

# healthwatch

Oldham



## We Matter

**Improving Children and Young  
People's Mental Health Services in  
Oldham**

**June 2019**

# Acknowledgements

Healthwatch Oldham (HWO) has four main areas of work: listening to local people about their health and social care experiences, influencing services, providing information and guidance on health and wellbeing and providing advocacy support to help resolve NHS Complaint cases.

As part of our listening and influencing roles this report sets out the views of parents of children and young people who have used, or who are currently using, mental health services in Oldham. Using the feedback and first-hand experiences we review the quality of services to highlight where services are working well and make recommendations to commissioners and providers where we feel services can be improved.

Healthwatch Oldham would like to acknowledge and thank everyone who took part in the review. Thanks go to all the families who took the time to complete the questionnaire and for their honesty and willingness to share their experiences. Special thanks also go to Natalie Williams, Oldham Council's Mental Well-being Co-ordinator for Education and Early Years who connected us to all the primary and secondary schools in Oldham and thank you to all the schools and colleges who took part in this review.

Healthwatch Oldham would also like to thank the Healthwatch volunteers who gave up their time to help with this review and for their ongoing professionalism and commitment to the work of Healthwatch Oldham.

## Disclaimer

Please note the stories within the report are subjective accounts by individuals given on the day they were interviewed, and do not represent the views of Healthwatch Oldham. If anyone has any queries relating to the content of this report, please contact a member of the Healthwatch Oldham team via [info@healthwatcholdham.co.uk](mailto:info@healthwatcholdham.co.uk)

# Contents

<b>Key messages</b>	4
<b>Executive Summary</b>	6
<b>Main Recommendations</b>	9
<b>Detailed Findings</b>	11
<b>What families told us</b>	13
<b>Case Study 1: Support for emotional and behavioural issues</b>	17
<b>Case Study 2: Transition from Children's to Adult's services</b>	24
<b>Case Study 3: A and E crisis support</b>	28
<b>What professional told us</b>	29
<b>Appendix</b>	36
i. List of questions we asked parents	36
ii. List of questions we asked professionals	36
iii. List of schools that took part in the review	37

# Key Messages

Between January and March 2019, we heard from 90 families whose children had experience of using mental health services in Oldham. The children and young adults using services were aged between 5 and 24 years. We also spoke to 35 professionals including teachers and GPs to find out about their experiences of referring children and young people into mental health services. These are the key messages.

## What families told us

- 70% of parents felt that Healthy Young Minds (HYM) offered a very professional service with high levels of confidentiality and trust between the clinician and young person.
- Waiting times for referrals to HYM are too long with 29% of young people waiting more than 3 months for their first appointment.
- Waiting times between appointments are too long, it is hard to get advice in between appointments, and there is a lack of consistent care.
- There is little support or coordination between services for young people with dual mental health and autism spectrum/attention deficit conditions.
- Families have mixed views about how well different therapies work.
- Some families struggle to find the right support first time and get passed around services.
- There is no follow up after discharge from HYM and 78% of parents were not satisfied with the advice provided on discharge.

## What families would like to see change

- Timely access to services with a single point of contact offering ongoing advice.
- Easy access to a choice of therapies provided through a single integrated offer between HYM and other low level mental health services.
- Offer holistic mental health services that support young people with dual mental health and autism spectrum/attention deficit conditions.
- Improve communication between all services involved in the wellbeing of a child including HYM, school/college, GP, social care, voluntary sector and community health teams.
- Create a shortcut back into services for a recurring mental health crisis.
- Ensure appropriate support at discharge including signposting to self help resources.
- Provide self-help information and training to parents and young people to support positive mental health.
- Better urgent care with timely access to specialist support, and front line staff who understand and respond appropriately to a young person with a mental health crisis.
- Increase the range of support for transition from Children's to Adult Mental Health Services.

## What the professionals told us

- Almost 50% of professional have identified improvements in young people's mental health services over the last year.
- The whole-school approach has helped to improve recognition and support for children and young people experiencing mental health difficulties within a school setting.
- Waiting times for referrals to HYM are too long.
- Many referrals from schools do not meet the HYM criteria but no feedback given to schools.
- There is a lack of provision for young people with a dual mental health and autism spectrum condition.

## What the professionals would like to see change

- More clarity on the eligibilty criteria for HYM.
- Better communication between HYM and schools to support young people following discharge.
- Greater choice of low level mental health services including easy access to low level counselling for young people in Oldham.
- Specialist mental health services provided in a choice of settings within a hospital, education, community or home setting, depending on the needs of the young person.
- Increase training for professionals who work with young people to build confidence to identify low level mental health issues and initiate discussions about coping strategies and self help solutions.
- Develop support for young people with dual diagnosis of mental health and other conditions such as anger management, ADHD (attention deficit hyperactivity disorder), autism spectrum conditions etc.

# Executive Summary

## Introduction

Healthwatch Oldham provides an independent consumer voice for Oldham residents who use NHS and social care services. Using the feedback and first-hand experiences of parents, children and young people we monitor the quality of services to highlight where they are working well and make recommendations to commissioners and providers where we feel services can be improved.

We also share information about local health and social care services with Healthwatch England and the Care Quality Commission (CQC). This way we ensure people's voices are heard at both local and national levels.

This children and young people's mental health service review is a joint project between Rochdale, Oldham, Bury and Trafford Healthwatch. The aim is to compare the different experiences of families, children and young people accessing mental health services across the combined area. As a result, two reports have been produced; one compares the key findings across the combined areas whilst **this report** provides a more detailed insight into the experiences of families accessing mental health services for children and young people in Oldham.

This work corresponds with national commitments set out in the NHS Long Term Plan as well as regional commitments by The Greater Manchester Health and Social Care Partnership to increase funding for children and young people's mental health services. Their aim is to improve access to services via schools and colleges and reduce waiting times for specialist support.

## Context for children and young people's mental health services

In 2018 Oldham Council and Oldham Clinical Commissioning Group (CCG) reviewed its children and young people's mental health services. As a result of talking to young people and their families Oldham adopted the iThrive model which focuses on prevention and early intervention in order to reduce the number of young people needing specialist mental health services provided through the hospital.

The specialist mental health service provided through the hospital is called Healthy Young Minds (HYM) and was formerly known as CAMHS.

The iThrive service brings together a range of organisations in order to tailor support to meet the needs of the young person. Referrals come through a single point of entry which means that young people can access low level support and specialist mental health services at the same time.

A key part of Oldham's new service involves a whole school approach to raise awareness of mental health issues with children and young people from primary school ages and to offer low level advice and support within the school setting.

This review gathers the experiences of families in Oldham using the iThrive service. A small number of families taking part in the review initially accessed services through the former CAMHS process. **It should be noted that children and young people's mental health services have gone through significant changes over the last few months and more time is needed to embed the single point of access and whole school approach to get a more accurate picture of how well the new arrangements are working.**

## What we did

Rochdale, Oldham, Bury and Trafford Healthwatch worked together to gather the experiences of parents and carers whose children use, or who have used local mental health services. We developed a range of questions to gather people's feedback which were presented in a questionnaire survey and as the basis for 3 focus group discussions. In Oldham the review was promoted in partnership with 26 local primary and secondary schools and colleges.

A total of 90 families from Oldham took part in the review.

We also gathered feedback through questionnaires and interviews with 35 professionals who work within schools and local services.

Whilst the questionnaires were promoted across a wide range of schools and colleges reflecting the ethnic profile of Oldham, the parents/carers who volunteered to take part in the review were overwhelmingly white British and female. In addition, none of the responses highlighted a dual mental health and drug or alcohol issue but we are aware that this can be an issue for some young people. As a result, it should be noted that the findings and recommendations in this report may not be reflective of the needs and wants of young people and families from black, Asian and minority ethnic communities or where the young person is experiencing dual mental health and drug/alcohol issues.

The following provides a summary of the themes that came out of the review.

## Themes

Families and professionals shared many positive experiences of children and young people's mental health services in Oldham. When it works well the referral processes are clear and families have access to timely support with good ongoing communication, and treatment that supports both the young person and the wider family.

Frustrations stem from long waiting times, poor communication and services that are hard to navigate. Some young people and their families have had a poor experience as a result of being passed around services and have failed to access timely or appropriate support. In some cases, young people have been left without any support.

Feedback suggests there is limited choice and availability of low-level preventative services or self-help resources for young people and their families. Children and young people's acute mental health services also tend to work in isolation rather than jointly with other services to focus on the holistic needs of the young person and their family.

**Access:** The most common concerns were difficulties getting a referral into the Healthy Young Minds Service (HYM); the length of time from the referral to the first appointment and the criteria for accessing the service being considered too high. Delays in the referral process and any subsequent refusal to take on the young person causes frustration and prevents timely access to diagnosis and treatment. Occasionally this results in the escalation of a mental health condition to a point of crisis.

The new single point of referral and triage into services should start to improve access, but waiting times continue to be raised as an issue.

**Communication:** Comments on the surveys raised several communication issues. Families get frustrated when they wait a long time to get answers in the early stages and there is no one to turn to for ongoing or accessible advice. Parents also want feedback after a session to understand how their child is progressing and what they can do to provide ongoing support.

Both parents and teachers are concerned about the lack of communication and joint working between HYM and the school/college to provide holistic support for the young person during treatment and after discharge.

**Autism:** Young people who were thought to be, or who were diagnosed as being, on the autism spectrum or with ADHD experience barriers to accessing the right treatment and support. Comments suggest that these conditions are dealt with in isolation by services and young people with a dual condition are considered too complex for HYM and either refused or discharged from the service. Families are then left without any alternative provision and the mental health issues, ranging from anxiety and depression to self-harming, go untreated.

**Staff:** When working well staff in HYM developed a rapport with young people, clarified what was happening and provided consistent care and support both for the young person and parents. Due to the turnover of staff at HYM some families had more than one therapist for the same treatment. This makes it harder for the young person to develop trust or a bond with the professional and reduces the effectiveness of talking therapy treatments.

When working well staff in schools/colleges were confident to manage low level mental health conversations, created effective peer support relationships within school, and had good two-way communication with parents. There is an expectation that teachers will manage more low-level conditions within a school/college setting and some schools want more support to ensure this is done effectively and consistently.

**Treatment:** There were mixed views about the effectiveness of treatment. Comments related to CBT, 1 to 1 counselling, group sessions and parent workshops. Concerns were raised that different treatment options are offered by different services and if one treatment isn't working for their child, families must wait to be referred to other treatment options with a different service. Where it works well families have easy access to alternative treatments without having to go through a new referral or waiting list.

Families expressed frustration about HYM sessions being infrequent and gaps between therapy sessions being too long.

**Discharge:** Many raised concerns about the lack of follow up support after discharge from the HYM service, or referral into alternative low-level support either within the community or the school. Parents want better access to information to help them and their child manage after discharge. They also want a shortcut back into services in the event of a recurring mental health crisis rather than start the referral process again.

**Crisis:** There were comments relating to self-harm and suicide and examples of this being the trigger to attend A and E and gain access to HYM. Some families tried to access services earlier but were not taken seriously whilst others were signposted to inappropriate low-level support and disengaged with services as a result, only to come back at a point of crisis. Concerns were also raised about urgent care services and front-line staff who did not understand how to support a young person experiencing a mental health crisis.

Parents want to know where to go in the event of a crisis and want front-line staff in urgent care to be trained to understand and respond appropriately.



# Main Recommendations

Mental health problems for young people can range from anxiety through to severe and persistent conditions that can be isolating and frightening. Some research suggests that 50% of mental health problems in adults take root before the age of 15. This review highlights the growing demand on Oldham's acute mental health services and the importance of focusing on early intervention and prevention to reduce the numbers of young people presenting with a mental health crisis. The following recommendations are based on the feedback from families and professional who took part in this review.

- 1. Prevention, Resilience and Early Intervention** - Provide a wider range of low-level mental health support as part of a consistent mainstream offer across schools and community settings. Options to include self-help resources, support for life skills to enable young people to manage low level anxiety and increased availability of low level counselling for families.
- 2. Timely Access** - Reduce referral waiting times through early triage and increase the impact of specialist mental health support through continuity of care and frequency of treatments. Routinely signpost to self-help, on-line and low-level mental health resources at the first point of access into services.
- 3. Knowledge of Services** - Professionals who work with young people to have access to up-to-date information on mental health services including the choice of support available, referral process, criteria, waiting times, who to speak to for advice and self-help resources. Professionals to routinely promote this information across mainstream services.
- 4. Holistic Support** - Explore options to join up or redesign existing provision to create services that support young people with a dual mental health and autism spectrum disorder or attention deficit disorder.
- 5. Joined Up Services** - Through the Oldham Single Point of Access ensure that young people have information on the choice of treatments available to help them find the right support first time.
- 6. Communication and Advice** - Build in time for parents/carers to ask questions and gain practical advice and feedback as a standard part of the HYM sessions. Include a final review on discharge to explore how the family is coping and to provide information on other mainstream support, self-help resources and crisis support through a standard information pack or website.
- 7. Information and Self Help** - Review current mental health information and resources to ensure that young people and their parents/carers have access to consistent information at the point when they need it. Information should include age and learning level appropriate self-help resources for young people and their parents/carers to develop their own skills and knowledge to help manage their situation, as well as videos, parents' blogs etc.
- 8. Training** - Continue to develop the whole school approach and increase the capacity of schools to understand and identify low level mental health issues and build the confidence of teachers to initiate discussions and explore coping strategies, for example managing exam anxiety etc.

**9. Discharge** - Establish processes to fast track young people back into services if their situation is getting harder to manage after discharge. Provide families with information about what to do and who to speak to if the young person experiences a mental health crisis in the future.

**10. Urgent Care** - Establish clear urgent care pathways for young people experiencing a mental health crisis to include timely support and designated safe spaces.

**11. Review** - For children and young people's mental health services to be reviewed within 18 months of this report. A future review should gather feedback from young people about service improvements as well as feedback from black, Asian and minority ethnic families about children and young people's mental health issues.

## Healthwatch commitment:

At Healthwatch Oldham we take our commitment to children and young people seriously and as a result of the findings and recommendations in this report we are planning our own contributions to children and young people's mental health awareness through the following events:

- The Active Health Outdoors Family Forum in August 2019 in partnership with Oldham Council.
- Young People's Health and Wellbeing Event in September 2019 (ages 16 to 24) in partnership with Oldham College.
- Children's Health and Wellbeing Event in October 2019 (ages 9 to 11) in partnership with The Oldham Pledge which is designed to help young people take an active role in their own health and wellbeing. For more information on The Oldham Pledge please visit:  
<https://www.theoldhampledge.co.uk/>

All these events will provide an interactive opportunity for young people to take part in a range of fun activities, ask questions and find out what is available to them to manage, maintain or improve their health and emotional wellbeing.

# Detailed Findings

## Profile of the young people

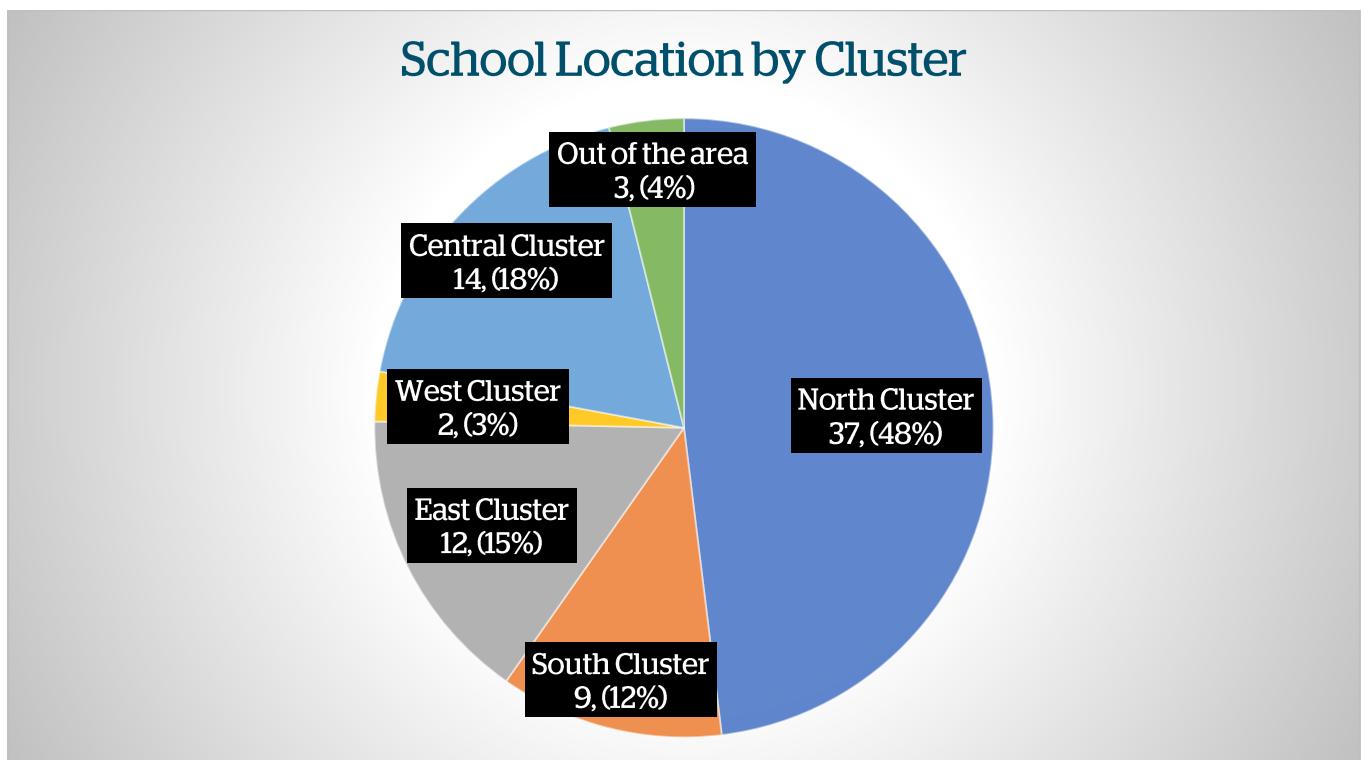
We received 90 completed questionnaires. Not all questions were answered by all the parents completing the forms. From the data we have been able to extract the following information.

Age Range	0-5	6-10	11-13	14-17	18-24	TOTAL
Number of Responses	1	16	31	36	5	89

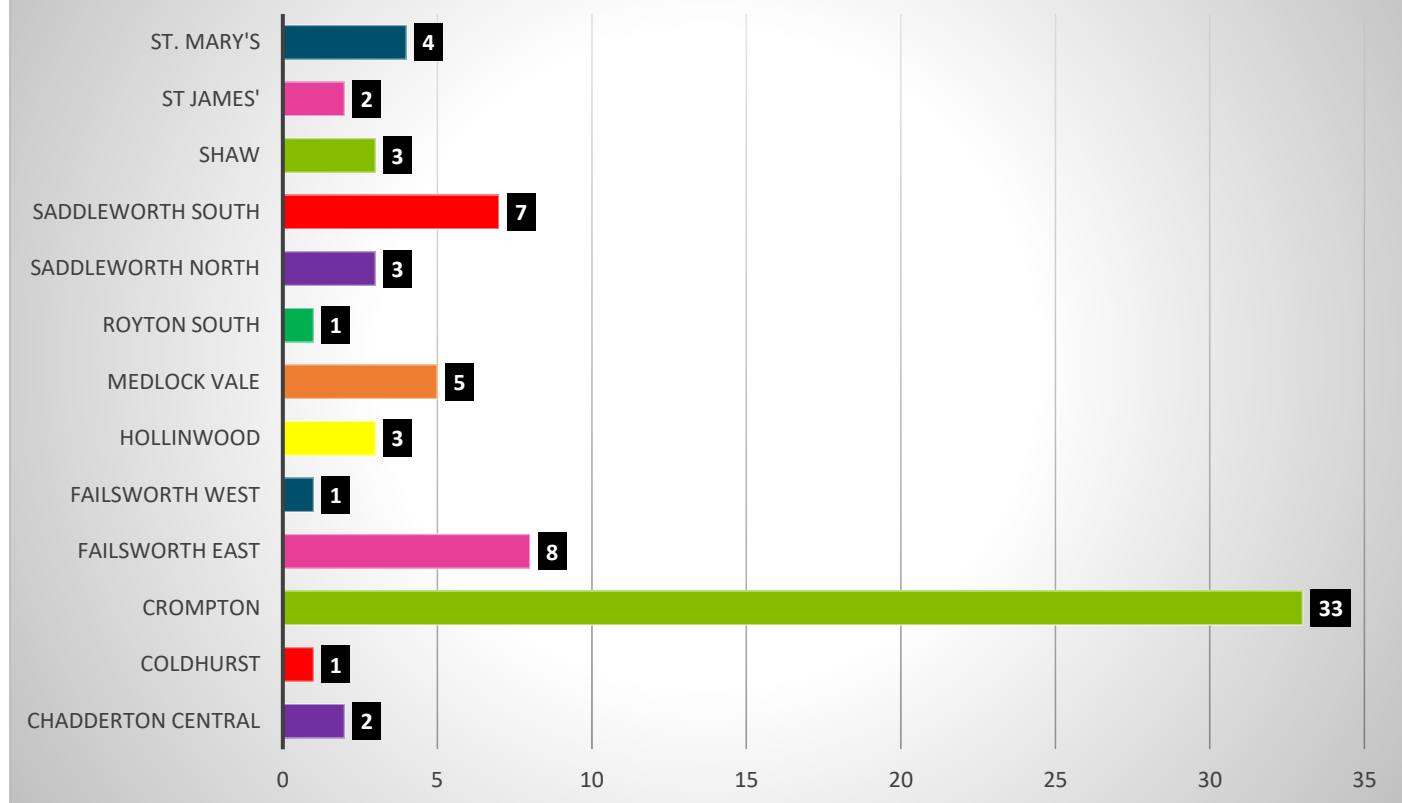
Childs/Young Persons Gender	Male	Female	TOTAL
Number of Responses	36	54	90

Ethnicity Group	White British	White and Black Caribbean	Pakistani	TOTAL
Number of Responses	61	2	1	64

## Where they go to school



## School Location by Ward



## Profile of parent or carer completing the survey

Whilst the questionnaires were promoted across a wide range of schools reflecting the ethnic profile of Oldham, the parents/carers who took part in the review fell into the following groups:

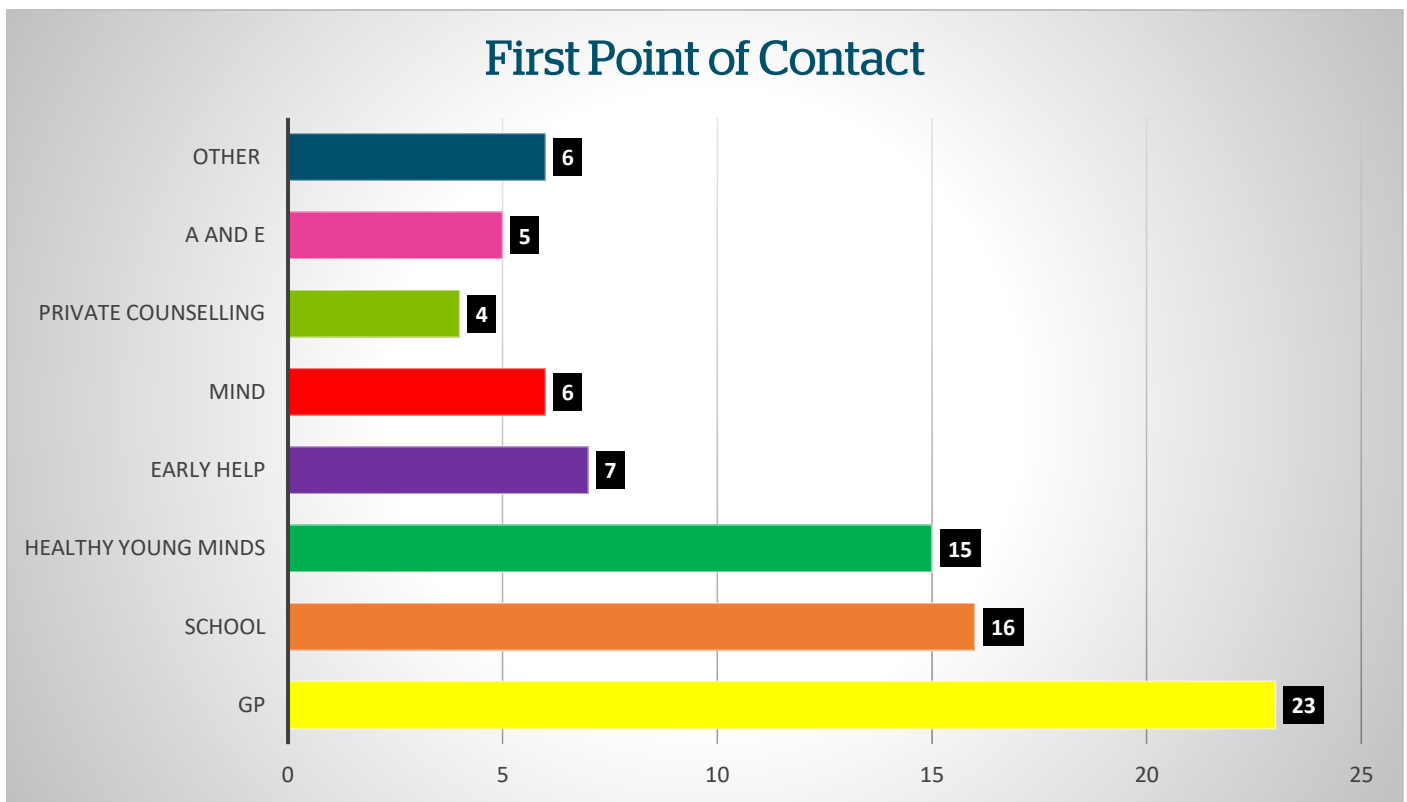
- Overwhelmingly female (93%)
- Overwhelmingly White British or Irish (95%)
- Overwhelmingly heterosexual (93%)
- Significant number who are married or in a long-term partnership (75%)

The very high numbers of White British are not representative of Oldham's population. Bearing in mind the spread of schools involved in the review our findings suggest further work is needed to understand the perceptions of people from other ethnic communities to children and young people's mental health issues.

Most parents were aged between 30 and 49 (75%) and 53% identified themselves as the main carer for one or more person.

# What families told us

## 1. Who was the first point of contact who referred you into services to help your child?



Of the parents who responded 28% (23) went to their GP as the first point of contact for advice and access to services. The feedback shows that schools also played an important role identifying and referring 19% (16) of young people into services, whilst 18% (15) made a self-referral directly into Healthy Young Minds (HYMs).

*“The self-referral system (HYMs) may save money, but in this type of illness, the likelihood of self-referral is diminished. It may work well for some, but it would be helpful if the GP could refer in addition to self-referral.”*

*“My son initially saw his GP in October who has been excellent with him.”*

*“When a staff member left the (HYM) service, my child was discharged, and we later had to again ask for referral via the GP. At this point we were told to self-refer and I tried to access services for my child but was told I can’t refer her. She won’t refer herself after the previous experience, so we are now in a limbo with no help / treatment.”*

## 2. What prompted you to get help?

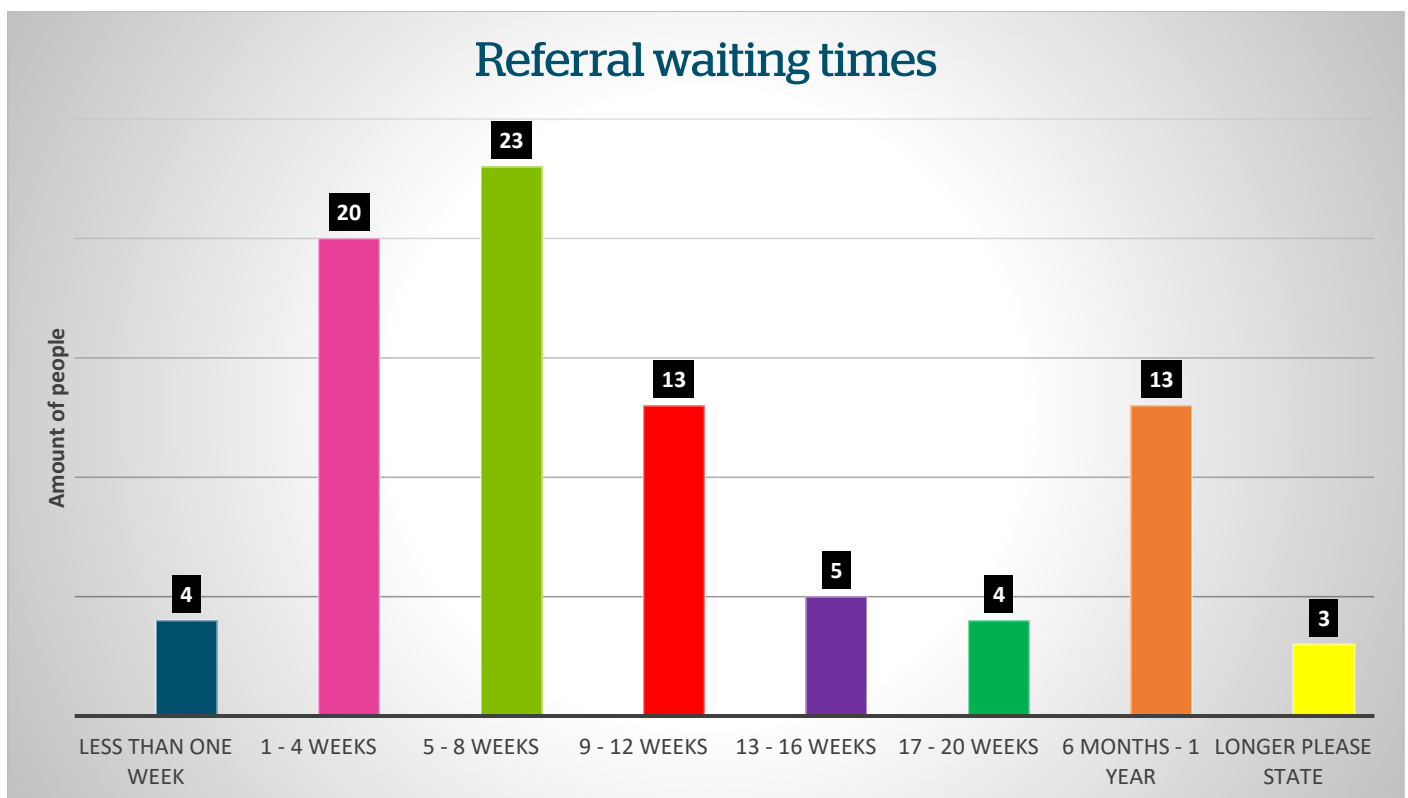
We asked parents about the triggers that prompted them to find out about mental health support for their child. This feedback came from the focus group interviews. One parent said their child started to experience anxiety during the transition from primary to secondary school whilst others sought help following behavioural issues. Three parents shared similar experiences of trying to access support earlier but having their concerns dismissed, so they finally accessed help and support when their child reached a crisis and went directly to A and E.

*“Starting point was GP ... said they would probably be fine and grow out of it. I thought that I must be doing something wrong as behaviour worsened.”*

*“they became very anxious about things, physically sick every morning, couldn't eat, worried about their parents dying and being on their own, what would happen...”*

## 3. How long did your child have to wait to see a professional from the time they were referred?

Of the children and young people who were referred into mental health services 55% (47) were seen within 8 weeks whilst 29% (25) waited more than 3 months to be seen and of these 18% (16) waited between 6 months and more than a year to be seen.



We asked parents how they felt about the waiting times and 45% (33) felt the waiting times were good or very good compared to 33% (25) who felt the waiting times were poor or very poor. The poor responses correlate with the number who had to wait at least 3 months to be seen.

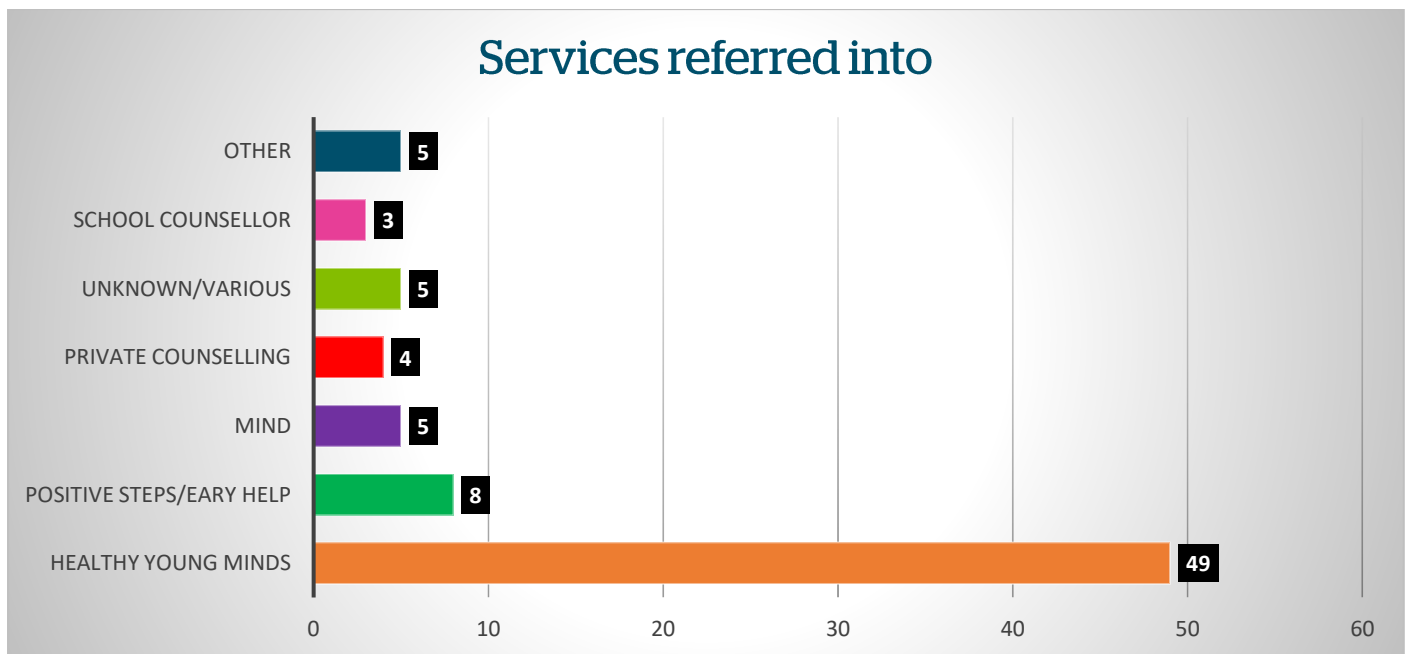
*“Quick access once we knew how to access it.”*

*“The initial appointment was quick due to her self-harming and really helped in stopping that.”*

*“Took way too long for initial appointments and then had to wait a few months for an assessment appointment as there was a long waiting list. Once my son was diagnosed with ASD he was discharged from the service and passed to Oldham POINT.”*

*“We chose a private counsellor as I was not willing to wait the length of time for an NHS referral, my daughter was too unwell to wait.”*

#### 4. Which service did your child use?

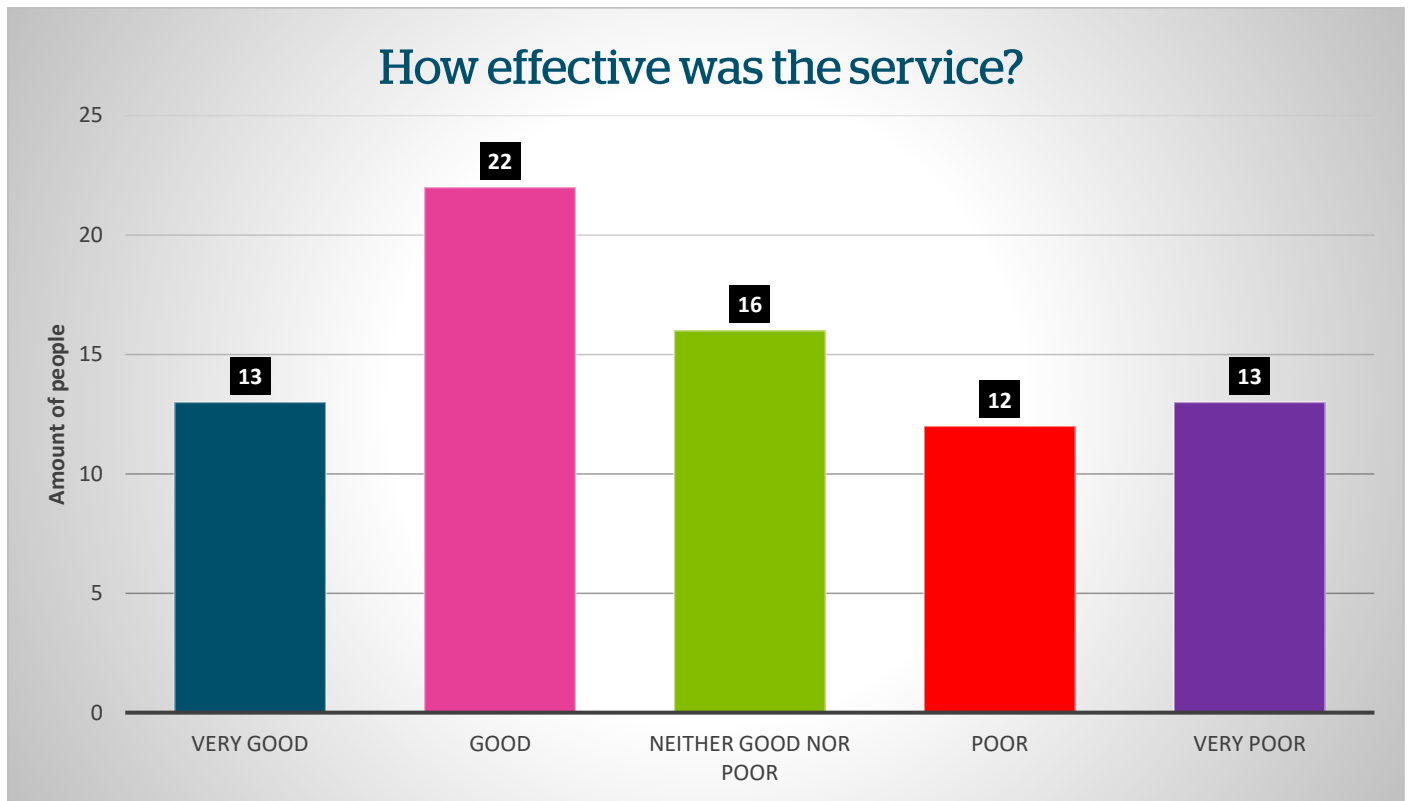


Of the children and young people who were referred into mental health services 62% (49) used the Healthy Young Minds Service. If we compare the length of referral waiting times by service these were evenly spread over all the different organisations and only the private counselling services consistently saw children and young people within the first 4 weeks.

We asked parents if they felt the support offered to their child was provided in a timely way. Of those who responded 45% (35) felt the timing of the support was good or very good compared to 40% (31) who felt that the timing of the support was poor or very poor.

*“I feel if my children were looked at years ago instead of me keep getting knocked back when I first needed the help it wouldn't have escalated to the place we are at now and would be a lot easier to help the children and support them better.”*

## 5. How effective was the service in helping your child deal with their problems?



Parents views on the effectiveness of the services were very mixed across all the different services that were accessed. Of those who responded 46% (35) felt the service accessed was good or very good at helping their child compared to 33% (25) who felt the service was poor or very poor at helping their child deal with their problems. Of those who used the Healthy Young Minds service 47% (23) felt it was either good or very good at helping their child compared to 27% (13) who felt that it was either poor or very poor in helping their child deal with their problems.

*"It was a gateway to opening up about her worries (HYM)."*

*"They made my daughter comfortable and spoke to her at the right level. She doesn't feel like there is something wrong with her. I was impressed they were prepared to help now before things got worse even though her problems seemed a little silly." (HYM)*

*"Working as a small group within school really helped with anxiety."*

*"Service for my child has been totally inadequate- this being the second time to access this service with similar experience. The first time, we were told that there was no mental health service for children with Autism (HYM)."*



We also asked parents how effective the service was in **helping them** deal with the difficulties their child was experiencing. The positive responses were slightly lower than those reported for help to their child (above), with 34% (26) of parents feeling that the service was good or very good at helping them to deal with their child's situation. This shows that 66% of parents did not feel that the service had **helped them** to deal with their child's situation.

*“(need to) listen more to parents concerns and help to educate parents and carers how best to deal with issues”*

*“I liked healthy young minds once you actually managed to get into the system because it took me three attempts before they took us on. They were very considerate of both parent and child and sympathetic to the fact that it took me so long to get in the system and that I had to put a complaint to the head of the service before we got accepted, but they put me on course to help me understand my child more and supported me whilst we were under them.”*

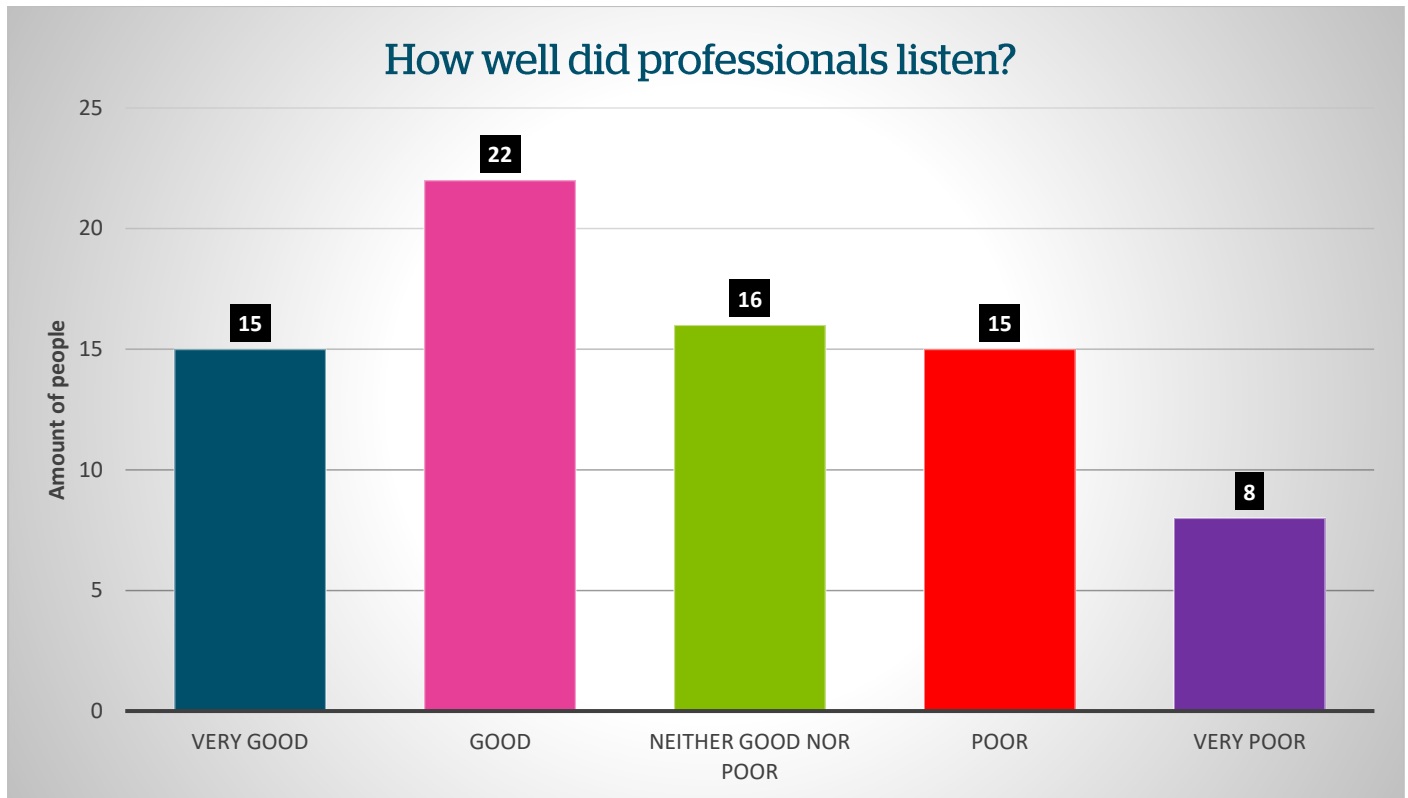
## Case Study 1: Accessing support for emotional and behavioural issues

It started off with some bad behaviour which just didn't feel right. By the time our child was 7 they were very strong and became physically violent. For almost a year we were passed between the GP, health visitor and school nurse but didn't find the right support.

Things got worse, and my child had a meltdown before school and locked themselves in the bathroom and shouted abuse. I really didn't know what to do. The school were 'absolutely brilliant' and the headteacher managed to talk them round and get them into school. The headteacher made a referral to CAMHS and we were seen within a month. CAMHS were very clear about the waiting times and what would happen.

Things really improved when my child attended the support group for children with emotional issues and we attended a parents 1 to 1 session with a therapist to talk through what was going on which was really useful. The CAMHS service was very good but a follow up after discharge would also help.

## 6. How well did you feel that the professionals (doctors, psychologists, nurses, therapists, session workers) listened to your child and understood their problems?



Of the parents who responded 49% (37) felt that professionals were good or very good at listening to their child and understanding their concerns compared to 30% (23) who felt that professionals were either poor or very poor at listening to their child.

*I liked ... "how well my daughter was listened to." (HYM)*

*I liked... "Staff spoke with my child not me at appointments." (HYM)*

*"I found the whole process disheartening and the two times my daughter attempted to seriously harm herself and attempted to take an overdose these concerns were never taken seriously." (HYM and Mind)*

*"They spotted straight away that my daughter was autistic and was suffering with mental health problems and self-harming." (HYM)*

*"Sometimes felt staff not listening to us, but listening to our child, who isn't always truthful."*

We also asked parents how well they felt the professionals listened to them about the concerns they had for their child's mental health. Of those who responded 54% (42) felt that the professionals were good or very good at listening to their concerns compared to 28% (22) who felt that the professionals were either poor or very poor at listening to them.

*"I felt they took my concerns seriously and did a thorough assessment of my child."  
(Autism Spectrum Disorder  
ASD Anxiety workshop)*

*"The professional explained and listened to me." (HYM)*

*"My child and family needed someone who fully understands the issues that comes with complex needs. Need one person to interact with my child/family so they can get to know us all."*

*"I feel that parents know their child best and that their voices should also matter, and their views should be considered when discussing my child"*

## 7. Providing a professional, trusting and confidential service

We asked parents to rate how professional they felt the service was and how well professionals managed their child's confidentiality and built up a trusting relationship. Of those who responded 71% (55) of parents felt that the services they accessed were either good or very good at offering a professional service compared to only 14% (11) who felt the service was poor or very poor. Services provided in a school setting and by Positive Steps were considered less professional but it should be noted that the number of responses were very small and therefore should not be considered as representative. 71% of parents also said that professionals were very good or good at keeping agreed appointment times but a few complained about appointments cancelled at short notice.

*"Always accommodating for appointments and seen regularly." (HYM)*

*"Was not always warned of the counsellor cancelling a session."  
(HYM)*

We also asked parents if they felt the professional had a trusting relationship with their child. Of those who responded 53% (41) felt that the professionals were good or very good at developing relationships compared to 17% (13) who felt that they were poor or very poor at developing trusting relationships.

*"It was good that my child felt able to open up about her anxiety to a school professional and was taken seriously in time for her GCSE exams."*

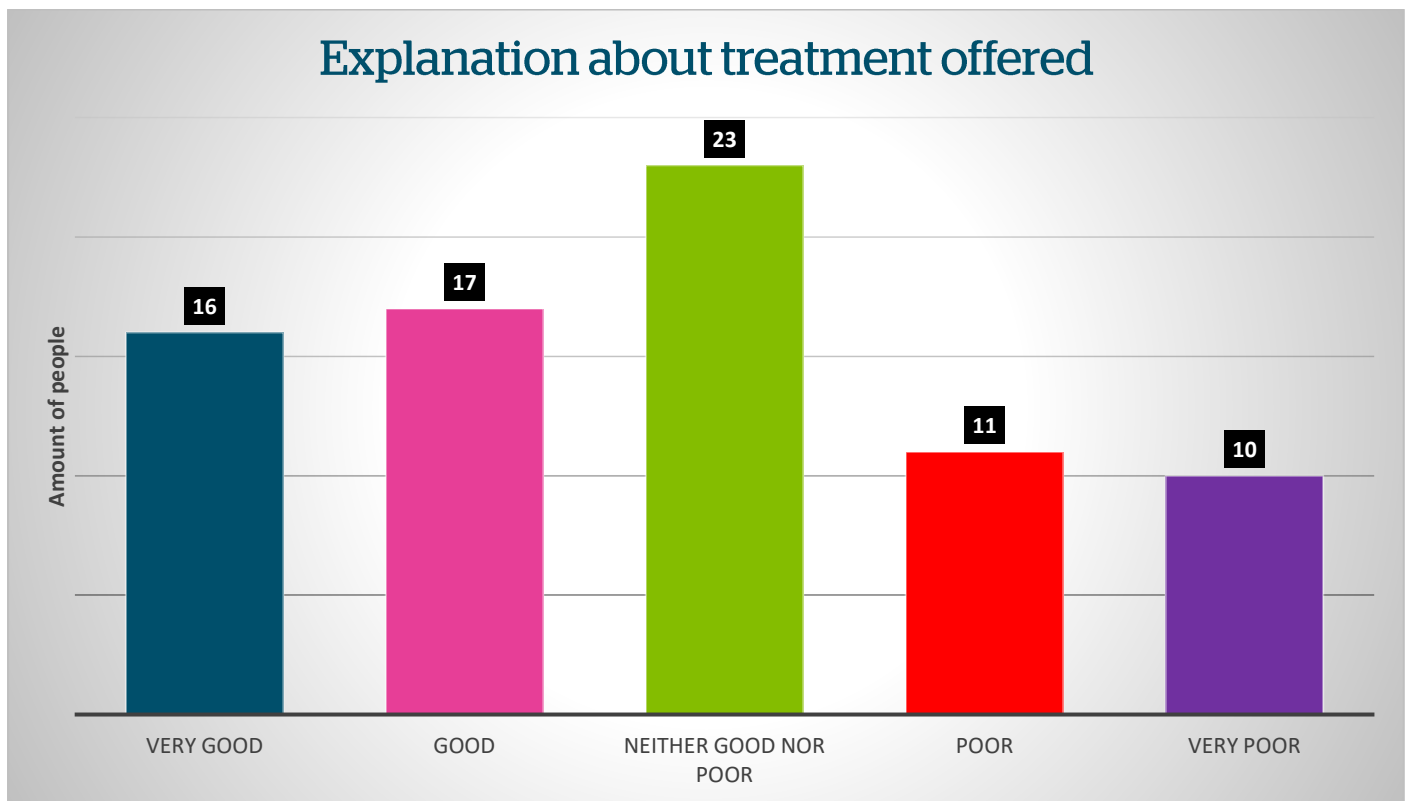
*"Friendly and approachable manner with my child and with us." (HYM)*

*"The HYM service is focused on talking therapy and based on how well the child engages with the counsellor and is prepared to talk to them. This didn't work for my daughter who didn't engage and didn't feel confident or comfortable."*

*"Discharged my son due to lack of engagement (because he didn't speak in sessions) my son needed more sessions to build a trusting relationship (HYM and Mind)."*

In terms of confidentiality 75% (58) of parents felt that the service was good or very good at respecting the rights of their child and maintaining their confidentiality, compared to only 9% (7) who felt they were poor or very poor.

## 8. How well did professionals explain the treatment your child would be offered?

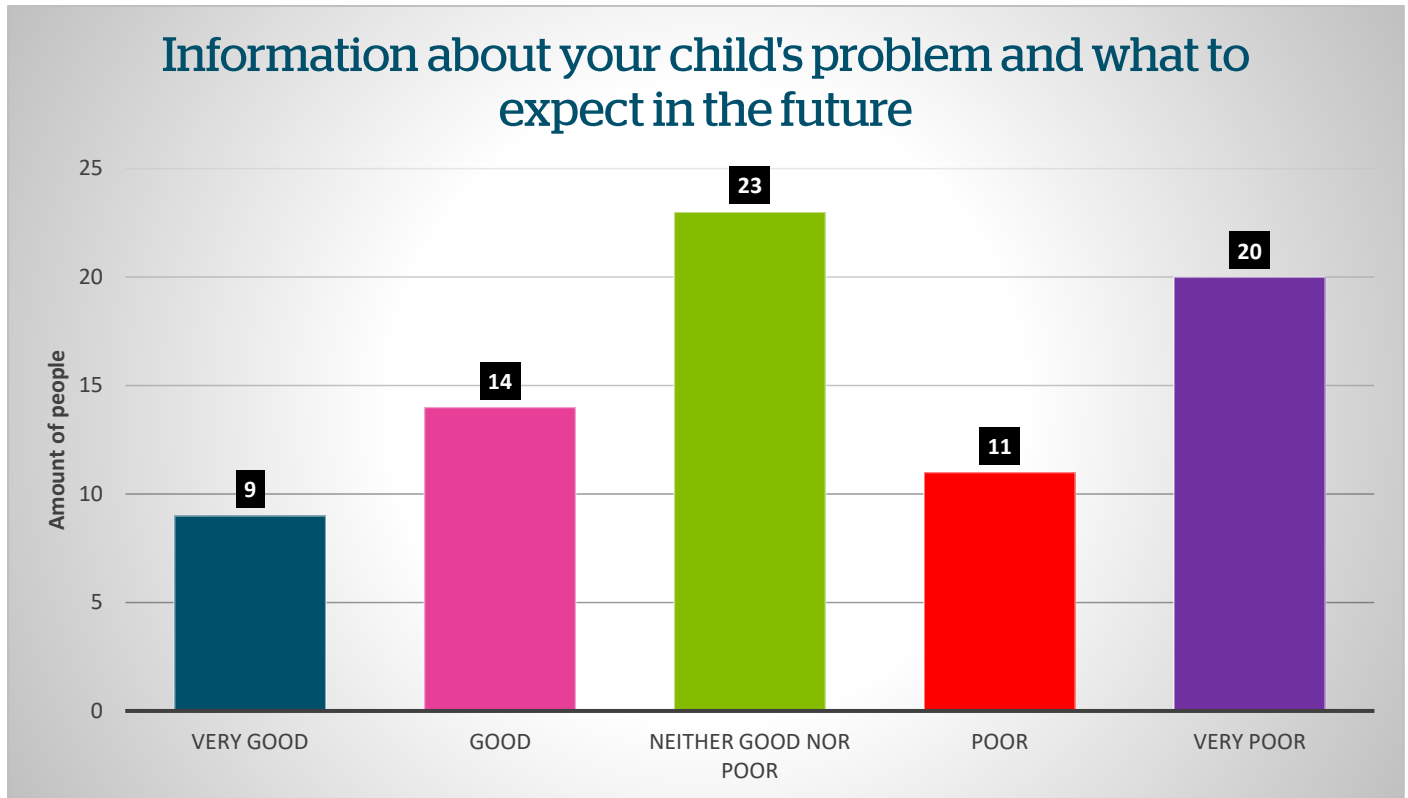


Of the parents who responded 43% (33) felt that professionals were either good or very good at explaining the treatment their child would be offered. This shows that 57% (44) of parents did not feel that they were offered a good explanation of the treatment for their child.

*Liked their... "Professional manner, explanation of treatment." (HYM)*

*"Very professional and understanding. Appointment date and time kept very prompt never rushed. Listened to my concerns and lots of advice given, referred me to after service which is the amazing POINT in Chadderton."*

## 9. Quality of information and advice for parents, children and young people



We asked parents to tell us about the quality of information given to them **about their child's problem** and what they could expect in the future. Of those who responded only 30% (23) felt the quality of information was good or very good whilst 40% (31) felt this was poor or very poor. In total 70% (54) of parents did not feel they had good quality information to help them understand their child's problem and what to expect in the future.

*"No feedback from sessions." (Mind)*

*"No feedback from the counsellor or update on how my son is doing, this should be a two way process. I need to know how I can help him (HYM)."*

We also asked parents to rate the quality of advice given to them to **help support their child**. Of those who responded 37% (29) felt this was good or very good compared to 45% (35) who felt this was poor or very poor.

*"More interaction as a family rather than just with the young individual."*

*"More input from therapists, talk to parents more not just child"*

## 10. Moving on from the service

We asked parents to tell us how they felt about the length of time between discharge from the service, or end of the sessions, and a follow up appointment with the same or different service. Of those who responded 25% (19) felt that this was good or very good compared to 40% (30) who felt that this was poor or very poor.

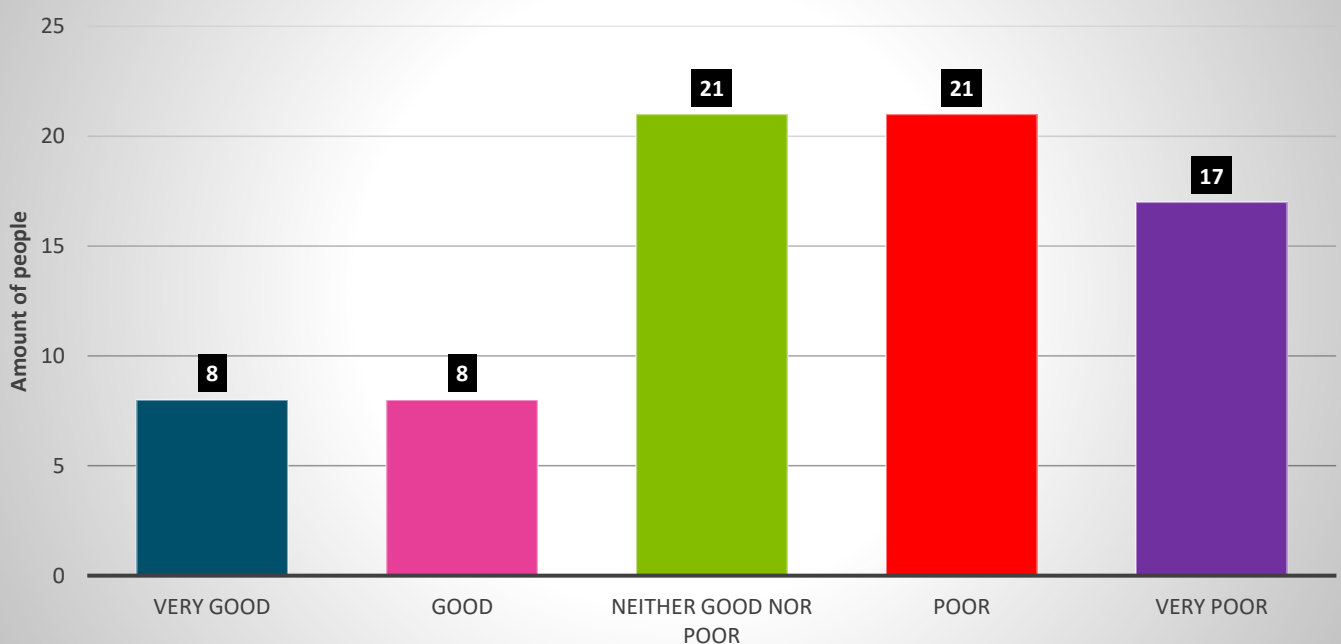
*“What she was referred for was found not to be the issue, so we were discharged but with no referral to another service so had to start again.”*

*“My child has been under the services since they were 8yrs old they are now 13 yrs old ... we get left for months between appointments there’s no real direction or advice. My child finished sessions in July, and we’ve been waiting to see a psychiatrist almost 7 months with one letter that says they will be in touch soon. They don’t communicate with school... so we just go around in circles and all the time my child’s mental health is deteriorating.”*

Parents were also asked how well they thought the service communicated with other external services. Of those who responded 29% (23) felt that there was good or very good communication whilst 32% (25) felt the communication with external services was poor or very poor.

*“All the professionals...should try and communicate with one another instead of the parent constantly being in the background.”*

### Advice you/your child was given on discharge



We also asked parents to rate the advice given to both them and their child on discharge or when the sessions finished. Only 21% (16) felt that the advice they received was good or very good compared to 50% (38) who felt the advice they received was poor or very poor. In total 78% (59) felt that they did not receive good advice at the point their child was discharged from the service.

*“After the Autism Diagnostic Observation Schedule (ADOS) assessment, having to wait nearly 4 months to see a copy of the report and once I was given the copy of the report, was discharged on that day. Not able to go through the ADOS report with the Psychologist.”*

*“They sign you off too soon instead of assessing you after 3 months, then 6 months, then a year because 6 months down the line we have been referred back in the system to fight all over again.”*

## 11. How would you rate the overall service your child received?

We asked parents to tell us what they thought about the types of mental health services offered to their child. The responses were evenly balanced with 40% (31) feeling the types of services offered were good or very good and 40% (31) feeling the types of services offered were poor or very poor.

*“Transition services needed, support during transition has been non-existent.”*

*“Not enough support given to foster carers with very damaged children especially through adolescent years.”*

*“no help after 5 pm Friday to 9am Monday... no care that she had attempted to take her life 3 times. No follow through to other services, no compromise with other services when Cognitive Behaviour Therapy (CBT) failed.”*

### Case Study 2:

#### Experience of transition from Children’s to Adult’s services

We tried to raise our concerns, but they were dismissed. It got to a crisis point and we ended up at A and E before we were offered any support. There is no clear pathway to support young people going through the transition from young people’s mental health services to adult services. We waited two years for our referral to be picked up by a learning disability nurse and during this time our child experienced sexual health, relationship, mental health and self-harming issues.

We were on a waiting list for a long time then had six weeks of support from HYM. It wasn’t long enough and felt like a sticking plaster. Only when our child reached 15 did we get some consistent support from a Young Persons Mental Health Worker and they went into college to offer support which was great. Our child also took part in a course called friendship skills run by Mind at Newbridge School which really helped.

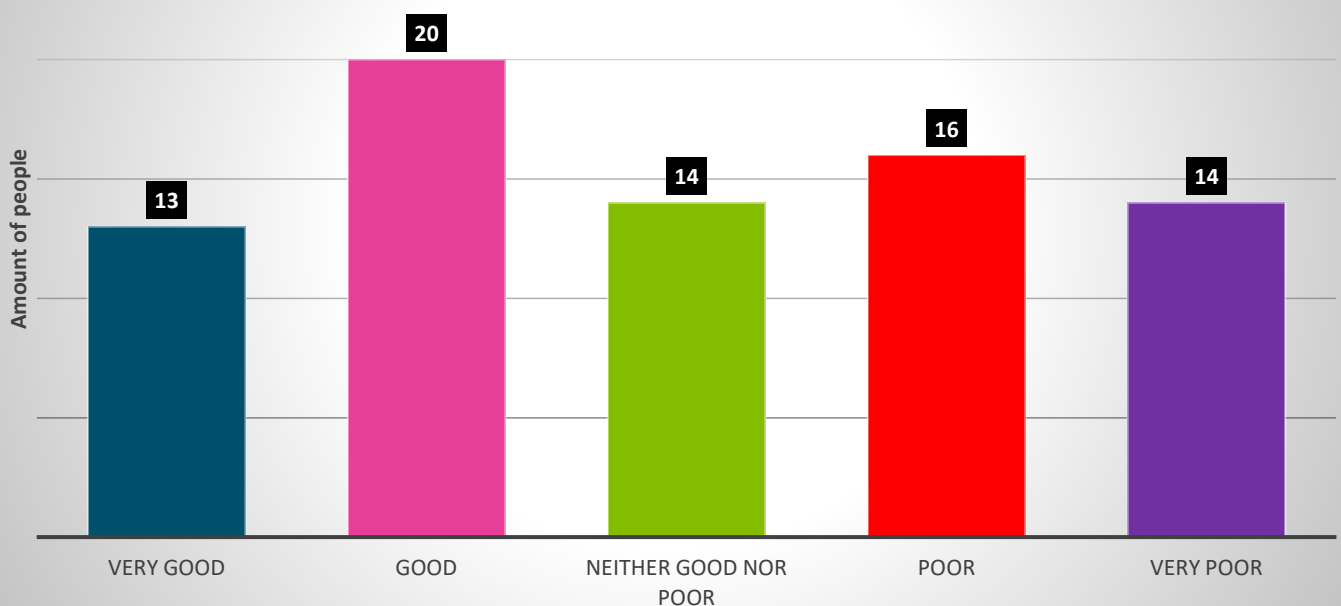


When asked to rate the overall service received by their child 42% (33) felt it had been good or very good compared to 38% (30) who felt it was poor or very poor.

*“Our child is currently still attending sessions and so it is difficult to assess how the overall experience will assist. However, our child is still suffering the same anxiety as previously although we would hope when the sessions are finished, she will have the ability to recognise and cope with situations which cause her anxiety better. I would say we have made more progress as a family at home than the sessions have so far which is disappointing.”*

*“Please continue with the good work from this very vital service. Helping the young people before they become adults is the key.” (HYM)*

### The overall service your child has received



*“HYM is such a vital service that a lot of people rely on. The staff there are truly amazing it would be nice to see this service get an increase in funding.”*

## 12. What changes would you like to see?

Overall parents and carers of children and young people who have used services, or who are currently using services, shared many positive experiences and highlighted some specific examples of best practice that often related to individual relationships. At the end of the questionnaire we invited parents to reflect on their experiences and tell how they think services could be improved.

### i) Waiting Times

The most repeated improvement requested by parents and carers is the reduction in waiting times. This was raised by families with a positive or negative experience of the service itself.

Parents want to see shorter waiting times between the referral and the first appointment, and once in services they wanted more frequent appointments over a longer period of time.

### What would you change/improve?

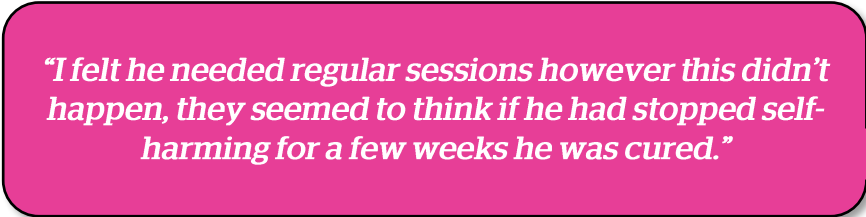
- Shorter waiting time from referral.
- Not waiting two months for next available telephone counselling session.
- Time given in a session should be longer.
- The length of time between appointments should be shorter.
- Ensure regular follow up appointments.



*“Appointments are promised but never received.”*



*“Clinician said he would get back to us within 3 days - still no contact after 4 weeks - despite me leaving several messages”*



*“I felt he needed regular sessions however this didn't happen, they seemed to think if he had stopped self-harming for a few weeks he was cured.”*

### ii) Autism Spectrum Disorders (ASD) and mental health

Parents face additional barriers to accessing services and support when their child is experiencing both an ASD condition and mental health issue. Some parents feel that services deal with mental health issues in isolation and as soon as the young person gets an ASD diagnosis they are discharged from mental health services. Feedback shows that many families are left frustrated as any underlying mental health issues are not addressed.

## What would you change/improve?

- Design services to work together and offer support regardless of the diagnosis.
- Provide more support for children and their families with ASD and mental health.
- Make it easier to get an earlier diagnosis.
- Make sure all professionals have a good understanding of ASD.
- Make sure clinicians are trained to understand how ASD creates significant levels of anxiety and the impact this has on accessing therapy.
- Make information and pre-appointment questionnaires accessible to children and young people with ASD.

*“Took way too long for initial appointments and then had to wait a few months for an assessment appointment as there was a long waiting list. Once my son was diagnosed with ASD he was discharged from the service... It’s been almost a year since his referral to healthy young minds and we have had no help at all with his original problems that we referred with i.e. anxiety and behavioural problems. Things have become worse, so I am going to have to self-refer again.”*

*“You get your diagnosis then it’s pretty much off you go. The post diagnosis workshops run by POINT are very helpful but for us it took too long for them to be up and running. Once she was discharged there was no help from services - re-referred in, had a workshop then discharged again, now there is nothing to help her.”*

### iii). Communication

Parents want feedback and progress updates from professionals following sessions with their child as well as clear lines of communication to help manage concerns. Parents would also welcome better communication between mental health professionals and the school to support their child.

## What would you change/improve?

- Single point of contact offering ongoing advice.
- Improve ways of contacting and communicating with the HYM service.
- More communication between school and HYM.
- More communication between school and GPs to work together for the good of the child
- Improve communication between health professionals supporting a child.

*“The whole system needs updating they don’t even have emails so you can’t contact anyone.” (HYM)*

## iv) Some General areas for improvement

The following are some of the general comments made by parents and carers.

### What would you change/improve?

- Make sure that mental health services look at the whole child and have a holistic view.
- Services should be non judgemental.
- Ensure consistent care from the same clinician.

*“young children associate hospital visits as being poorly and that’s not the idea I wanted to give my daughter. (Services) should be in a children’s centre... or similar.”*

*“...on average waiting 1 month between appointments and have had a change in worker which is difficult for my child to manage.”*

### Case Study 3: A and E crisis support

Our child first showed signs when they talked about being depressed. By the time we went to the GP our child was in a crisis and was referred to HYM. We waited 2 months for the basic assessment before seeing a counsellor. Things got worse and our child started self-harming and became suicidal, so we went to A and E. For their own safety they were kept in overnight and seen by HYM but there was no follow up appointment even though they were suicidal.

The A and E service needs rethinking for young people with mental health issues. The waiting environment for a child with severe anxiety makes the condition worse. My child was seen by a nurse and told the doctor needed to check she was physically well. We waited 5 hours to see the doctor on duty and only then was a request put in for a psychologist. This request should have gone in asap. It was a challenge keeping our child in the waiting room as their anxiety increased and they wanted to leave but they were suicidal. Finally, after repeatedly asking the nurse we were put into a cubicle and they calmed down.

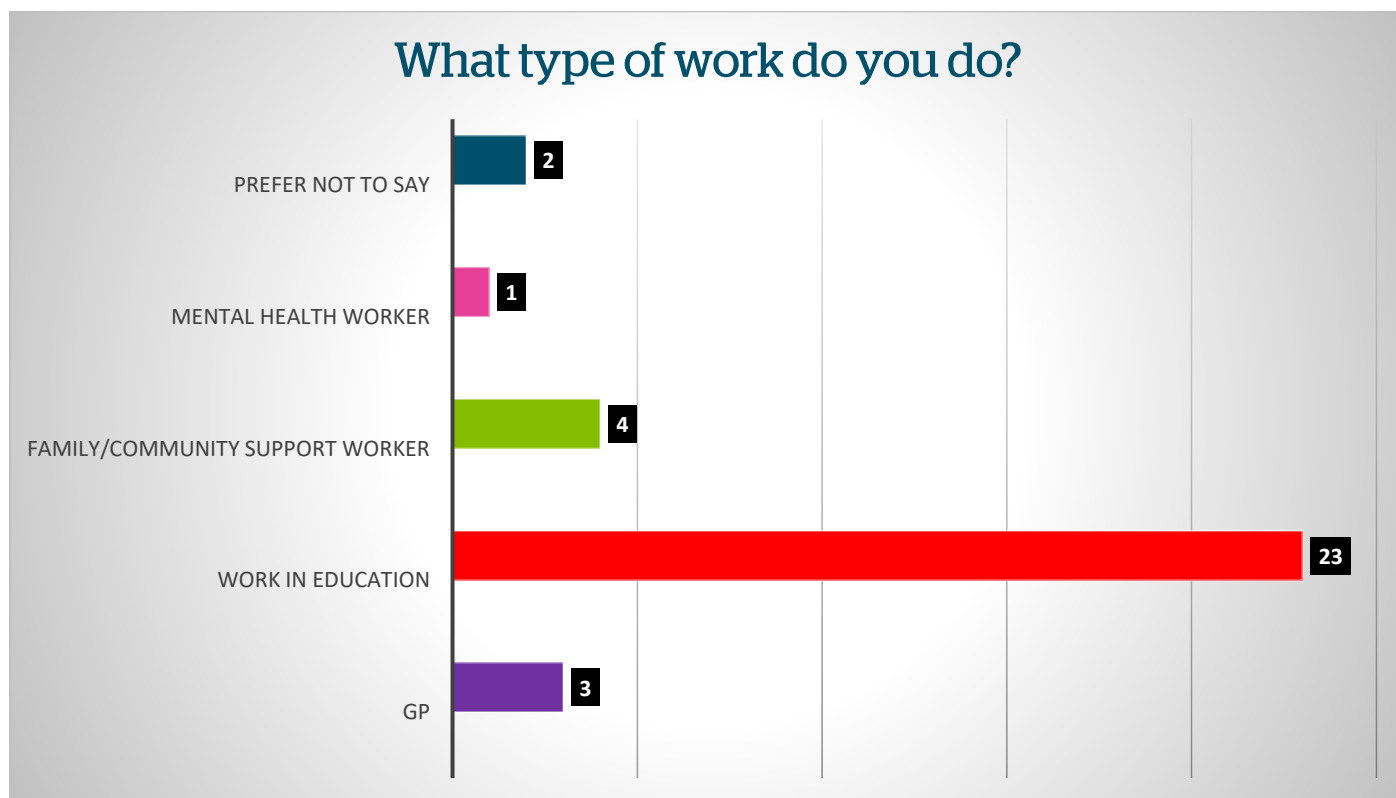
School have been really fantastic. I get support by phone, email and face to face. The biggest problem is that the School have been unable to access HYM to continue the support they are offering in a school setting after the sessions finish.

## What Professionals told us

This section looks at the responses from professionals about their experience of referring or signposting children or young people into mental health services in Oldham. We received 35 completed questionnaires from professionals and were able to extract the following information.

### 1. What type of work do you do?

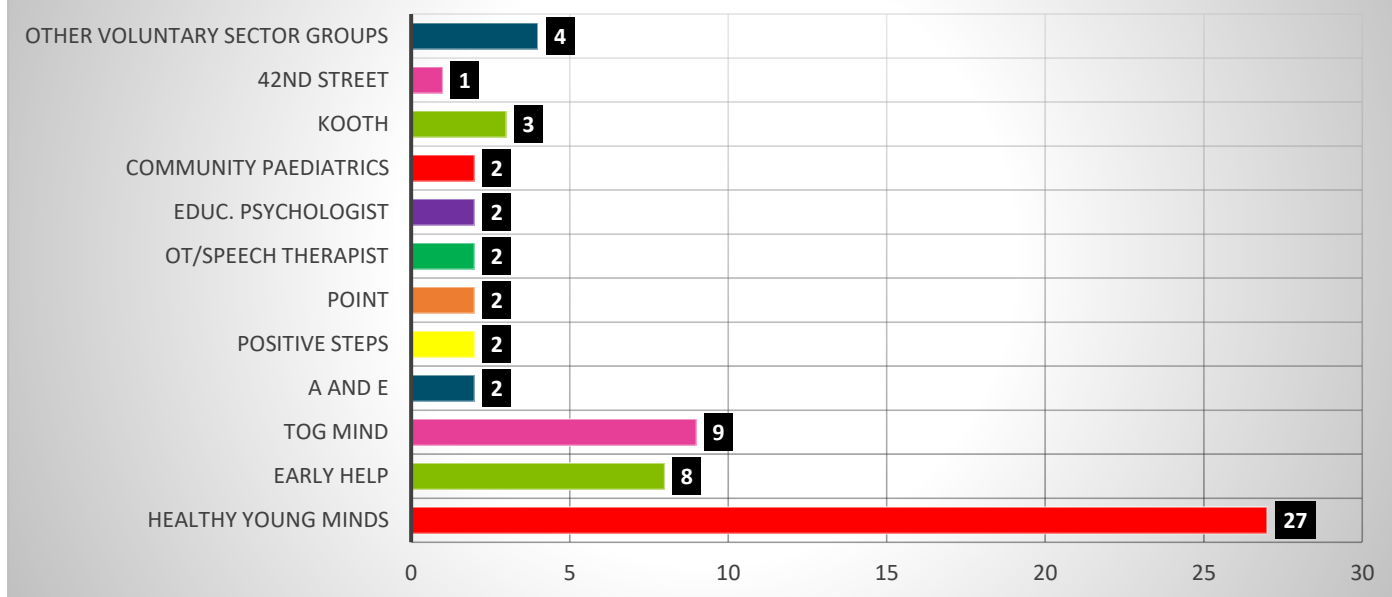
The breakdown shows a significant number of responses (70%) came from professionals working within an educational setting. As a result, the findings and recommendations may be more reflective of educational professionals rather than other health professionals.



### 2. Tell us about the mental health services you refer or signpost to

Professionals were asked about the mental health services they referred children and young people to in the last year. Of those who responded 40% (14) tended to refer children and young people to more than one service or organisation depending on the issue. The most common service combination to refer to were Healthy Young Minds (HYMs) and TOG Mind.

## Services referred or signposted to in last year



Parents tell us that it is important for their child to get the support they need as soon as possible, so finding the right service first time is key. Some families are turned away because they do not meet the ‘criteria’ for the service. Each service has its own referral criteria which means it will only accept people who present with certain health conditions or behaviours. So, we asked professionals if they felt they knew what the referral criteria was for each service they referred children and young people into.

Of those who responded 46% (16) felt they knew the referral criteria for the children and young people’s mental health services they referred or signposted to, compared to 54% who felt they did not know. Some schoolteachers said they would get advice from the school nurse or head teacher before making a referral.

*“Vaguely - not seen a specific document”*

*“I know who to refer to, however, the criteria is not clear. We have made referrals that have been rejected even though we feel the child needs support from HYM.”*

*“Criteria is often unclear especially on referrals that are declined.” (Early Help)*

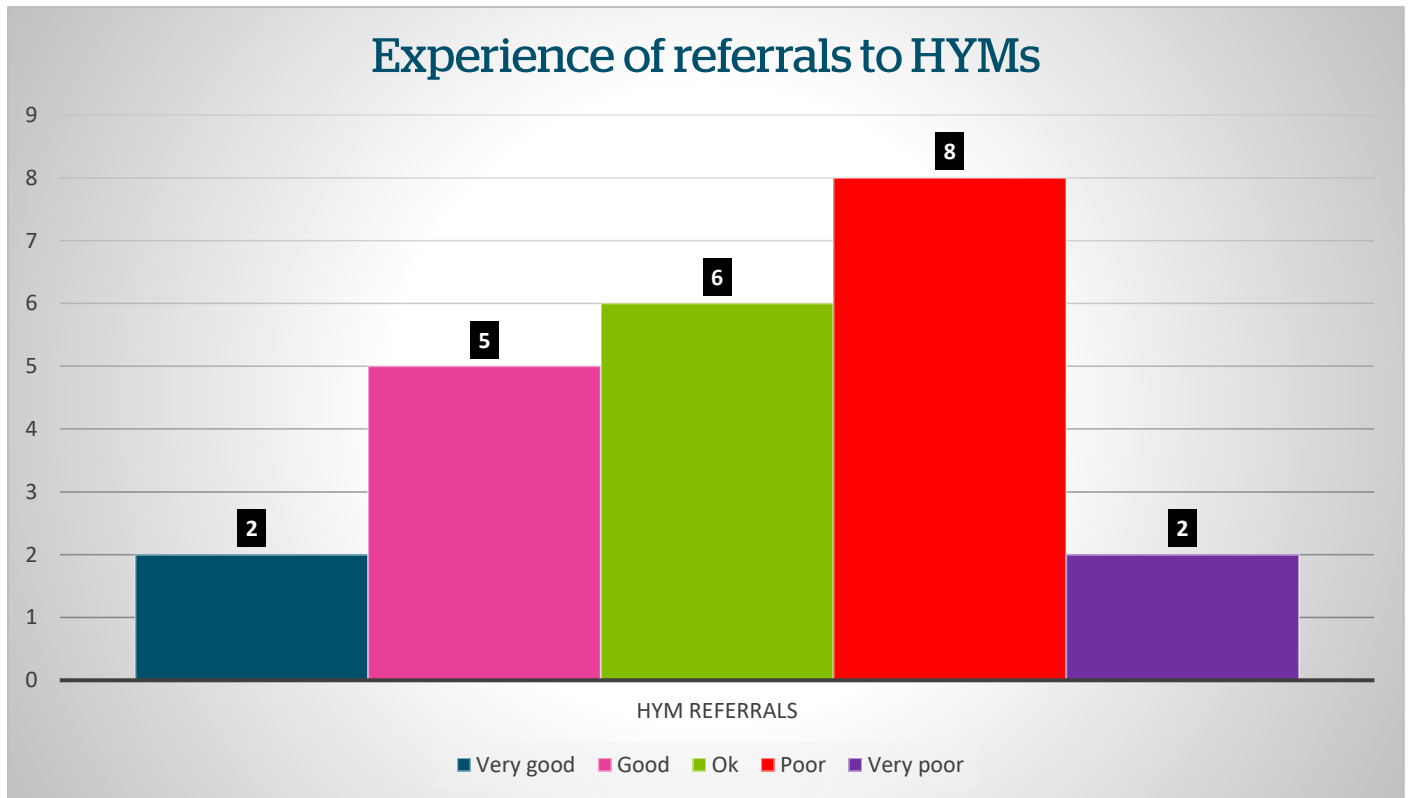
*“Because of the immense service pressures on HYM children are not reaching the “criteria” to be seen by the service. This means that instead of working with children when issues could be dealt with, it seems that mental health needs have to escalate to suicidal thoughts before an appointment is deemed to be necessary.”*

*“I normally complete a medical form and send it to our school nurse. It then goes through triage to the correct service.”*

### 3. What is your experience of referring into services?

Professionals were asked to share their experiences of referring into one of the services they listed, and most responses shared their experiences of referring into the Healthy Young Minds (HYM) service. Referral processes into all the other services were rated as very good, good or Ok by professionals who felt that processes were easy to use or straight forward. TOG Mind was highlighted by a number of teachers as an easy service to refer into and one that would accept some of the more complex cases.

However, experiences of referring into the HYM service were more mixed.



Of the 25 responses relating to the HYM service 24% (7) felt that the referral process was good or very good compared to 45% (10) who felt their experience had been poor or very poor. We asked professionals to explain their ratings. The feedback highlighted three common themes which were raised across both good and poor ratings:

- Length of time between the referral and the first appointment is too long.
- Many referrals are rejected without any feedback to explain why.
- Referrals are rejected because the 'patient does not meet threshold' but there is no clarity about the threshold.

## Some comments about the length of time for referrals:

*"We have a good relationship with the (HYM) staff but the process between referral and available appointment is far too slow."*

*"Mostly rejected referrals even in serious cases of suicide. Very long waiting list if they are accepted and no support in mean time."*

*"The time it takes for a referral to be accepted is often too long when a child is in crisis."*

## Some comments about the criteria and feedback for referrals:

*"Signposting feels more effective to this service (TOG Mind) who work directly with parents and provide drop in services...they will accept the referral even though the child's needs are complex and require specialist intervention"*

*"Very few referrals are accepted by HYM. MIND is easy to signpost to but, if the sessions aren't the school sessions, then parents don't always take their children to the drop-ins."*

*"Immediate response, reassured staff member making the referral. Professional advice, support and guidance given enabling the correct support to be offered to the young person and the family." (Referral to HYM)*

*"The referral did not meet their criteria. The only way I have managed to get a child to be seen by Healthy Young Minds is to tell the parent to take the child to A&E."*

*"Some referrals (which are made as school feels the case is more complex and requires specialist input) do not meet threshold - but we do not have a definition of the threshold."*

*"When asked why they referred someone to Kooth.com and 42<sup>nd</sup> Street the professional said "Self-referral and not location restricted so safer option"*



## 4. Have you noticed any service improvements over the last year?

Over the last year children and young people's mental health services have been changing in Oldham. We asked professionals to share their experiences about any service improvements they have seen. Of the professionals who responded to the questionnaire 49% (17) identified at least one area of improvement over the last year. The most reported improvements related to greater mental health awareness in schools and training for teachers.

### These are some of the service improvements professionals have seen in the last year:

- More mental health training available for teachers.
- The Oldham single point of access and online referral process is clearly set out and easy to follow.
- Communications between health professionals have improved.
- More awareness of mental health issues within a school setting and through school assemblies.
- MIND sessions have been more widely available in schools.
- There are more counsellors in schools.

### Some comments about improvements:

*"None. I appreciate the long waiting list, but I am concerned that young people are not being supported."*

*"The parents who have attended the post-diagnosis Autism workshops at Point in Oldham feedback that they are invaluable in helping them to understand their child's condition to support and protect their children's mental health."*

*"There is a greater emphasis on understanding in education but not sure the message has filtered down to all schools. The experience for all children is not good in all schools. We need more training of school staff to support children."*

*"Schools are playing a bigger role in supporting students with mental health difficulties."*

*"Whole school approach in Oldham is very proactive in engaging with schools, giving vital information and support to professionals working with young people. A number of conferences have been held recently along with regular updates/information."*

## 5. What do you think could be done to improve services?

Professionals were asked what they felt could be done to improve mental health services for children and young people in Oldham. Professionals told us that services in Oldham can be complex and fragmented with mental health services being funded, commissioned and provided by many different organisations that do not always work together. As a result, children and young people often have a poor experience and some are unable to access timely and appropriate support.

Feedback from professionals reflected many of the experiences described by parents, especially about children and young people with ASD who fall into a gap between services. Professionals said that more support for early intervention to stop children and young people hitting a crisis were needed, as well as services to support children and young people with complex needs who do not meet social care thresholds.

### These are some of the service improvements professionals said they would like to see:

- Shorter waiting times for referrals and more frequent appointments.
- More counselling services for children and young people that are easy to access.
- More services available within a school setting and better links between HYM and schools.
- Mandatory training for professionals who work with children and young people to identify mental health issues.
- Minimum age restrictions removed from services to support children experiencing trauma.
- More services to support young people with anger management and ASD.
- Single point of contact for advice and drop in.
- Clarity about the criteria for services.

### Some comments about counselling services:

*“As funding has been reduced there has been less offered to schools for pupils requiring counselling or lower level support.”*

*“Counselling in Oldham is difficult to access as I was sat today with a parent who rang the Mind information line and they said that the nearest available counselling service is in Rochdale.”*

## Some comments about gaps in services:

*"A toolkit to empower young people to manage their mental health difficulties at the earliest stage could be developed."*

*"More resources for pre-school children who experience adverse childhood experiences. training for universal services."*

*"Healthy Young Minds...only seem to be accepting the really top tier of need but there seems to be a gap e.g. children who have received intervention at school but MIND have said the child's needs are too complex for their service but HYM have rejected the referral - where do we go with this child?"*

*"Parents need to be given more support when they discover that their child/young person is self-harming instead of the Oldham response which is "if you believe that your child is at risk of suicide take him/her to A&E" this is of no use to anyone."*

*"Support in the preventative stage rather than waiting until a crisis. All professionals in contact with children to have compulsory training...(like) first aiders and safeguarding staff."*

*"Needs to be improvements in Mental Health support offered for Children who are Looked After. We have a high number of CLA who are presenting with issues stemming from trauma or attachment that we aren't equipped to deal with yet Healthy Young Minds won't accept them - what do we do?"*

*"Be more 'out there'. Come into schools and visit more often. Have MH workers that come into school to speak to all pupils regularly."*

# Appendix

## 1. Questions we asked parents:

1. Name of service, session or course that your child has accessed (if known)?
2. What was your first point of contact with services that could help your child?
3. How long did you/they have to wait to see a professional in this service from the time they were referred?
4. The length of time before a first appointment was arranged.
5. The effectiveness of service in helping your child deal with his/her problems?
6. How well professionals (doctors, psychologists, nurses, therapists, session worker) listened to your child and understood their problems.
7. Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, medication changes etc.).
8. How well professionals listened to your concerns regarding your child's mental health and wellbeing?
9. The professionals keeping of appointment times.
10. Support given to your child when they needed it.
11. The confidentiality and respect for your child's rights.
12. The explanation given about treatment.
13. The effectiveness of service in helping your child feel better.
14. The types of service offered to your child.
15. The overall service your child has received.
16. The advice given to you about how you could help your child.
17. How effective the service was in helping you to deal with the difficulties your child was experiencing.
18. How information was given to you about your child's problem and what to expect in the future.
19. The advice your child was given on discharge/when sessions finished.
20. The length of time between discharge and follow up appointments.
21. The things I liked most about my experience of the service.
22. The things I disliked most about my experience of the service.
23. The things I would like to change.
24. Please add any other information you feel is relevant.

## 2. Questions we asked professionals:

1. Do you know who or which service to refer young people to and what the referral criteria is?
2. Name a service which you have signposted a patient or made a referral to in the last 12 months?
3. Please tell us which other service you tried to make a referral to?
4. Thinking about mental health and wellbeing support for children and young people in Oldham please tell us about any improvements you have noticed in the last year?
5. What do you think could be done to make mental health support services in Oldham better for young people?
  - i. Focus on specific issue
  - ii. Funding
  - iii. Service improvement
  - iv. Schools

### 3. List of schools that took part in the review:

