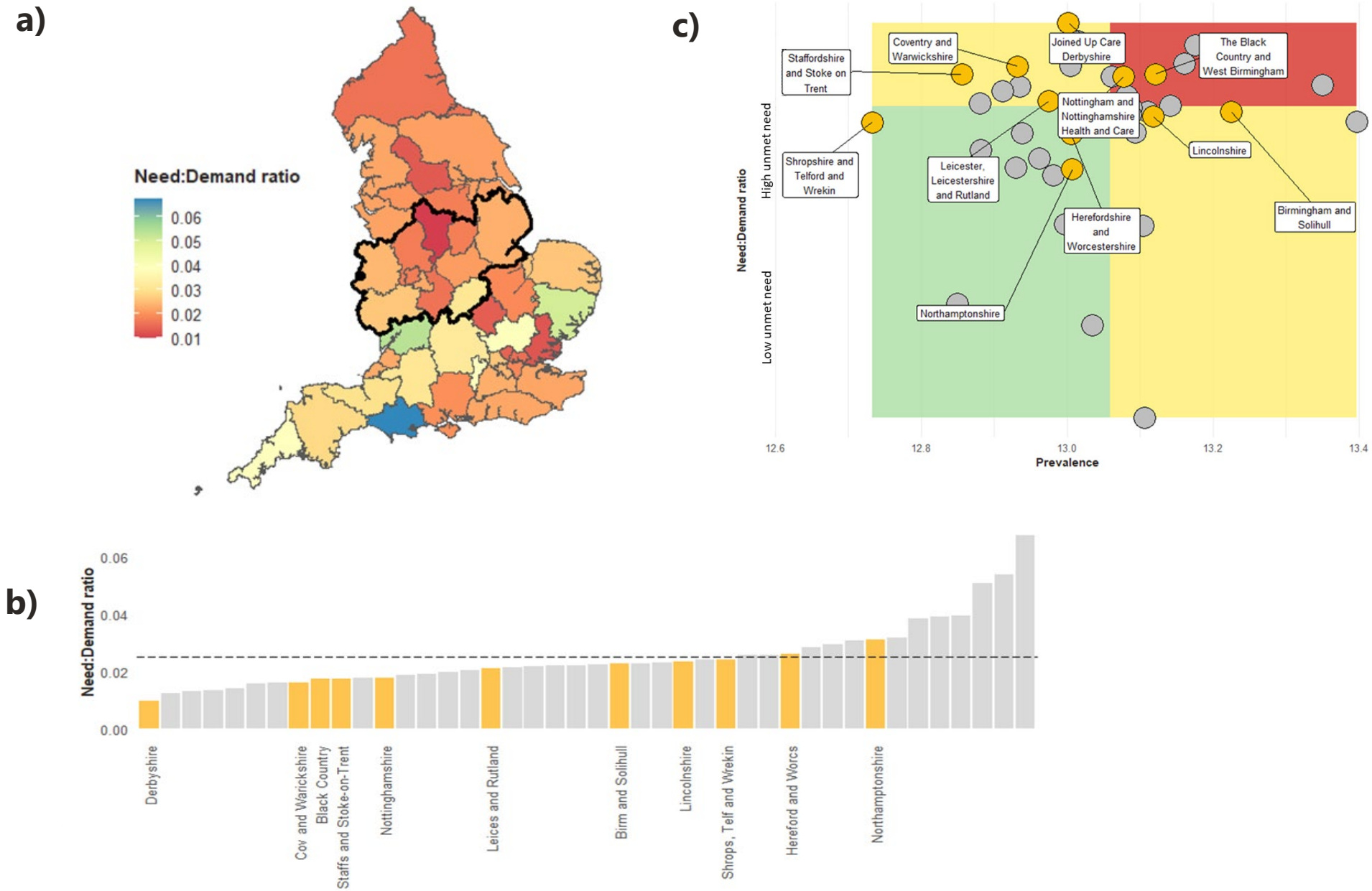
*Table 2: The estimated need and supply of CYP MH services in each of the Midland's Integrated Care System*

| System | Estimated CYP Population with a diagnosable MH condition | CYP Population in contact with services | Supply Ratio |
|---|---|---|---|
| Lincolnshire | 20,736 | 6,148 | 0.30 |
| Birmingham and Solihull | 47,282 | 10,800 | 0.23 |
| Staffordshire and Stoke-on-Trent | 33,921 | 6,587 | 0.19 |
| Nottingham and Nottinghamshire | 36,065 | 6,992 | 0.19 |
| Coventry and Warwickshire | 28,701 | 4,951 | 0.17 |
| Joined Up Care Derbyshire | 30,701 | 4,448 | 0.14 |
| The Black Country & West Birmingham | 43,911 | 6,086 | 0.14 |
| Herefordshire and Worcestershire | 20,921 | 2,724 | 0.13 |
| Northamptonshire | 21,695 | 2,550 | 0.12 |
| Leicester, Leicestershire and Rutland | 34,474 | 3,840 | 0.11 |
| Shropshire, Telford and Wrekin | 14,008 | 1,303 | 0.09 |

*Table 3: Absolute and relative unmet needs by mental health condition sub-groups*

| Condition | Estimate of 'need' | Population 'demands' | Supply ratio Midlands | *Supply ratio England* |
|---|---|---|---|---|
| Looked after children with emotional wellbeing issues | 2,755 | 1,784 | 0.65 | *0.72* |
| Self harm | 22,139 | 8,960 | 0.40 | *0.34* |
| Emotional disorders | 53,342 | 19,465 | 0.36 | *0.37* |
| Hyperkinetic disorders | 22,635 | 4,853 | 0.22 | *0.22* |
| Conduct disorders | 84,092 | 5,003 | 0.05 | *0.06* |
| Eating disorders | 160,631 | 3,185 | 0.02 | *0.02* |

*Figure 16: Unmet need for Eating Disorders by ICS in England (a), Midlands ICS (b) and prevalence vs unmet need (c).*



MH professionals interviewed reflected that one of the reasons for eating disorders having a high unmet need is a feature of the disease; those suffering from it inevitably present late to health services. However, it was also understood that health professionals needed to better recognise the symptoms of eating disorders, potentially by working with other services.

> *"I mean, the nature of the illness is that sometimes it is a bit secretive and hidden, the young person may not be that upfront about their behaviours, so there's part thinking presentation of the illness that lead to, you know, hidden symptoms, but also poor recognition by other health professionals can lead to them presenting late."*
>
> **CYP MH Professional**

There was widespread agreement that the demand for eating disorder services would increase post pandemic, with some areas already observing this with a change in presenting demographics:

> *"So there has been an age difference in terms of eating disorders, so we're seeing during the pandemic a much younger profile coming through with eating, with disordered eating and eating disorders."*
>
> **CYP MH Professional**

## 6.3 Predicting longer-term need

There is a paucity of evidence documented relating to the longer-term impact of poor access by specific population groups of CYP as adults, even if there is evidence that some groups of adults access services less. For example, a study of the Leicestershire population found that the proportion of female Asian referrals to mental health services was much lower than would be expected based on their population size (Sinha and Warfa, 2013). Furthermore, Mitra and Hodes (2019) showed that of the 60% of unaccompanied refugee minors who sought help for psychological distress only a fifth received it. There is some evidence to suggest minority ethnic groups have an increased risk of repeat emergency attendance due to mental illness; lower socioeconomic status and age may also be a significant predictor of recurrent emergency department visits due to mental health issues (Leon et al., 2017).

The lack of support within adult services for those with ADHD is noted to create a high level of burden on those caring for the young person and unmet need in anxiety and depression that could increase demands on other parts of the healthcare system such as increased admission rates in emergency departments (Swift et al., 2014; Young et al., 2011). Similarly, the inability to find age-appropriate services has led some older young people to end up in juvenile justice systems and/or experience higher morbidity rates due to disengagement from services (Abidi. 2017; Paul et al., 2015; MacDonald et al., 2018; Embrett et al., 2016).

### 6.3.1 Factors relating to longer-term support needs

The longer-term outcomes associated with poor mental health in childhood are well researched: suicide, chronic depression, loss of social functioning, unemployment. What is less well known are the factors in childhood and adolescence that might be associated with longer-term specialist support needs:

- What might the non-clinical signs of more complex needs be?
- Which populations might benefit from earlier intervention?
- To what extent are some factors stronger predictors than others?

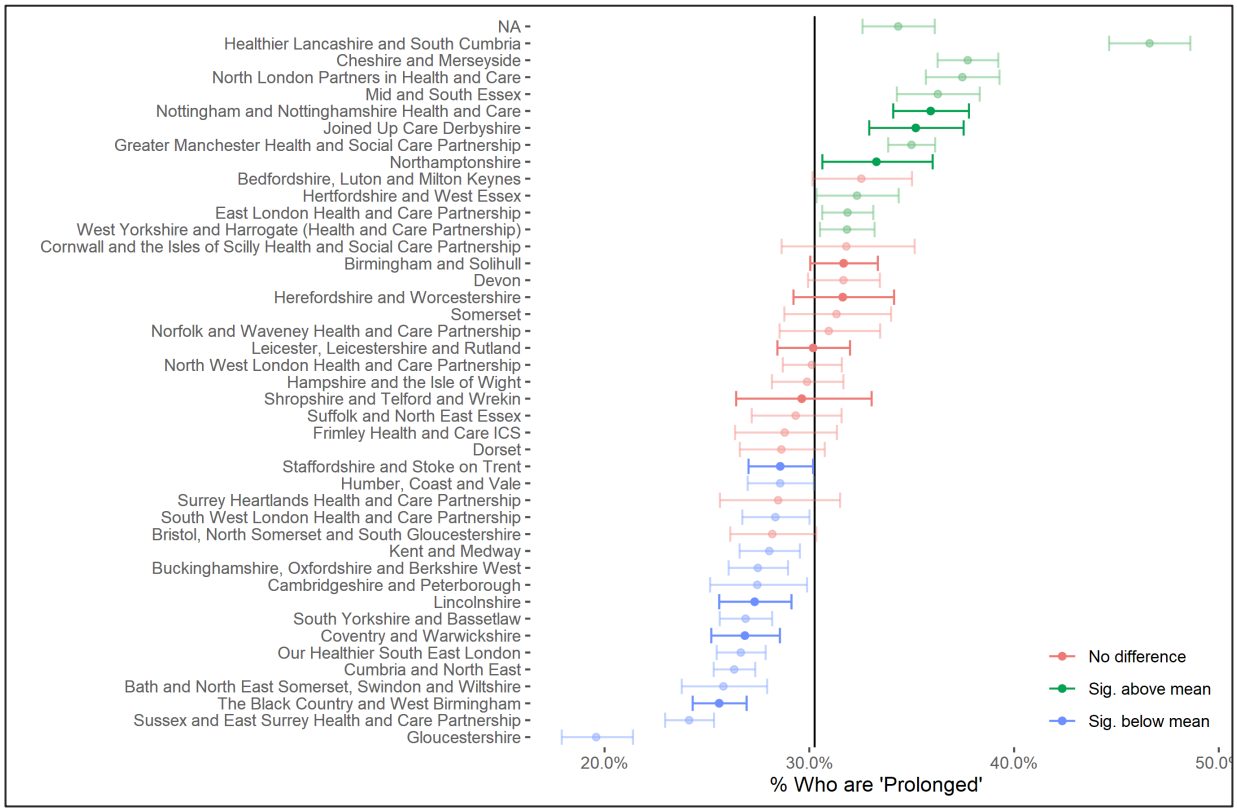
In order to explore these questions, we undertook a cohort analysis using mental health datasets linked over time to try and predict whether individuals would require shorter/simpler or longer/complex support. Further detail on the data, methods and results can be found in Appendix A.

The first notable observation is that there is significant variation in support needs as determined by where young people live. This is reinforced by looking at the distribution of those with greater support needs by the ICS areas across England (Figure 17). Almost half of those CYP in contact with mental health services in Lancashire and Cumbria will have prolonged support needs. The equivalent figure for Gloucestershire is just 1 in 5.

Within the Midlands there is also significant variation with the BCWB ICS having the least prolonged support needs (26%) and N&N the most (36%). The East Midlands tends to have greater percentage of prolonged support needs than the West Midlands.

To test whether the prolonged needs are a function of different service models or a result of more complex and persistent population needs, we developed a predictive model (see Appendix A for full methodology). The overall predictive value (balanced accuracy) of our model in correctly allocating patients in the cohort to one of the two classes based on the baseline variable dataset was 0.7 (70%).

*Figure 17: Percentage of population with prolonged support needs 08/09 to 18/19 by ICS area in England (Midlands ICS area bars highlighted in bold).*



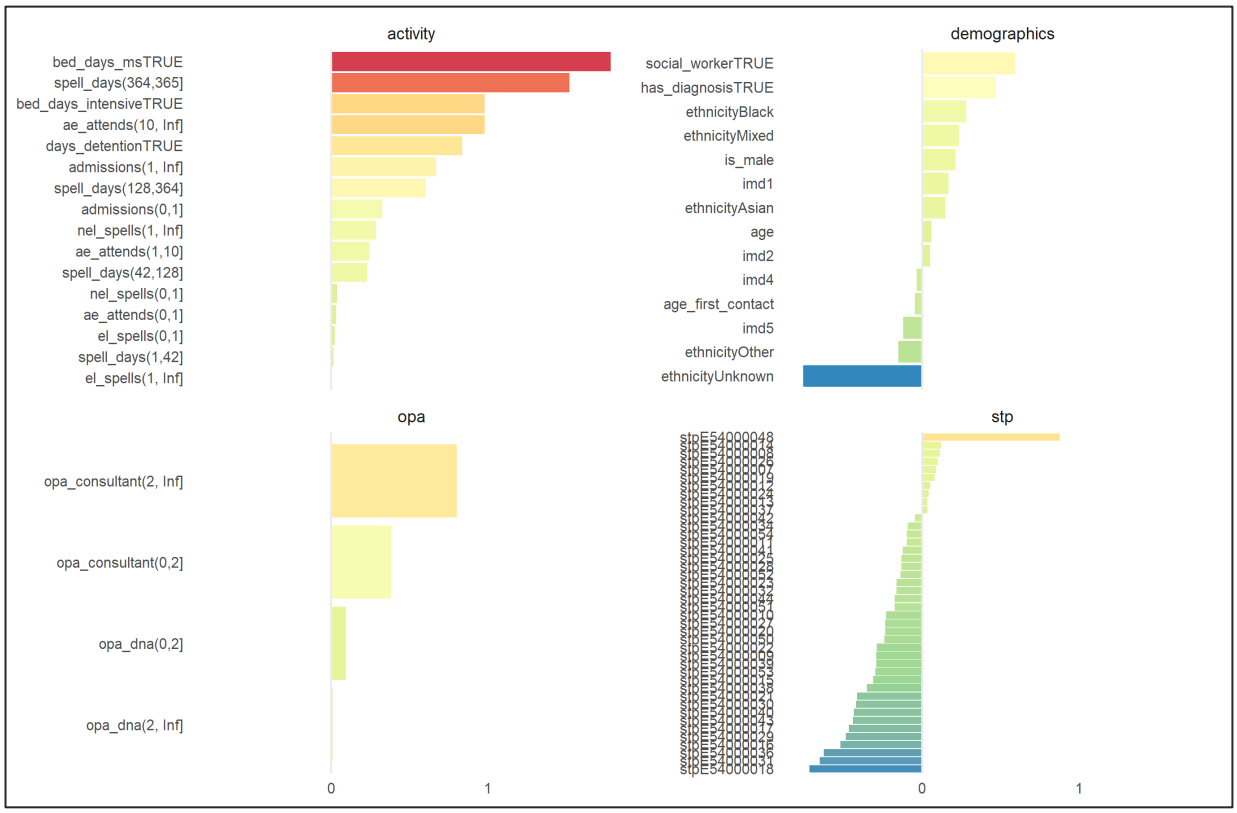

Poor, incomplete data and inconsistent data structure over time was a significant obstacle in designing and developing our explanatory model. With this limitation in mind, Figure 18 highlights that the most influential variables in terms of predicting **longer support needs** were:

- Long inpatient spells in baseline year
- Intensive bed stays
- Subject to MHA detention
- Multiple A&E attendances over 12 months
- Social worker involvement
- In receipt of a formal diagnosis

The most influential variables in terms of predicting **lesser support needs** were:

- Other and unknown ethnicity
- Area lived in – Coventry & Warwickshire, South West London and Cornwall have very strong protective affects
- Affluence – IMD quintile 5

*Figure 18: Logistic regression variable coefficients*




## 6.4 Chapter Conclusion

There is a three-fold difference in the levels of unmet need within the systems that make-up the Midlands region and further variation in this need by mental health condition and for different population groups. Eating disorders is a clear blind spot for all systems nationally; in the Midlands only a tiny fraction of CYP who need this specialist support receive it.

Addressing unmet need is important across the board, but CYP with social care involvement, those from lower socio-economic groups and some of those identified as minority ethnic are more likely to require longer-term support once in the specialist mental health care system.

The triangulation of the data shows that whilst some of the evidence around need, demand and supply is limited due to poor data collection and analysis, those working in MH services are aware of the underpinning issues that lead to variation in access. Some variation is a result of demand-side social, cultural, behavioural and other demographic factors that both recognise need and the ability to self-manage those needs before specialist support are required. Other examples of variation will be due to the differences in how systems are configured – how and how much they are funded, how services are commissioned and how those services are designed and delivered.

# 7. Conclusions

The Strategy Unit has undertaken this specific mixed-methods analysis on behalf of the 11 ICSs in the Midlands. This project, examining equity in access to CYP MH services, represents a significant analytical project for the MDSN and sets a precedence for triangulating different types of evidence that can then be used to inform decision-making. It is also expected that findings will be generalisable to other systems and regions, given that there is a known national evidence gap in this subject area.

The headline findings are bleaker than expected. In the Midlands there are an estimated 350,000 children and young people with a range of mental health needs; only 43,000 of these are receiving some kind of specialist support. Health and care professionals do not know which CYP need support, where they live and how best to reach them. And when they do, there is simply not enough support available. For example, only 2% of the estimated 160,000 CYP in the Midlands with eating disorders are finding their way to specialist support.

Some groups of CYP access services far more than others; there are numerous reasons for this variation in access. But even the better-performing systems are only giving the right support to 30% of those who need it. The Midlands as a region is therefore the most underperforming of the seven English regions, with only one other region not meeting the low ambition set nationally that 35% of CYP who need mental health and wellbeing support should be able to access it.

CYP needing support don't know where to go, who and how to ask for support. Those who are Black, socially deprived, are adolescents (aged 18 to 24), or have a neurodevelopmental condition are further disadvantaged more than their peers with access, appropriate support and treatment outcomes. Those who are better able to navigate the complex services, for example through parental advocacy, have an advantage in accessing support.

On the whole CYP have limited involvement in co-designing the services intended for them, despite mental health and care professionals knowing this is the right thing to do. Similarly, health and care professionals suspect that services are not being provided equitably, but they can't evidence it with current data and they don't collect the relevant data as there is no impetus to do so. The current focus on a process-driven access target and lack of meaningful analysis on who should and who does use services is the result of systems not prioritising the improvement of health inequities and inequalities.

It was beyond the scope of our work to recommend 'fixes' on this scale. Nonetheless, we have made recommendations (listed in the Executive Summary) that focus specifically on more immediate improvements that are within current regional and system control. Here we suggest other activities related more specifically to improvements in data quality and their use. We recommend that these are formally considered within the MDSN with the expectation of a consensus of how to adopt these into routine practice and how to fund the activities.

- Improve the completion and quality of data recorded in mandatory data collections (MHSDS and IAPT)
- Develop a set of reproducible outcome variables in terms of subjective measurement of mental health and wellbeing, adverse outcome events and utilisation patterns that can be linked to individuals across multiple services and over time
- Segment populations according to mental health need and health and care usage
- Experiment with machine learning classification methods as a potentially powerful tool for prediction of individual and population risk
- Invest in analysis and learning from the data including needs assessments across the life course
- Prioritise improvements based on qualitative evidence of user and staff experience of MH services
- Critically appraise and incorporate evidence and guidance and learning from other regions.

To conclude, this report is the output of the Midlands response to the guidance set out in 2019 by the National Collaborating Centre for Mental Health on commissioning and delivering equality in mental health care. By commissioning this work, the Midlands as a region has fulfilled the first responsibility of identifying where inequities exist for CYP. Now it's time for more direct action to design and deliver more equitable services and to evaluate them.

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# Glossary of terms

| | |
|---|---|
| CCG | Clinical Commissioning Group |
| BSol | Birmingham and Solihull |
| BCWB | Black Country and West Birmingham |
| CAMHS | Child and Adolescent Mental Health Services |
| CCG | Clinical Commissioning Group |
| C&W | Coventry and Warwickshire |
| CYP | Children and Young People |
| Derbs | Derbyshire |
| DoE | Department of Education |
| DoH | Department of Health |
| DPIA | Data Protection Impact Assessment |
| DSN | Decision Support Network |
| ICS | Integrated Care System |
| IMD | Index of Multiple Deprivation |
| H&W | Herefordshire and Worcestershire |
| LAC | Looked after children |
| LLR | Leicester, Leicestershire and Rutland |
| Lincs | Lincolnshire |
| MH | Mental health |
| MHST | Mental Health Support Teams |
| MHSDS | Mental Health Services Data Set |
| NCCMH | National Collaborating Centre for Mental Health |
| NHSE/I | National Health Service England & Improvement |
| Northants | Northamptonshire |
| N&N | Nottingham and Nottinghamshire |
| ONS | Office of National Statistics |

| | |
|---|---|
| PHE | Public Health England |
| SPA | Single Point of Access |
| STW | Shropshire, Telford and Wrekin |
| SST | Staffordshire and Stoke-on-Trent |
| VCS | Voluntary and Community Sector |

# Appendix A: Research methodology

This study employed a mixed-methods approach, designed to source data from existing literature as well as gather new data through the means described below. This has inevitably led to a deep and broad range of information on this topic and the core task of the project team has been to collate and distil this to form actionable content for the eleven health and care systems in the Midlands. As a result, there is much that has not been reported here as it goes beyond the remit of inequities in *access* but may be useful for any further studies focusing on these services.

The following methods have been employed to gather and analyse relevant data:

1. A review of relevant academic literature
2. Semi-structured interviews with stakeholders;
3. A survey of users of mental health services for CYP
4. Quantitative data collection and analysis

## Literature review

Academic literature from the international evidence base was consulted to review what is *already known* about the issue of inequalities in access to CYP mental health services. This focused on:

- Known causes of inequities/barriers to access
- Known consequences of these inequities
- Interventions to enhance access

The research was categorised according to the *PROGRESS-Plus* framework. This filters information by:

- Place of residence
- Race/ethnicity
- Occupation
- Gender/sex
- Religion
- Education
- Socioeconomic status
- Social capital
- Plus – age and disability

An evidence map of relevant research is available as a supplementary product to this report.

## Semi-structured interviews with sector stakeholders

At the outset of this research the project team conducted thirty-eight interviews to inform the study. These were carried out under conditions of anonymity but included representatives from each of the eleven stakeholder systems. Coverage is described in the table below:

*Table 4: Number of CYP MH services stakeholder interviews per system in the Midlands region*

| System | No. of participants |
|---|---|
| **BCWB** | 8 |
| **Derbs** | 5 |
| **C&W** | 5 |
| **Lincs** | 4 |
| **Northants** | 3 |
| **LLR** | 3 |
| **H&W** | 3 |
| **BSol** | 3 |
| **N&N** | 2 |
| **STW** | 1 |
| **SST** | 1 |

Given the low number of participants from some systems, interviews have been used to inform the regional-level findings, and have not been included in the system-level data packs that support this report. This has also been necessary to ensure the identity of interviewees cannot be ascertained from their comments. All quotations used in this report sourced from these interviews have been anonymised.

Interviewees were from a variety of professions including commissioners; clinicians and service providers.

The topic guide for these interviews is included as appendix B and the content from them has informed all chapters of this report. Interviews lasted between 30-60 minutes; they were recorded with consent and coded using NVivo 12 software by the project team and analysed against the objectives of the project outlined in the next chapter. Where quotations from these interviews are used in this study, they are assigned only to the unique identifier of the participant.

## Service user survey

In order to understand the experience of accessing mental health services on the part of CYP themselves, the project team designed and conducted a service user survey. This was opened in February 2021 and closed at the end of March 2021. Responses were collected through 'snowballing' where the survey was shared with relevant networks and via social media encouraging it to be shared widely. Eighty-five responses to the survey were collected. As this level of response made it difficult to make assertions at a system-level, as with the interviews, the survey responses have been used only to inform this regional report, and have not been included in system-specific data packs. Again, quotations used in this report have been anonymised.

A copy of the survey questions has been included as appendix C.

## Quantitative data

There are three main components of the quantitative analysis undertaken for this study, each drawing on different data and methods.

Our **unmet needs** analysis evaluates the ratio of observed demand to estimated needs for a sub-set of common mental health disorders. This draws on published data from Public Health England (PHE fingertips) and routine data from the Mental Health Services Dataset (MHSDS). More on the methodology for this analysis is included in the ICS area packs that are provided as supplementary products to this report.

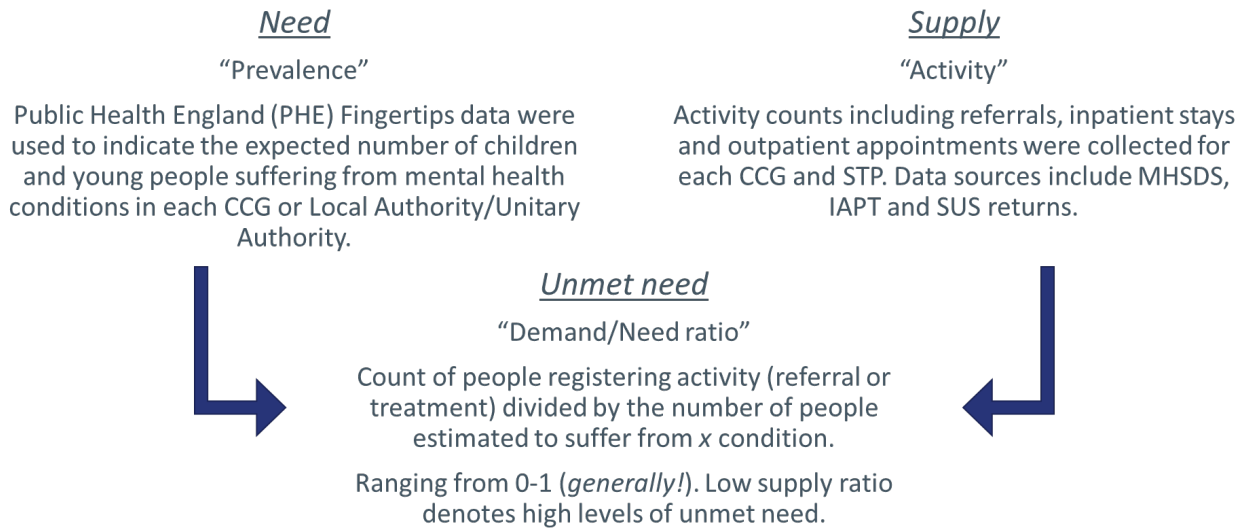
The classical economic definition of need is termed as 'the ability of people to benefit from health care provision". More broadly, healthcare needs are those where an individual feels they might benefit from intervention by a 3rd party (Felt), where they demand support (Expressed) and a healthcare gatekeeper, typically GP, agrees with them (Normative).

Unmet need occurs when those expressed needs cannot be met with the existing provision of healthcare services.

The government's aspiration for CYP access to specialist mental health support is based on the principle that all those with a diagnosable mental health condition will recognise it, express it and receive a certain level of support. In reality, none of these assumptions are likely to be true at a population level.

Our analysis of unmet need, given the limitations of available public and routine data, is simple.

*Figure 19: Concepts of 'need', 'supply' and 'unmet need' expressed as supply ratio.*




The code frameworks and datasets used to identify the supply aspect of the equation are provided with this report.

Analysis of **pathway inequities** again draws on completed spell discharge data from the MHSDS to demonstrate the variation in referral pathways, suitability of referrals, intensity of treatment, completion of treatment and re-referrals for different population sub-groups – age, gender, ethnic group, deprivation and other health and social exposures. More on the methodology for this analysis is included in the ICS area packs.

**Exploratory analysis** of 10-year cohort data from MHSDS and its ascendant dataset versions. This logistic regression analysis sets out to explore the nature and extent of exposure to demographic, social, health and care factors and their relationship to future mental health support needs. The full methods report for this analysis is included as appendix A.

## Ethics and Information Governance

Given the multiple sources of data collected as part of this project, the project team have completed a Data Protection Impact Assessment (DPIA), supported by the Midlands and Lancashire Commissioning Support Unit, to ensure that the methods above comply with data protection requirements.

In addition all interviews have been conducted to high ethical and governance standards as is routine for the Strategy Unit. This includes:

- Protecting and promoting the dignity, rights, safety and wellbeing of participants, patients and staff involved through informed consent.

- Conducting all work in accordance with the *UK Framework for Health and Social Care Research* code of conduct.
- Applying the highest practical standards of handling patient identifiable information according to the *7 Caldicott principles* and *7 GDPR principles*.

# Appendix B: CYP MH Professionals Interview Topic Guide

## Improving access to children and young peoples' mental health services

**Stakeholder interviews: topic guide**

Purpose of interview (to be introduced at the beginning of the interview)

To include:

*Introduction to the Strategy Unit and the DSC*

The Strategy Unit is part of the Midlands and Lancashire Commissioning Support Unit (MLCSU). We provide a broad range of consultancy services including evaluation, evidence reviews, service improvement and data analytics, employing a range of methods and approaches.

We are acting on behalf of the Midlands Decision Support Centre that supports the region's Decision Support Network.

*Introduction to the project:*

This project is being supported and funded by the Midlands DSC and has been deemed a priority analytical project for the region. It is a mixed methods study including quantitative data analysis, stakeholder interviews, service user survey and a review of the relevant evidence.

The purpose of this interview is to understand the barriers to, and the opportunities for, accessing mental health services for CYP from your perspective as a provider/professional working within this service.

We expect to report our findings in May 2021 and we aim to release region-wide, as well as system-specific, reports the combine the qualitative findings with the quantitative and evidence.

Format:

45-60 minute telephone/MS Teams interview.

Supporting information

Participants will be sent an information sheet prior to the interview explaining: the purpose of the interviews (outlined above); data security; and how their contributions will be used in confidence.

Interviewees should be informed of the relevant system's access rate for supporting information.

Interviewees should be familiar with the 4 tiers of mental health services.

**Processes for data security will be explained and all participants will be asked for consent to record the interview.**

Topic guide

*These questions are only a guide, intended to provide some structure to the interview.*

*Note for interviewee: Although we do consider the impact of the pandemic on CYPMH services later in the interview, we ask that you consider the first questions from the perspective of 'normal' times.*

**Introductions**

1) Can you please briefly introduce yourself and your current role?

**System Performance**

This year, the government aimed for access to NHS-funded community services for CYP with diagnosable mental health conditions to be 35%.

2) **Show participant slide detailing their system's performance against the 35% target.**

   *Confirm the performance with the interviewee*

   What, in your view, are the main reasons for this performance?

3) For your system, what have been the enablers to support accessing services for?
   a. Users (how have users been supported to access services?)
   b. Providers (how have providers been supported to enable access?)
   c. Service tiers - Variation in access to the different tiers; what are the features of the different tiers to support access? Are the enablers described more effective in different tiers?

4) For your system what are the barriers to access?
   a. For users?
   b. For providers?
   c. Service tiers – how do barriers vary across the tiers and why?

5) Can you describe any interventions that your system has put in place to improve access to CYP MH services in the last few years (pre-COVID)?

    a. What was the specific feature of access being improved?
    b. Was the intervention(s) implemented across the system or in certain areas?
    c. Was the intervention(s) aimed at specific tiers of CYP MH services?
    d. Who has led and been involved in these activities? (e.g. NHS; voluntary sector; local authority; schools?).
    e. What was the provenance of the activity (e.g. learning from elsewhere, or local?)
    f. What were the challenges to delivering the interventions?
    g. Were the interventions replicated wider? In the system? Nationally?

**Variation in access**

6) Are there particular groups of children or young people who were (pre-COVID) more dis/advantaged than others in accessing mental health services in your system? Why?

    *a. Ethnicity*
    *b. Homelessness*
    *c. Sexual orientation*
    *d. Gender including non-binary and transgender*
    *e. Poverty*
    *f. Refugee/migrant status*
    *g. Residence*
    *h. Autism*
    *i. Types/Tier of service required*
    *j. Those transistioning to adult services*

**Consequences**

7) What impact have any interventions (pre pandemic) to improve access to CYP MH services had?

    a. Inequities in access
    b. Inequalities in outcomes

8) What impact has the pandemic had on CYP MHs in your system ?

a. *Demand*

b. *Supply*

c. *Access*

9) What are the likely consequences of the inequities in access?
   a. *Have you identified/confirmed any for your system? How ?*
   b. *Consequences of increased remote/digital provision?*
   c. *Service users' health now and in the future?*
   d. *Use of health and care services now and in the future?*

**4. Other comments**

10) If you could make a single actionable recommendation to improve access to CYP MH services what would this be?

11) Is there anything else you would like to add in terms of access to CYPMH services that we haven't already discussed ?

12) Recommend other colleagues to be involved?

**Thank you for your time**

**Close interview by explaining next steps.**

# Appendix C: Service User Survey

A copy of the questions used in this survey can be found here.

# Appendix D: Evidence map

As described in the research methodology, evidence relating to causes, consequences and interventions of inequity in access to CYP MH services was reviewed and summarised as part of this study. The full evidence map can be download here.

# Appendix E: Presentation of findings

A supporting presentation summarising the findings in this report was presented to the DSU Network in June 2021. This presentation can be accessed here.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Midlands and Lancashire

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