COMMON ROOM







Healthwatch Leeds is here to help local people get the best out of their local health and care services by bringing their voice to those who plan and deliver services in Leeds.

YouthWatch Leeds is a group of 14-25 year old volunteers that work with Healthwatch Leeds to make sure children and young people's views of health and social care services are listened to.

Common Room promotes the views and expertise of children, young people and adults with lived experience across disability, health and mental health.



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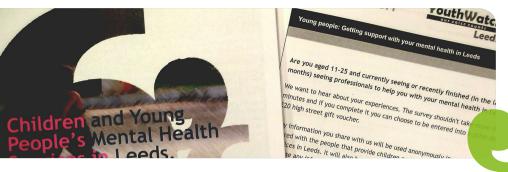
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Summary



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In 2015, Healthwatch Leeds in partnership with YoungMinds published the report 'Children and Young People's Mental Health Services in Leeds; Conversations with young people, parents and professionals' 1. In 2016, Healthwatch Leeds (supported by Common Room) were commissioned by NHS Leeds South and East CCG to get an up to date snapshot of the views and experiences of young people, parents* and professionals. The target group were those who had referred to. or accessed mental health and wellbeing services in Leeds in the last 6 months.

This report looks at overall experiences of services, with a particular focus on the following changes made as a result of the Future in Mind: Leeds strategy, priorities and Local Transformation Plan (LTP):

- Development of the Mindmate.org.uk website
- Introduction in January 2016 of the MindMate Single Point of Access (SPA)
- More integrated working
- Improved waiting times

*Throughout this report, we will use the term parents to refer to parents and carers of children and young people who have recently used mental health and wellbeing services.

During autumn 2016, we gathered experiences about children and young people's mental health and wellbeing service provision across Leeds. We did this using a combination of surveys and workshops. 126 young people, 59 parents and 120 professionals completed the surveys. 6 parents and 9 young people attended the respective workshops.

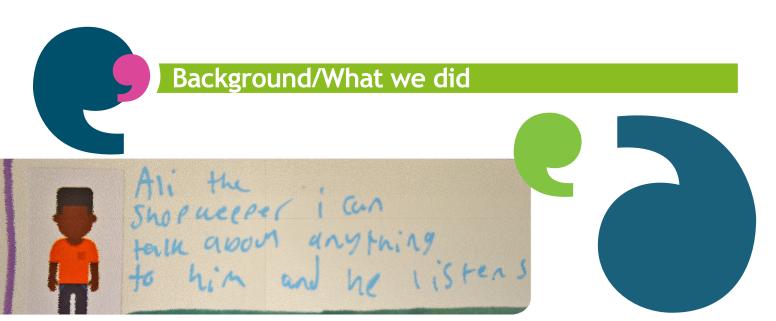
The following findings and recommendations focus on the whole system of mental health and wellbeing support for children and young people in Leeds, and are targeted at commissioners of services. The report also covers findings and suggestions for improvement for individual services in Leeds (see appendices 1-6).

Summary





Key findings	Key Recommendations
There is an overall trend toward Improvements to waiting times, particularly within specialist CAMHS. 54 (81%) young people said that they had waited 12 weeks or less.	Commissioners should consider ways they can work with providers to ensure that communication and support offered during the wait is consistent across services.
Young people and families were generally not aware of the MindMate website.	Explore ways in which the MindMate website can be more widely publicised, and include more detailed, useful information.
There is a lack of awareness amongst young people and parents of MindMate Single Point of Access (SPA)	Raise awareness and accessibility of MindMate SPA amongst parents and young people.
The introduction of MindMate SPA has been welcomed by professionals but there is room for improvement in terms of communication with referrers and parents.	Continue to evaluate MindMate SPA. Identify how referral pathways and communication with referrers and par- ents could be improved.
Family and friends were a vital source of support for children and young people who were waiting to access or using services.	Ensure services build in ways (where appropriate) to support parents to help their children.



Background

In March 2015, Healthwatch Leeds and YoungMinds produced a report, 'Children and Young People's Mental health Services in Leeds; Conversations with young people, parents and professionals'

The recommendations from this report fed into a 2015 review of the whole system of local support and services for children and young people's mental health and wellbeing, led by the Leeds Clinical Commissioning Groups (CCGs). This review supported the development of the Future in Mind: Leeds strategy 2016-20 and associated Implementation Plan to improve the social, emotional, mental health and wellbeing of children and young people aged 0-25.

In 2016, Healthwatch Leeds (supported by Common Room) were commissioned by NHS Leeds South and East CCG (lead commissioner of the Future in Mind: Leeds strategy) to engage with young people, parents and professionals to provide a further snapshot of their experiences of mental health and wellbeing services.

Why we did it

NHS Leeds South and East CCG asked us to find out the views and experiences of young people, parents and professionals who had recently used any children and young people's mental health and wellbeing services in Leeds.

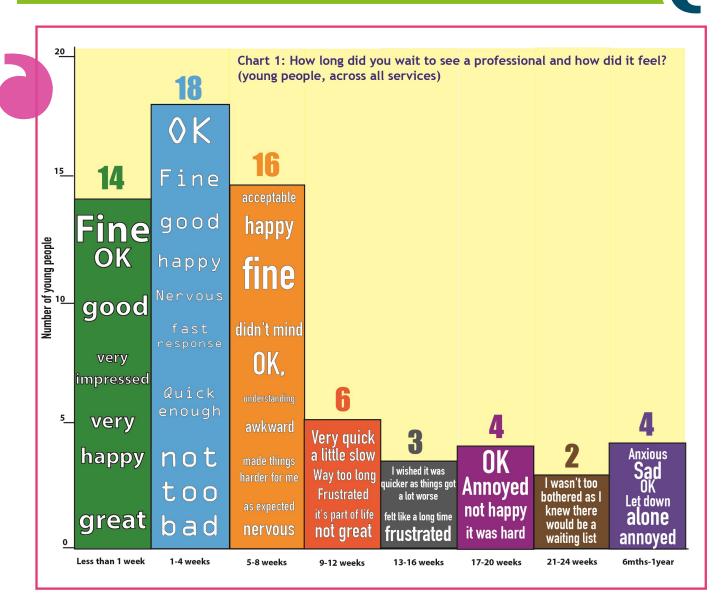
As well as being interested in their overall experience, they were also keen to find out about experiences in relation to changes made so far as a result of the Future in Mind: Leeds Strategy, priorities and Local Transformation Plan (LTP), specifically;

- Development of the <u>Mindmate.org.uk</u> website, a Leeds website which provides information on support available and how to access it.
- Introduction in January 2016 of the MindMate Single Point of Access (SPA) for referrals that works with the whole Leeds system of young people's mental health and wellbeing services in the city
- More integrated working across the whole system to improve the experience and offer for Leeds' young people and families
- Improved waiting times across all services and the whole system

What we did

During autumn 2016, we gathered experiences about children and young people's mental health and wellbeing service provision across Leeds. There were three strands:

- young people aged 11-25 who had recently* used one or more support service
- Parents of children or young people who had recently* used



mental health services

 Professionals in Leeds who had recently* supported children and young people to access services.

*we specified that all people participating should either currently be using services, or have used them in the last 6 months.

Online and hard copies of three short questionnaires (tailored for the above groups) asked questions about experience of services, referral/access, waiting times, MindMate SPA and the MindMate website.

The surveys were complimented by two feedback workshops, one for parents and one for young people.

126 young people, 59 parents and 120 professionals completed the surveys. 6 parents and 9 young people attended the respective workshops.

For details of the methodology we used, please see appendix 7. For equal opportunities monitoring data of participants, see appendix 8.

What we found

These findings focus on the whole system of mental health and wellbeing support for children and young people in Leeds. For detailed findings on individual services, please see appendices 1-6.





Waiting for help

There has been a general trend towards improvement in waiting times since our 2015 report, in which only 38% parents said that their children had waited 3 months or less to see a professional to get help. As chart 1 (on page 7) shows, 54 (81%) young people said that they had waited 12 weeks or less from point of referral to accessing the service.

How did you feel about the wait?

Chart 1 also shows the range of feelings experienced by young people whilst waiting to access services. They were generally positive about waiting times of less than five weeks. When waiting times exceeded five weeks, a range of feelings about the wait were expressed, both positive and negative.

The comments given suggest that young people's experience of their wait, unsurprisingly, is very subjective. This was echoed in the workshops where parents and young people were asked to write on a postit how long they waited to get support and place it on a traffic light scale. One young person who waited 1 month placed their post-it between red and amber, whilst another young person who had waited longer (2 months) placed their post-it near to the green light.

"The wait seemed like a very long time and I wasn't sure what options there were whilst I was waiting" (young person waiting 5-8 weeks)

Similar to young people, parents whose children waited less than five weeks were generally positive about the waiting time. Those waiting over five weeks to see a professional said that they felt frustrated, stressed, anxious or concerned about their child's health, and overwhelmed by the responsibility of looking after their child with no support. Six parents whose children had waited over 9 weeks spoke of a deterioration in their child's or their own health over that time.

"It was too long resulting in catastrophe" (parent of child waiting 9-12 weeks)

"could see child deteriorate week by week with no sign of any improvement or idea when help would be offered." (parent of child waiting 6 months-1 year)

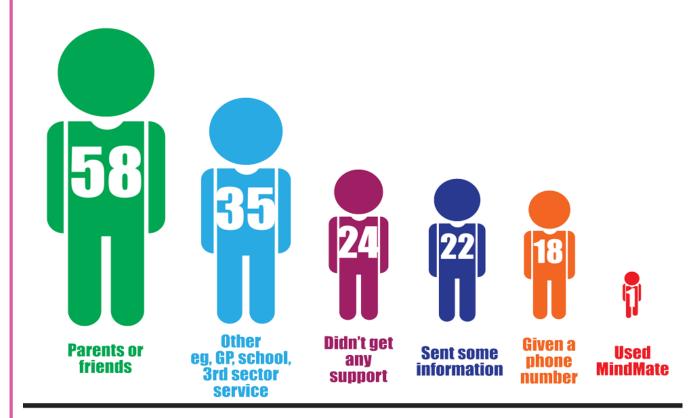
"stressful and has affected my mental health" (parent of child waiting more than a year)

Some of the frustrations expressed by

What we roun

Chart 2:

Where did you get support whilst waiting to be seen by the service?



both young people and parents were around poor communication from the services about waiting times:

"I was annoyed by the fact that they said it would take less time than it did" (young person waiting 5-8 weeks)

Other young people and parents were more accepting of the wait because they'd been given a realistic idea of how long they would have to wait.

"I wasn't too bothered as I knew there would be a waiting list" (young person waiting 21-24 weeks)

Support during the wait

Chart 2 shows how young people were supported during their wait. It highlights that 24 (19%) young people said they

didn't receive any help whilst they were waiting to be seen by a service. Of those who said they did get support, the majority said it was from their parents or friends. Only one person said they found help and support on the MindMate website.

"Perhaps being directed to some help and support whilst waiting (12 months) for the full assessment would have been helpful." (parent, cluster support)

Some people who said 'other' mentioned they got support from a third sector support organisation (eg. Forward Leeds, Barca, The Market Place drop-in), their school or college, or their GP.

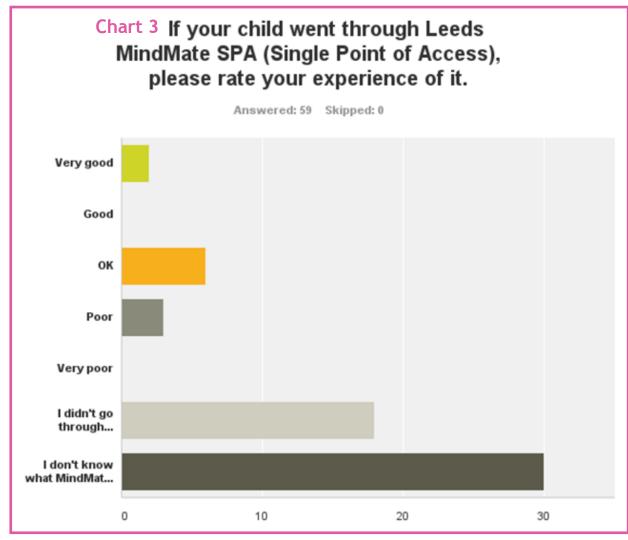


Leeds MindMate Single Point of Access (MindMate SPA)

MindMate SPA, launched in January 2016, is a clinically led triage process managed by Leeds Community Healthcare. The MindMate SPA team work with young people and families and all services available locally to find the right

support for the child / young person (up to 18 years). Professionals can refer young people and families through the SPA system.

107 (84%) of young people who responded to the survey said they didn't go through the MindMate SPA or weren't aware of what the SPA







was. This was also reflected during the workshops with young people in that their journey maps didn't include MindMate SPA and they were unaware what it was.

Parents' feedback about MindMate SPA was similar to young people in that few were aware of, or felt they had engaged with SPA as shown in Chart 3.

Several comments from parents about MindMate SPA mentioned lack of communication as a problem.

"It was quite confusing, the letter I received with the outcome didn't really explain what MindMate was, or how we ended up being referred there (I didn't know if it was through the GP, or school, or Speech therapist)." (parent)

112 (93%) professionals who completed the survey were aware of MindMate SPA and 76 (63%) of these had direct experience of referring young people / families through SPA. 66 (87%) of those who had referred using SPA rated their experience of it as "very good", "good" or "OK".

There was a wide range of feedback from professionals about MindMate SPA, mostly positive.

"I got the referrals into the agency I wanted, felt heard and the response was quick" (professional)

"CAMHS staff have done a great job with MindMate SPA" (professional)

"I don't have to worry about whether I have sent the referral to the correct place as I feel the SPA have triaged all my referrals to [the] appropriate place efficiently."

(professional)

The range of responses about MindMate SPA included mixed feedback about professionals' experiences of receiving referrals through the SPA team.

"I work in a CAMHS team so we receive referrals now via this avenue. I find that the referrals are extremely well processed and all referrals that come my way from MindMate are appropriate." (professional)

"I find that the referrals I receive are very poor and there is very little supporting information. I have to do a considerable amount of work, and when I have rung for help, MindMate have not been very helpful" (professional)

Several comments were about the quality of referrals and the need for improved communication.

W

What we found



"(the) form is easy to complete but apart from the generic email saying the referral has been received we don't get to hear if the referral has been accepted unless we chase/ ask parents/school if they have heard anything, etc." (professional)

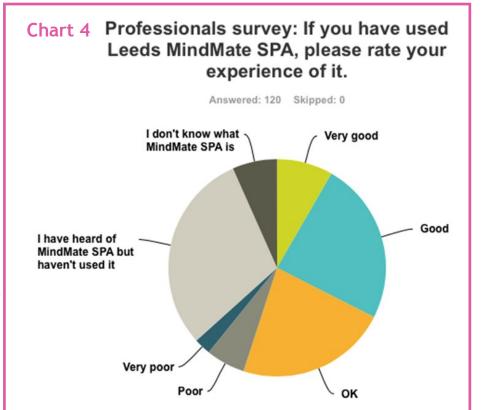
"A conversation with relevant professionals before making referrals on Framework i to Cluster should always be encouraged to ensure referrals are appropriate for Cluster." (professional)

"I think the system is much better as cases can be triaged by the SPA and we can work together to offer early support to children and young people. I think it will take some time for parents to become used to this new format as they might immediately look to CAMHS for mental health support and be disappointed if they don't get a referral to CAMHS. I think if we are able to stick with this format it will eventually become the way to work" (professional)

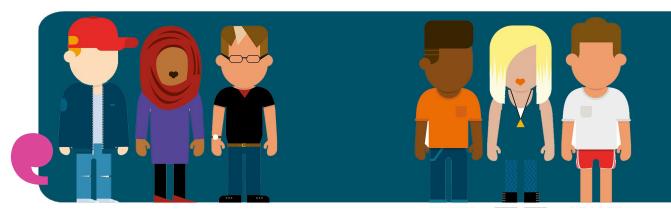
Professionals' comments were often about the overall system and some acknowledged teething problems for SPA with the hope that things would settle over time.

"MindMate would be great if there were sufficient staff offering services to meet the need" (professional)

"Good and convenient to have a single point of access" (professional)







MindMate Website

MindMate.org.uk is a Leeds-based website for young people, their families and the professionals who support them. The website was launched in October 2015. It gives information about a variety of emotional wellbeing and mental health issues, and information about where support is available.

74 (59%) young people who completed the survey hadn't heard of the website. This reflects findings from a recent consultation as part of Leeds' antistigma campaign where 88 (83%) of students and Leeds City College said they weren't aware of the MindMate website.³

Of the 14 young people who said they had used the website, there were mixed views as to how useful they found it.

"It's easy to find information" (young person)

"Haven't used it much but it is a good site" (young person)

Several comments from young people and parents who had used the MindMate website mentioned the information was limited or unhelpful.

"I have used MindMate & it wasn't that helpful" (young person)

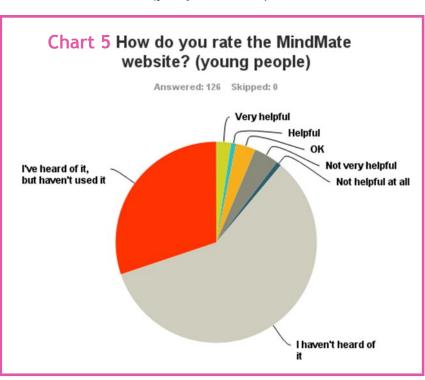
"It wasn't massively helpful, but it wasn't bad either." (young person)

"Never knew it existed" (parent)

"It hasn't helped us in our particular situation" (parent)

Professionals' comments about the MindMate website echoed those of young people and parents.

"(it would be) useful to have referral criteria" (professional)





"there is limited info on serious mental health issues"

(professional)

Some of the comments by professionals about the MindMate website were actually referring to MindMate SPA indicating that there is a level of confusion between the two.

Who supports me with my mental health?

In the workshop, young people were asked to make a 'circles of support' picture which showed who supported them with their mental health. With themselves at the centre, they were



asked to place those who most support them on the circles nearest to them.

For most young people, professionals were just part of the jigsaw of their networks of support. People identified as most important in providing support were parents, teachers and other people in school (e.g. learning mentors and teaching assistants) and counsellors. Friends, grandparents and other members of extended family were also mentioned as important sources of support.

Just under half (4 out of 9) of the young people, put professionals before their parents in terms of who supported them most.

One person told us that being around any people too much was stressful for him, and that apart from the support he got from The Market Place, it was his hobbies and pets that he looked to for support more than family and friends.

Another young person placed meditation alongside their mum as the most important form of support, followed by YouTube videos (by people with experience of mental health issues) and God.



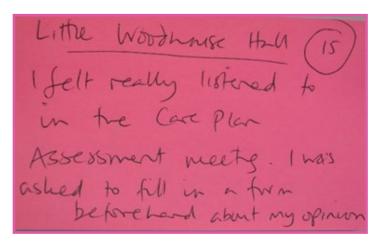


The exercise shows that although young people's circles of support were highly individual and varied, parents and family should be recognised as a key source of support. This was also evident from the 58 (46%) young people who said they got support from their parents or friends whilst waiting to access a service.

Involvement of parents

Parents were asked in the workshop how involved they felt in their child's care.

Parents who weren't involved said they felt "let down" or "not listened to or respected". Other parents who weren't involved felt that this was a good thing as allowed their child to make their own choices and have a space to talk.



There were some good examples of involvement of parents within CAMHS. One parent said they had "quite a lot of involvement in decisions being made".



"I appreciate that I get a 'round up' at end of each session. My daughter always gets asked if it's ok to pass on info to me. I think it's been done really professionally and sensitively."

(parent, CAMHS Eating Disorder Service)

Another parent had a negative experience of CAMHS. She said that she was "not believed about son's condition", and as a result felt "blamed for situation".

What young people say could be done to improve services

"There should be groups for young people, I want some friends. And now this is making me cry coz I'm so lonely." (young person)

"Loads and loads of people with mental health issues have problems with using the phone. Having no choice



Recommendations



but to use the phone to get information/access to a service presents a major barrier and can delay and even stop somebody from getting help altogether. Personally, find email and website best. Others may prefer text message. A variety of options would be helpful!" (young person)

"The NHS should be able to provide long term care to people. Depression and anxiety won't go away with 20 sessions... It seems like you have to be really really ill to get help, like an inpatient." (young person)

"Better recognition of more complex sexual/romantic orientation and gender identity is needed across services." (young person)

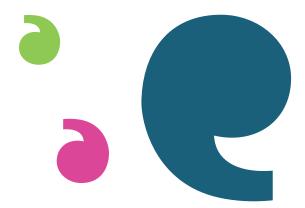
Our recommendations for commissioners

- Commissioners should consider ways they can work with providers to ensure that communication and support offered during the wait is consistent across services.
- Explore ways in which the MindMate website can be more widely publicised, and include more detailed, useful information for young people and families.
- Raise awareness and accessibility of MindMate SPA amongst parents and young people.
- Continue to evaluate MindMate SPA. Identify how referral pathways and communication with referrers and parents could be improved.
- Ensure services build in ways (where appropriate) to support parents to help their children.

Commissioners' Response

"I warmly welcome this report and its findings. The results indicate good progress since the original report in 2015. This helps assure partners that we are moving in the right direction and improving access to support and services for children and young people in

Next Steps



Leeds. We are ambitious, as reflected in our Future in Mind: Leeds strategy, to continue this journey of improvement and this report provides some very useful pointers on the areas we need to focus upon. Our commitment to involving young people and parents in their care and in driving forward service development remains as strong as ever."

Jane Mischenko, Lead commissioner: Children and Maternity Services, NHS Leeds CCGs.

Response from Councillor Mulherin

"This exciting collaboration between Leeds City Council, the NHS and key partners has helped create a pioneering strategy which works across health, education and the social care system, to improve the social, emotional and mental health of some of the most vulnerable children in Leeds. We are committed to working restoratively with children, young people and their families, listening to their concerns and ensuring their voices influence and inform the way organisations and services respond to their needs. From this report we can reflect on the improvements we have already made and understand what further improvement is required."

Cllr Mulherin, the council's executive member for children and families and Chair of the Future in Mind: Leeds Programme Board

Next Steps

The report will be shared with the Future in Mind: Leeds Strategic Board, Leeds Community Healthcare (providers of Leeds CAMHS), Community Links (providers of IAPT for young people and aspire), Therapeutic Social Work Team, The Market Place and cluster support providers. We have asked them to share it with their service leads and teams that deliver the services mentioned in this report.

We will agree with the above the next steps to be taken in response to our recommendations and work with them to ensure any agreed actions are followed through and implemented.

The report will also be published on the Healthwatch Leeds website and shared with those who took part in workshops where requested.



Thank you/References



Thank you

This report has been written by Harriet Wright, Community Project Worker at Healthwatch Leeds and Liz Neill, Associate Consultant, Common Room Consulting Ltd.

Many thanks to YouthWatch volunteers Harriet Childs, Melika Griffith and Alice Wayman for helping run the workshops. Also to Patience Vundla and Liv Powell for inputting all the survey data. And finally, to Alice, Liv and Harriet for helping to analyse the data.

We would also like to thank all the organisations mentioned in this report for helping us promote our workshop and surveys to their service users. In particular, thanks to Hannah Beal and Chris Lake from Leeds CAMHS and to Ruth Hirst and the team at The Market Place for their help and input.

Most importantly, both ourselves and the commissioners want to thank all the professionals, parents and young people who have taken the time to share their experiences with us.

References

- 1. Children and young people's mental health services in Leeds. Conversations with young people, parents and professionals, March 2015, Healthwatch Leeds and YoungMinds.
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 for children and young people
 Quality Report, 20/09/2016, Care
 Quality Commission





Appendix 1: Leeds Child and Adolescent Mental Health Service (CAMHS)

Brief description of service

CAMHS specialist mental health service (delivered by Leeds Community Healthcare NHS Trust) works with children and young people and their families across three community teams, eating disorder team, infant mental health service, transitions team and CAMHS Outreach Service (COS). CAMHS inpatient provision is based at Little Woodhouse Hall.

Number of responses about service

43 (34%) young people gave feedback about CAMHS through the survey. There were 52 responses from professionals, and 37 from parents

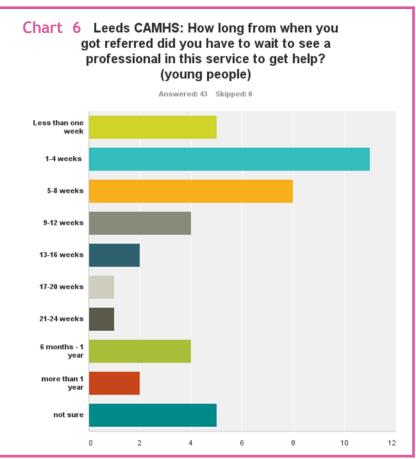
Waiting to get help

Young people who had sought help in the last 12 months were most likely to report a waiting time of 1-4 weeks shown in Chart 6.

Waiting times reported by young people and parents echo improvements reported in a recent Care Quality Commission Inspection Report (Sep 2016) where it was noted that

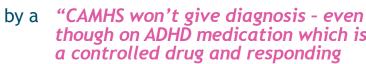
'Children and young people experienced shorter waiting times for assessment and treatment than at the last inspection. The teams had mechanisms in place to monitor wait times and were continuously aiming to improve them.'

6 (14%) young people said they were sent some information which helped them during the wait and 5 (12%) said they were given a phone number they could call for support. 6 (14%) young people said they did not receive any







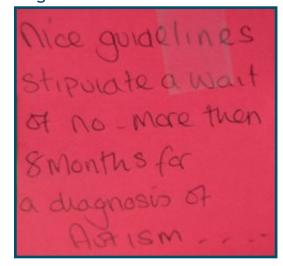


support whilst waiting to be seen by a professional in CAMHS.

Waiting for autism/Attention Deficit Hyperactivity Disorder (ADHD) assessments and diagnosis

Parents who attended the workshop talked of the long periods of time it took for their children to be assessed and receive diagnoses of ADHD and autism. One parent told us that she had waited 18 months from her child's first contact with CAMHS to begin the process of assessment for autism. They got the diagnosis of autism 3 months later (in 2016), a total of 21 months from first contact with CAMHS.

Another parent expressed frustration that despite her child receiving and functioning well with medication for ADHD, they were not being given a diagnosis.



though on ADHD medication which is well to treatment" (parent)

The recent Care Quality Commission Report highlights waiting times for these assessments acknowledging that despite waiting times decreasing since 2014, "Children and young people waiting for assessments in autism and attention deficit hyperactivity disorder (ADHD) had to wait longer than the trust's 12 week assessment target"

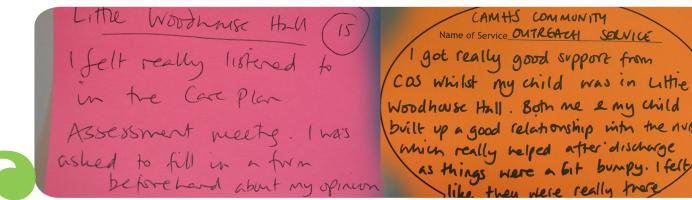
Professionals' experience of referral to Leeds CAMHS

Chart 7 shows that the 52 responses from professionals about referral and signposting to CAMHS were very mixed. Some commented about the difficulties in accessing specialist CAMHS service and the high threshold criteria, and described the impact of this.

"By the time you make a referral the situation is usually heading for crisis, because you've tried everything you and other professional can think of" (professional)

"The waiting times and frustration this causes parents makes the process very challenging. Children

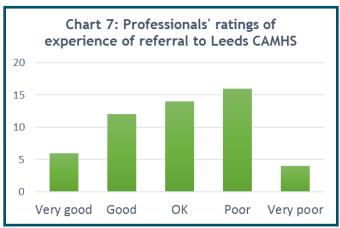




are waiting for long periods of time for support and diagnosis. Once they are within the system the team at CAMHS for our area is very good." (professional)

"We are told that unless there is an eating disorder or risk of suicide they cannot see you." (professional)

"Even children at significant risk and in crisis don't meet threshold, very difficult to manage long waiting times with families concerned" (professional)



There were several positive comments from professionals about their experience of supporting a referral into CAMHS

"They assessed promptly, and gave answer back, (accepted) and work started next day" (professional) "The availability of the CAMHS outreach service greatly aids smooth and successful discharge from Tier 4 (inpatients).

"They are very responsive to taking on this crossover joint working and are very well informed of our Leeds inpatients and their potential needs/ suitability." (professional)

What's good about this service?

Several young people mentioned positives as being the friendliness of the staff and feeling supported and listened to.

"I saw CAMHS with Forward Leeds and it was easy to get stuff sorted in sessions together. They knew how to help and listened" (young person)

"Everyone is really understanding, helpful and kind. They try to empathise with you and are really caring." (young person)

Young people also commented about different services within CAMHS provision.

"Feel very safe, contained and feel they believe me, support me and are with me with my illness" (young person, drama therapy)



"The best thing about this service was they came out to see me at my own home, which made me feel more comfortable talking to them" (young person, COS)

"...very caring and friendly made to feel like a person" (young person, Little Woodhouse Hall)

There were many comments from parents about how supportive the staff were, and how consistency of staff is beneficial.

"They were all very professional and friendly and really understood the problem" (parent)

"both me & my child built up a good relationship with the nurse which really helped after discharge as things were a bit bumpy. I felt like they were really there for me" (parent)

What would make this service better for children, young people and their families?

Young people and families had suggestions which might improve their experience of using CAMHS services, including several about more flexible appointment times.

"Meet in different settings to get me out of the house like a coffee shop" (young person, 14-17)

"More friendly building" referring to Little Woodhouse Hall, (young person)

"If some of the staff were more accepting of individual needs and more aware of signs that kids are showing when they can't voice themselves" (young person, 14-17)

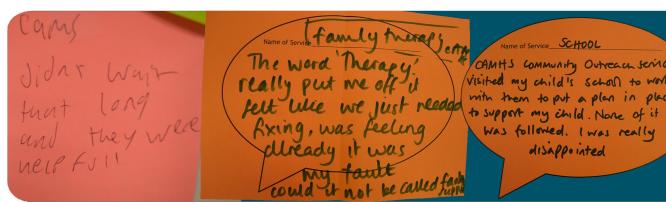
"On the whole I think we have a very good mental health service. However some workers I feel need some training on how to talk to young people without giving advice, Being patronising and allowing Young person to have a part in their care planning." (young person)

"There are difficulties for both [parents and young people] to access sessions based on session times and work" (parent of young person, 14-17 years)

"Need more out of hours help for young people (after 5pm)" (parent)

Some parents were concerned with the poor communication between different CAMHS services, with GPs and with themselves as parents.





"CAMHS need to communicate not only with parents, but also with GPs, schools & clusters (this did not happen in our case)" (parent)

"I wish my daughter had more info/ advice on mental health in school and staff had better training and there was time and resources for CAMHS and schools to liaise"

(parent)

"Paediatrics said they couldn't get involved when family is already 'in CAMHS' but we were only on a waiting list NOT getting any support whatsoever" (parent)

Other comments

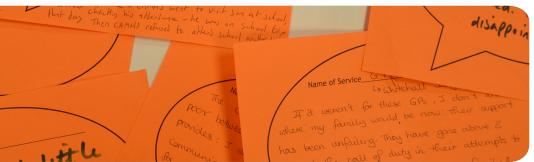
Two young people referred to their perception of workers 'breaching confidentialities' within CAMHS. The full picture is not given, but presumably relates to cases where information was shared because of safeguarding concerns. It highlights the importance of young people being told clearly if, why and how their information will be shared.

"As I am nearly 18 I also feel my parents should not have been written to with a summary of my consultation without consent. My parents were also contacted to say I could take an overdose." (young person, 14-17)

Our suggestions for improvement

- Explore ways in which assessment and diagnosis of autism and ADHD can be made quicker and easier.
- Explore further ways in which young people can be supported while they wait for specialist services.
- Work towards offering more flexible appointment times (e.g. early evening slots)
- Raise awareness amongst staff and service users about young people's rights in relation to confidentiality, ensuring clear communication with young people when information needs to be shared.
- All services to consider ways of using more gendersensitive approaches. Some good practice examples can be found in a recent NCB report on gender-sensitive approaches
- All services to ensure there are different ways that young people can get in touch, not purely by phone.





Service provider response

"Leeds CAMHS welcomes the report from Healthwatch and their recommendations. The report will be presented at a CAMHS briefing for all staff and copies of the report will be made available for service users.

It is good to hear that so many of the young people and carers gave positive responses for example feeling listened to by staff and being seen in 12 weeks or less. This is particularly pleasing as we have been making efforts to improve access times. We recognise the continued need to improve waiting times and are currently working hard to reduce the length of time children and young people wait for an autism assessment. There is also the need to prioritise young people with severe mental health rìsk.

We along with partners need to give consideration to further ways in which we can support young people and their carers whilst they are waiting, It is also really important for us to review the information we share regarding confidentiality.

In terms of flexible appointment times we have been actively encouraging staff to offer before

and after school time appointments.

We are also currently working with young people and their families to consider ways in which they want to be contacted and whether we can offer these.

We have produced a detailed action plan relating to the suggestions in this report which will be available on the Healthwatch Leeds website."

Hannah Beal, Clinical Lead, Leeds CAMHS







Appendix 2: The Market Place

Brief description of service

The Market Place is a Leeds based city centre city wide third sector organisation. It offers support to young people aged 11 - 25 around emotional well-being and/or mental health through a drop-in service, 1:1 support, counselling and group work.

Number of responses about service

49 (39%) young people gave feedback about the Market Place through the survey. There were nine responses from professionals, and three responses from parents.

Waiting to get help

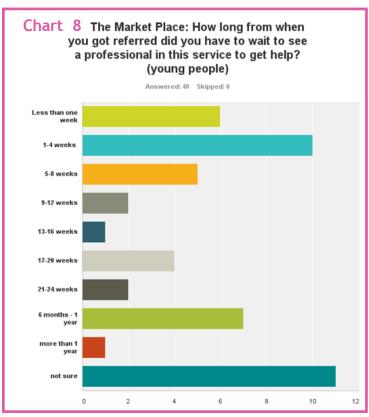
Chart 8 shows that young people report varying waiting times for this service with peaks at 1-4 weeks and 6-12 months. This may be related to the fact that young people can usually access the drop-in service at the Market Place very quickly, whereas there is usually a longer wait for counselling:

"Drop in has no wait. Counselling have had to wait up to 6-12 months!" (young person)

12 (23%) young people said they were sent some information which helped them during the wait, 11 (20%) said they were given a phone

number they could call for support (eg. ChildLine) and six mentioned other Market Place services such as drop-in and my plan. Seven young people said they didn't get any support whilst they were waiting.

"The Market Place at Leeds were friendly and helpful on the phone and managed to arrange a first appointment in a matter of weeks. They told me about their drop in service which could have been used if couldn't have waited for the appointment." (parent)







Professionals' experience of signposting to The Market Place

Chart 9 shows that of nine professionals who reported experiences of signposting to The Market Place, all were rated as "good", "very good" or "OK". One professional outlined difficulties with accessing counselling at The Market Place:

"Only two mornings a month you can make a referral. Referrals have to be made by calling; if you call later in morning they may have reached referral capacity so your case is not accepted and have to wait a further two weeks..."

(professional)

What's good about this service?

Young people commented on how friendly and welcoming this service was and how staff were supportive and kind. A lot of young people said it was good that The Market Place provided someone to talk to who would listen without judging them.

"It's a warm and friendly environment, makes a really big difference than being clinical." (young person)

"getting to speak to someone and been able to trust them" (young person) "This service is good because you be able talk about your feelings and if a risk, they always help with that. They always listen to people" (young person)

"Very supportive, excellent service and an amazing space." (young person)

"It is very helpful and makes me feel better." (young person)

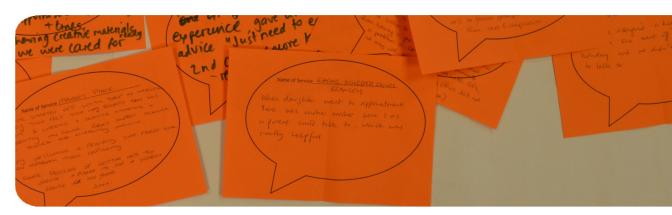
"It is easily accessible and welcoming" (young person)

"The Market Place has been fantastic with all the staff warm and welcoming. It makes such a difference being treated as a person and not a number!" (young person)

"It's really helped me and I'm very grateful for it, I would recommend

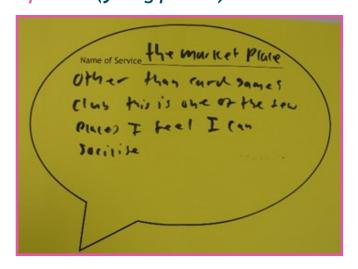






it to other young people" (young person)

"Because they are really supportive and whatever I say doesn't get spread" (young person)



"They are doing it right" (young person)

Parents also had praise for the service and commented on its good accessibility.

"Simple process of getting onto the service and pleased to see a discreet service for the young" (parent)

"A worker from Mind Mate rang me and arranged for The Market Place to contact me. I was contacted swiftly and impressed with the service." (parent) What would make this service better for children, young people and their families?

The main themes which young people mentioned were:

- more funding and staff to decrease waiting times,
- increase opening times
- advertising the service more so that more young people know about it.

"Have more counsellors so less time on the waiting list" (young person)

"Spread the word about it so young people know it's more for them" (young person)

"More funding to hire more staff and have longer opening hours" (young person)

"It's fine as it is" (young person)

"Make it feel a bit less kiddish (lots of primary colours etc.) as it makes me feel old!" (young person)

"Could have drop in mon - sat from 10 - 5pm" (young person)

"More group activities sessions e.g. Hype Group" (young person)

"It would have been helpful for me to know in the phone conversation





before that I wasn't allowed in whilst my daughter went to the drop-in" (parent of young person, aged 13)

Our suggestions for improvement

- Consider ways to further raise awareness of the different aspects of provision at The Market Place amongst young people
- Review communication with parents of younger service users.
- Review current self-referral systems for one to one support, to increase access and improve young people's experience of the process.
- All services to consider ways of using more gender-sensitive approaches. Some good practice examples can be found in a recent NCB report on gendersensitive approaches
- All services to ensure there are different ways that young people can get in touch, not purely by phone.

Service provider response

"I think the report is great and the recommendations reflect the work we are already doing to reduce the waiting times for counselling, review the referral process to the



service and to increase the ways we communicate with young people and visa versa. I think any report like this that is driven by what young people tell us is an invaluable resource."

Emma Holmes, CEO, The Market Place

"The Market Place has been fantastic with all the staff warm and welcoming. It makes such a difference being treated as a person and not a number!"

(young person)

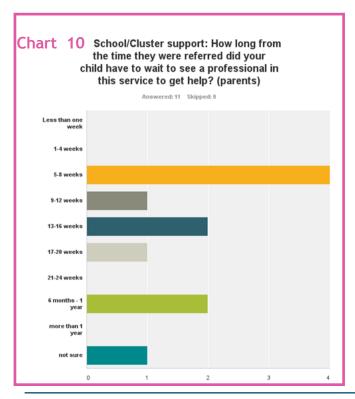




Appendix 3: MindMate Wellbeing (Cluster based mental health support)

Brief description of service

MindMate Wellbeing (previously known as TaMHS) provides support for young people and their families. Services are commissioned locally by school clusters and usually accessed where the child or young person attends school. Providers of cluster based mental health support are Northpoint Wellbeing, Impact North, Relate Mid Yorkshire, Barca-Leeds, CAMHS in schools and The Beck. These services work alongside with the other cluster based professionals for a joined up approach.



Number of responses about service

10 young people and 11 parents gave feedback about support through their school or cluster via the survey. Only five out of the 25 clusters in Leeds were mentioned by parents and young people. These were Morley, Aireborough, Bramley, EPOSS and inner North-West. There were 15 responses from professionals.

Waiting to get help

The majority of parents stated that their children had to wait 5-20 weeks from time of referral to accessing support from the cluster.

During this wait, four out of 10 young people and five out of 11 parents said they didn't get any support. One young person said they were sent information and a phone number to ring for support.

Other young people mentioned support from their parents and Barca (third sector organisation) whilst they were waiting. Parents also mentioned family support through an early help assessment and support from community CAMHS and a child paediatrician.

Professionals' experience of referral to MindMate Wellbeing

Chart 11 shows that of 15 professionals' ratings about experiences of referring to cluster support, the majority were rated as "good", "very good" or "OK".







A comprehensive spread of clusters across Leeds was represented in the responses including professionals who mentioned they were referring to 'various' clusters or 'all over the city'.

Overall comments reflected the ratings, for example, "Immediate response, got involved, excellent communication.", also, "(the service) kept us well updated re progress"

Inconsistency across different clusters was raised: "The referral pathway can be difficult to work out and often different clusters offer different types of support and different levels of skill" (professional)

What's good about this service?

Parents and young people said it was good that one to one sessions were available, that staff were supportive,

easy to talk to and they didn't feel judged. Parents also mentioned positives as "support for the family" and their children being able to get support in a familiar setting.

"The staff are very kind and really lovely and really just wanna help you" (young person, Morley Cluster)

"The activities as you weren't just talking you had a task. Also there was play dough and pens which I personally found helpful as it helped me concentrate." (young person, Aireborough cluster)

"It happened in school, in a familiar setting which was a great advantage for a child who lacks confidence on such a short programme" (parent, Inner North-West cluster)

"She benefited from the one-to-one support as she can lack confidence in groups." (parent, Bramley cluster)

"The person helping my son was also available via telephone for me when I needed questions answering about my child's behaviour."

(Parent, Bramley cluster)







What would make this service better for children, young people and their families?

Five out of the 11 parents who responded to the survey said that they would like better communication from the service so that they could know how better to support their child. The majority of these parents had children in the 6-10 age range and were accessing services in the Bramley and Inner North-West Cluster.

"Feedback to parents of young children is helpful - offer ways we can carry on the help at home." (parent, Bramley cluster)

Other parents and young people said that more sessions should be available for young people. One person said that they didn't feel that 6 weeks of counselling was long enough for their child who had experienced a bereavement.

"I had a counsellor in school... it was effective short term, like it helped week to week but after finishing using the service I didn't feel like it had given me help to deal with things long term" (young person)

Young people mentioned that they would like waiting times to be shorter, and also suggested a drop-in service and being able to have more intensive support.

"They could have a drop in service so that children and young people didn't have to wait very long to talk to someone" (young person)

"Some may benefit with two appointments a week, one at the start, one at the end." (young person)

"Perhaps being directed to some help and support whilst waiting (12 months) for the full assessment would have been helpful." (parent, EPOSS)

"(my child)
was very self-conscious
that it had to take place
within a school setting
and that teachers were
made aware, which
I believe hindered
the experience and
made her distrust
it." (parent)





Our suggestions for improvement

- Work towards better communication with parents, particularly when working with younger children.
- Aim for better consistency of support during the wait, for example working more closely with schools to support young people while they wait.
- Where further support of a young person is needed, consider more flexibility around the number of sessions allocated.
- All services to consider ways of using more gender-sensitive approaches. Some good practice examples can be found in a recent NCB report on gendersensitive approaches
- All services to ensure there are different ways that young people can get in touch, not purely by phone.

Service provider response
"The cluster service is commissioned locally to give more flexibility for local variation to meet need, while maintaining a core offer of early intervention and short term support. Therefore there will be variation in waiting list times, protocols, types of support and support on offer while waiting.

It is pleasing to see the high satisfaction rate with the service and some quick responses despite the increasing volume of referrals to these services. We know in a 12 month period last year there were 5886 referrals with a social, emotional and mental health need to cluster services.

A wide range of needs are supported, often more complex than an early intervention service would offer, as many children and young people prefer a local offer. This can impact on waiting times and availability of support as it increases workload.

Clusters are able to work beyond a six session offer if needed, depending on a review of support. They are also able to refer onwards for longer term support.

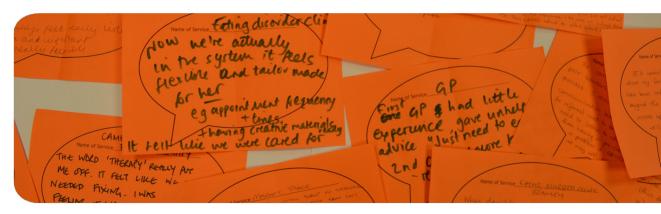
We are looking at ways of ensuring a more consistent approach across all cluster services within the limitations of funding and locally led services.

We will also review as a group the benefits of communication to families, drop-in services, waiting list support, onward referrals, and self-help once support is ended to see what good practice and variation exists, as well as how consistency could be improved."

Joseph Krasinski, MindMate Wellbeing Co-Commissioning Officer, NHS Leeds South and East CCG

Appendix 4 - IAPT for young people





Appendix 4: IAPT (Improving Access to Psychological Therapies) for young people (17-21)

Brief description of service

IAPT is provided by the Leeds IAPT Partnership that includes Leeds Community Healthcare NHS Trust, Community Links, Touchstone and Northpoint. The Young People focussed services is led by Community Links. It offers mainly Cognitive Behavioural Therapy to 17-21 year olds with common mental health problems.

Number of responses about service

Seven young people gave feedback about IAPT through the survey. There were eight responses from professionals, and one response from a parent.

Waiting to get help

The vast majority (seven out of eight respondents) reported waiting less than eight weeks for their appointment.

Three of eight young people reported having no support while they waited, another three said they were supported by family or friends in that time.

"The wait seemed very long and I wasn't sure what to do whilst waiting for the service" (young person)

Professionals' experience of referral to IAPT for young people

Chart 12 shows a mixed response from professionals about experience of referral to IAPT.

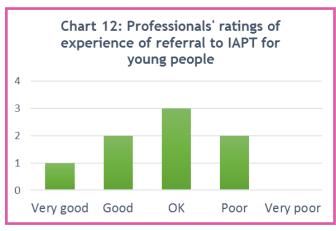
Difficulties with access were mentioned;

"I was told the young person (who has extreme anxiety and a bus phobia) would have to travel across the city to access a service. This was totally un-achievable"

(professional)

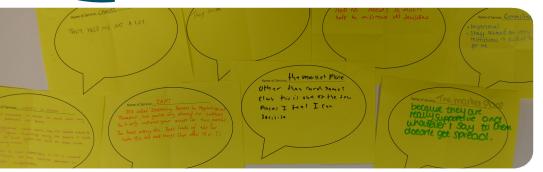
"The young person received contact relatively quickly" (professional)

"Easy referral process, workers respond to your calls efficiently. Difficulty is managing risk within their team and expecting case holders to remain in place whilst work in their service is undertaken." (professional)





Appendix 4 - IAPT for young people



"I have noticed improved access and improved response, good communication with myself. I feel confident in referring my clients to this service." (professional)

What's good about the IAPT service? Young people mentioned quick access, effectiveness of therapies and the staff.

"The service was helpful as it gave me a better way to cope with everything going on and helped me get through it all" (young person)

"How quickly I got access to it, so I didn't have to wait until my mental health got extremely bad and it gave me hope of getting better." (young person)

"Someone I don't know to talk to. Someplace I can go to, to let my feelings out and get supported ways to make my feel better" (young person)

"(the practitioner) who led my sessions was amazing, he was really patient, and encouraged me to look at things from a different point of view" (young person)

One young person couldn't find anything positive to say about the service:

"Nothing, they didn't help and weren't interested in helping" (young person)

What would make this service better for children, young people and their families?

Two young people suggested the service should be more widely publicised. Another young person commented:

"In the initial phone referral, the lady I spoke to was incredibly condescending and made me feel as though I was deliberately making my problems worse or being difficult."

Our suggestions for improvement

- Explore ways in which young people might be supported while they wait for support from IAPT eg. by providing information or signposting
- Explore ways of publicising the IAPT for young people service more widely
- All services to consider ways of using more gender-sensitive approaches. Some good practice examples can be found in a recent NCB report on gender-sensitive approaches
- All services to ensure there are different ways that young people can get in touch, not purely by phone.

Appendix 4 - IAPT for young people

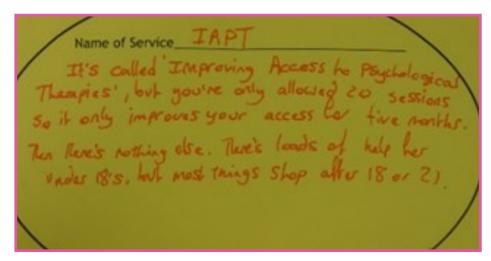


Service provider response "This piece of work has provided a useful opportunity to focus on areas that require some attention.

- At the point of initial screening appointment, young people are generally provided with self-help materials and signposted to other services for interim support/information. We will review this to ensure it is consistently achieved. The IAPT consortium is also developing an information handbook that will be sent to all clients at point of allocation onto any waiting list. This will be adapted to include specific young people's information/advice.
- Review of marketing will be undertaken in the coming year. In particular on MindMate and Mindwell. Current young people specific publicity does not currently show the new online access route and this will be rectified.

- Young people are currently able to refer themselves online as well as by telephone this will be publicised more widely. However, if they refer themselves online they will not necessarily be dealt with by a member of the young people's team. This must be balanced against ease of access.
- We are now able to text as well as telephone in order to make appointments. This is a fairly recent development.
- We are currently reviewing the geographical spread of clinics and undertaking work to ensure that if locations are not suitable we liaise with the general IAPT teams in order to offer alternatives.
- NCB gender sensitive approaches report will form part of the team's service development away day in the first quarter of the year."

Soo Lincoln, IAPT Service Manager, Community Links





Appendix 5 - aspire



Appendix 5: aspire

Brief description of service

Aspire is the citywide NHS commissioned Early Intervention in Psychosis Service run by Community Links. It provides holistic care coordination to people between the ages of 14 - 65 who are, or may be, experiencing their first episode of psychosis.

Number of responses about service

Three young people gave feedback about aspire through the survey and workshop. There were seven responses from professionals, and no responses from parents.

Waiting to get help

One young person said they'd waited a month to access this service. The other young people who gave



feedback weren't sure how long they had waited, or about any support they'd received during the wait.

Professionals' experience of referral to aspire

Of the seven professional responses about aspire, most were rated "good" or "very good" which reflected the comments, e.g. "the duty worker there to speak to, easy referral process. Have also been to just ask advice which was very helpful also". One professional mentioned the "long waiting list"

What's good about this service?

We didn't have enough data to comment about what was good about this service. or make any suggestions for improvement.

What would make this service better for children, young people and their families?

"Meet in different settings to get me out of the house like coffee shop" (young person)

Appendix 5 - aspire







Other comments

"staff seemed on very tight time restrictions - didn't have time for me." (young person)

"seen worker on wait and watch programme - supposed to ring me every 3 months but sometimes it is 5 months" (young person)

Our suggestions for improvement

- If not already in place, consider a service user engagement process which will help gain understanding of young people's and families experience of aspire.
- All services to consider ways of using more gender-sensitive approaches. Some good practice examples can be found in a recent NCB report on gendersensitive approaches
- All services to ensure there are different ways that young people can get in touch, not purely by phone.

Service provider response

"aspire works in partnership with CAMHS tier 4 services to provide assessment and support for anyone aged 14-18 who has, or is suspected to have, a first episode psychosis. We have an open referral system and therefore take referrals from any source (including MindMate SPA).

Once a first episode of psychosis is suspected, aspire (in line with all Early Intervention services in England) must report against a 2 week Referral to Treatment target, regardless of the referral source. In reporting against this target we are able to identify waiting times for those under 18 and therefore will be able to identify any pressure points that lead to longer waiting times and seek to address these."

Fiona Barber, Service Manager, Community Links



Appendix 6 - Therapeutic Social Work Team



Appendix 6: Therapeutic Social Work Team (TSWT)

Brief description of service

The TSWT offers emotional wellbeing support and therapeutic interventions to children, young people and their caregiving systems. The team supports Children looked after, Children on Supervision Orders and subject to child protection plans or in Kinship care who have a Leeds social worker.

Number of responses about service

There were no survey responses from parents, carers or young people about TSWT.

Professionals' experience of referral to TSWT

Chart 14 shows that the 8 responses from professionals about referral and signposting to TSWT were mixed, half described their experiences as "poor".



"...(I) was told that TSWT would not work with young person as their waiting was too long and there was a provision in school for young person" (professional)

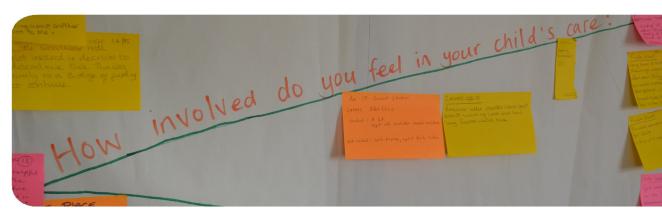
What's good about this service?

We didn't have enough data to comment about what was good about this service or make any suggestions for improvements.

"Sometimes there is discrepancy between what we believe they ought to be able to facilitate and patients they should engage with, and what they actually choose to. However, it is a very good service." (professional)

Appendix 6 - Therapeutic Social Work Team





Our suggestions for improvement

- Explore ways of increasing awareness amongst professionals about TSWT and how it works.
- If not already in place, consider a service user engagement process which will help gain understanding of young people's and families experience of the TSWT provision.
- All services to consider ways of using more gender-sensitive approaches. Some good practice examples can be found in a recent NCB report on gender-sensitive approaches
- All services to ensure there are different ways that young people can get in touch, not purely by phone.

Service provider response

"We're grateful for the feedback contained in this report and will use it to continue to develop our service. We are disappointed that, despite our promotion of the survey, we didn't get any feedback from children, young people and their families.

We have looked at our own satisfaction questionnaires from the same period, which we hope is representative of people's experiences of accessing support from the TSWT. From 16 parent/carers and

30 foster/kinship carers there was an average response of 4.5 out of 5 for overall satisfaction levels, whilst 7 children and young people rated the service with an average of 4 out of 5 for how helpful they found the service.

There is clearly some work to be done with colleagues in Children's Social Work Service in relation to clarity around our service offer, and have produced an action plan to address this (available on Healthwatch Leeds website).

We make decisions around whether to offer a therapeutic service based on assessments of clinical need but also, particularly where there are safeguarding concerns, by looking at both the indicators and contra indicators for therapy in the system at the time of referral. We would never reject a referral based on the length of our waiting list, but we would be unlikely to offer individual therapy to a child who is already working with a therapist in school."

Katie Wrench, Team Manager, Therapeutic Social Work Team



Appendix 7 - Methodology







Appendix 7: Methodology

Surveys

The surveys and how best to distribute them within each provider were developed in consultation with all key providers and commissioners. We also had a young people's planning group who had input into the surveys and consultation workshop content.

The parent/carer and young people's surveys were made available to complete online via a widely publicised link, or by paper based copies made available in all the key services. We worked closely with service providers who encouraged their service users to complete the surveys. A freepost envelope was attached to each paper based survey to increase confidentiality. People had the option of either posting the completed survey to us or posting into a confidential box which was left at each provider. The surveys were open for three months between 1st September and 30th November 2016

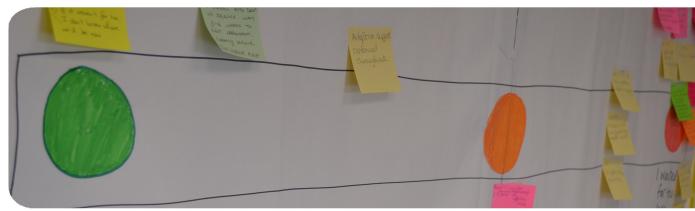
In additional to monitoring

information, some of the key information, we asked people for in the parent/carer and young people's surveys were:

- Name of the service where child/young person most recently got help.
- When the child/young person first had contact with the service to get help
- How long from the time they were referred they waited to see a professional in the service to get help.
- How they felt about the wait
- What they thought the best thing about the service was
- What they thought could be done to make the service better for children, young people and their families.
- What, if any support they got whilst they were waiting
- Whether they knew about the Leeds website mindmate.org.uk and how they would rate it.
- An opportunity to say anything else about the service they had used.

Appendix 7 - Methodology





The questions were tailored appropriately for each group.

The professionals' survey was completed via an online link which was shared widely through various networks and directly with service providers. It asked questions to capture the following information:

- The professional's type of work
- Experience of using MindMate SPA
- Experience in the last six months of signposting or making a referral to up to three mental health and wellbeing services.
- Any improvements they had noticed in mental health and wellbeing support services for children and young people in the last year.
- What they think could be done to make services better for children and young people.

Workshops

Two feedback workshops took place; one with parents and one with young people. Young volunteers from YouthWatch helped staff to facilitate

the workshops. Each workshop included the following interactive activities:

How involved do you feel in your child's care? (parents only)

Parents were asked to write on a post-it how they felt services involved them, and place them on a scale from "not involved at all" to "very involved"

Waiting times

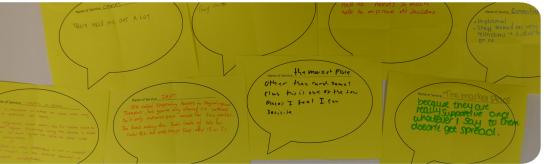
 People were asked to write the name of the service, how long they had waited from the time of referral to when they saw a professional and how that had felt. They were asked to place it on a scale from "I saw someone when I needed to" at one end to "I waited far too long" at the other.

My journey to get support with my mental health and wellbeing

People were asked to chart their journey on a picture chart featuring all the main providers in Leeds, using arrows and writing how long it had taken between each stage. They used a star to show where they started and a dot to show where they were now or



Appendix 7 - Methodology



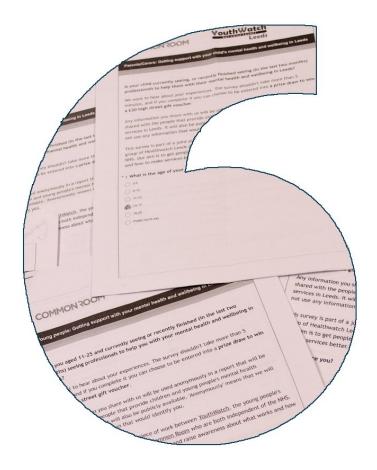
the last place they had accessed for support.

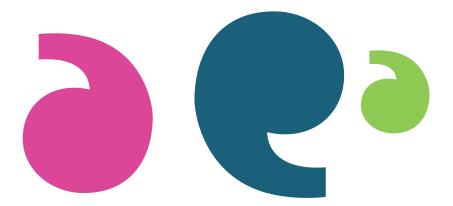
Who supports me with my mental health and wellbeing? (young people only)

 Using MindMate characters or drawing their own, young people were asked to stick pictures of who supports them on a 'circles of support' chart with themselves at the centre. They were asked to place those who support them the most nearest to them on the chart.

Any other comments about the service(s) they had used.

 People were given the opportunity to write on speech bubbles anything else they wanted to say about a service they had used and place it in a 'talking box' post box.



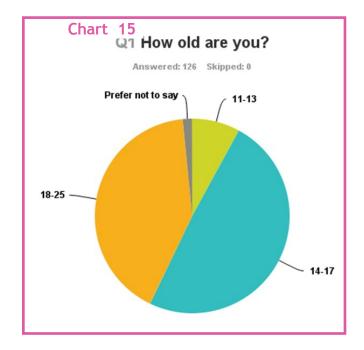


Appendix 8: Monitoring Data

Workshop Data

- 9 young people attended the workshop:
- Their ages were 11, 13, 15, 16, 17, 18 (x2), 21 and 24.
- 6 were female, 3 were male.
- 2 identified as disabled, 2 were unsure and 5 didn't identify as disabled
- 6 described their sexual identity as straight/heterosexual, 1 identified as bi-sexual and 2 didn't answer the question
- 7 described their ethnic origin as White British, 1 as white with any other background and 1 preferred not to say.
- One young person said they had been in care, the remaining 8 said they had not.

- of those who ticked 'Other' postcodes, specified them as Wakefield and Bradford postcodes which fall in the Leeds area (eg. WF1, WF3)
- 37 (29%) of the young people were male, 83 (66%) were female 2 were trans, 2 were 'unsure' and 2 preferred not to say



Survey data

- Charts 15 shows ages of young people who completed the survey.
- Chart 16 shows young people's home post code areas. The majority
- 10 (8%) identified as disabled, 12 (9%) were unsure and 93 (74%) didn't identify as disabled. 11 (9%) preferred not to say (Chart 17).
 - 86 (68%) described their sexual





identity as straight/ heterosexual, 15 (12%) identified as bi-sexual, 10 (8%) as questioning/unsure, 4 as lesbian, 2 as gay and 9 preferred not to say (Chart 18).

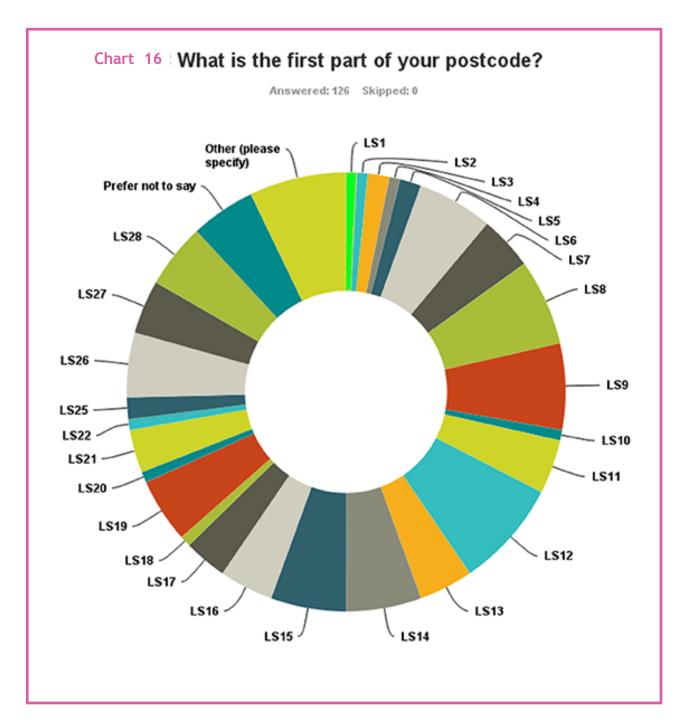
- Table 1 shows how young people who responded to the survey described their ethnicity.
- 13 (10%) young people said they had been in care, 100 (79%) said

- they hadn't been in care, 6 preferred not to say and 7 didn't answer the question.
- 6 young people stated that they were the main carer for someone else whilst 3 preferred not to say. 10 young people didn't answer this question and remaining 107 (85%) said they weren't the main carer for anyone.

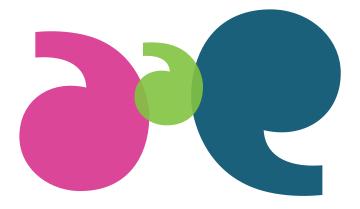
Table 1: Ethnicity of young people completing the survey

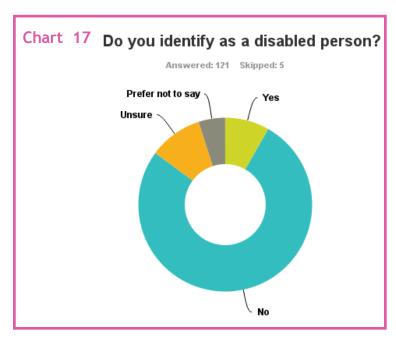
Ethnicity	Number of young people
White British	97 (77%)
Irish	1
Black African	2
Black Caribbean	1
Mixed heritage: Black Caribbean/white	3
Mixed heritage: Black African/white	1
Mixed heritage: Asian/white	1
Any other ethnicity	11
Prefer not to say	9

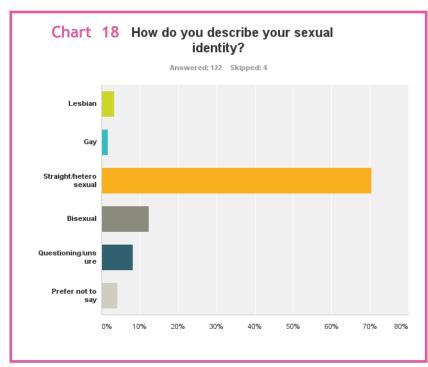












Healthwatch Leeds is here to help local people get the best out of their local health and care services by bringing their voice to those who plan and deliver services in Leeds. YouthWatch Leeds is a group of 14-25 year old volunteers that work with Healthwatch Leeds to make sure children and young people's views of health and social care services are listened to. Common Room promotes the views and expertise of children, young people and adults with lived experience across disability, health and mental health.





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