



MindMate Single Point of Access

**Young people's and parents' views
about present experiences
and future options.**

July 2017

About Us

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 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.

Summary

Introduction

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 and parents who had recently been referred via MindMate Single Point of Access (SPA).

We asked them about their experiences of MindMate SPA and their views about possible future developments including the option to self-refer and the introduction of an online parenting course.

Key Findings

- The majority (81%) of young people and parents supported the idea of a self-referral option into MindMate SPA.
- Parents and young people said that having different ways to self-refer was important. Being able to complete an online form and make a phone call were the most popular options for young people and parents respectively. Drop-in was also popular amongst young people, with the idea of support available to make a self-referral.
- There was mixed feedback of parents' experiences of MindMate SPA. Some parents spoke positively of their interaction with the SPA team whilst others expressed dissatisfaction at what they felt was an impersonal approach.
- Some parents mentioned not being clear about what SPA was, not having a contact number, and instances of services not contacting them in the timescales given.
- Triple P online is not appropriate for everyone. It requires a level of confidence in IT, self-motivation, headspace, and time and ongoing support from a professional is key to its success.

Key recommendations / messages

- Use the comments in this report as a basis to explore how self-referral for parents and young people can be built in as an additional option to the referral pathway for MindMate SPA.
- Ensure that any future self-referral process allows for a choice of communication modes, to include as a minimum online and phone options.
- Ensure that SPA offers a consistent collaborative approach in which parents and young people feel involved.
- Ensure that realistic, appropriate and up to date information about services is given to service users of MindMate SPA both verbally by phone and in a follow up letter. This should include accurate waiting times and what they can do if services do not contact them in the timeframe given.
- Involve service users in refreshing the [leaflet about MindMate SPA](#) making it more clear that SPA isn't delivering a support service but is a 'gateway' to other forms of support.
- The MindMate SPA leaflet states: *"If you want to get back in touch with the SPA while you are waiting, we will tell you how you can do this"*. Ensure that there is a robust system in place so that during their initial phone call, and in subsequent letters, all parents and young people are given a way to contact SPA.
- Further work needs to be done on considering carefully when and how Triple P online is offered to parents, and ensure that those who take up the offer are given appropriate support during the programme.

Background

One of the changes implemented as part of the [Future in Mind: Leeds Strategy and Local Transformation Plan](#) was the launch of MindMate Single Point of Access (SPA), in January 2016. It is a clinically led triage process managed by Leeds Community Healthcare which works with young people and families and all services available locally to find the right mental health and wellbeing support for children/young people (up to 18 years). Professionals can refer young people and families through the SPA system.

Why we did it

Healthwatch Leeds (supported by Common Room) have been commissioned by NHS Leeds South and East CCG (lead commissioner of the Future in Mind: Leeds strategy) to engage with young people and parents who had recently been referred via MindMate SPA. It follows on from some of the recommendations (see table) in our [Future in Mind: Leeds report](#) which gave an insight into young people’s and parents* views of mental health and wellbeing services in the city.

| Healthwatch Leeds Recommendation | Commissioner Response (including any actions you will take) |
|---|--|
| Raise awareness and accessibility of MindMate SPA amongst parents and young people. | The MindMate SPA was originally set up for referrals from professionals. Commissioners will review the possibility of self-referral by parents and children and young people to the MindMate SPA during 2017/18. |
| Continue to evaluate MindMate SPA. Identify how referral pathways and communication with referrers and parents could be improved. | Commissioners will continue to work with the MindMate SPA and professionals to ensure effective communication and promotion. HealthWatch and Common Room have been commissioned to undertake a detailed piece of evaluation with parents and carers and young people of the role of MindMate SPA. |
| Ensure services build in ways (where appropriate) to support parents to help their children. | A pilot of the on-line parenting support tool, Triple P, will begin in April 2017. Initially this will be offered to parents of young people going through MindMate SPA. If successful we will consider how to roll out to all parents of young people accessing or waiting for targeted and specialist SEMH services. |

| | |
|--|---|
| | The Future in Mind Programme Board will also consider how to further ensure parents are supported to help their children. |
|--|---|

**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.*

What we did

During Spring and Summer 2017 we spoke to 14 young people and 7 parents who'd had some input from mental health services for young people in Leeds or had something to say about the referral pathways to these services. The vast majority of children and young people in question were between 14 and 18 years.

Three parents completed the survey online and we visited 4 parents in their homes. We did several one to one interviews with young people as well as running a consultation workshop with 6 young people to explore:

- People's experience of MindMate Single Point of Access (if relevant)
- People's thoughts on the benefits or drawbacks of having a self-referral route into MindMate SPA for children, young people, parents and carers
- How people would most like to communicate and engage directly with the MindMate SPA team if they were able to self-refer
- Parents' thoughts on being offered [Triple P Online](#) - an online parenting course. In addition, Liz and Harriet (authors of this report) personally trialled the Triple P online course - both the 0-12s and teen programme.

What we found

Experience of MindMate SPA

Over half (9) of the young people and all of the parents (7) said they had at some point asked for support from a professional with their/their child's mental health. Of these, four parents and one young person said they had been through MindMate SPA. One parent and two young people said they weren't sure whether they had been through SPA.

Three out of the four parents who'd had contact with MindMate SPA rated it as OK, good or very good. One rated it as very poor. The young person rated it as 'very good' but didn't elaborate.

Some parents spoke highly of the phone communication they had with SPA. However, there were reports of instances where communication had not been so good. For example, two parents said they were not contacted by services in the time frame SPA said they would be, whilst another parent said that their conversation with SPA did not make them feel at all involved in the process.

“They wrote on the letter from MindMate SPA that I could contact The Market Place but my son is too young to access this service.” (parent)

“Talked to me in depth and got a lot of background about situation. Felt it was good she also spoke to my daughter. They explained about triage and how people were prioritised. She gave me a number to ring if things escalated.” (parent)

“Got a phone call from them, they asked me a couple of questions and then said he's on a list and would get an appointment in 6 months, they didn't say who with or what would happen next. I've not received a confirmation letter and it's now 10 weeks after I spoke to them. I felt 6 months was too long for my son to wait - felt the long wait was because I said he wasn't currently suicidal even though he had been in the past. They didn't ask to speak to my son, or ask me for his contact details. I felt like the decision had already been made and I didn't feel at all involved in the process.” (parent)

“I thought MindMate SPA was a service, even from looking at the leaflet. Felt like no one treated him as an individual, more of a tick box on a flow chart rather than considering individual circumstances.” (parent)

“Really nice on phone and listened to me. Lady was as helpful as she could be. She said she would need to do some research as didn't know where to refer him and then ring me back. She rang back when she said she would and I felt she was honest in terms of how difficult it was to find appropriate service for a child who doesn't have a clear diagnosis. It feels as if my child falls through gaps because they don't have a clear-cut diagnosis but has complex needs. Currently waiting for CAMHS to get

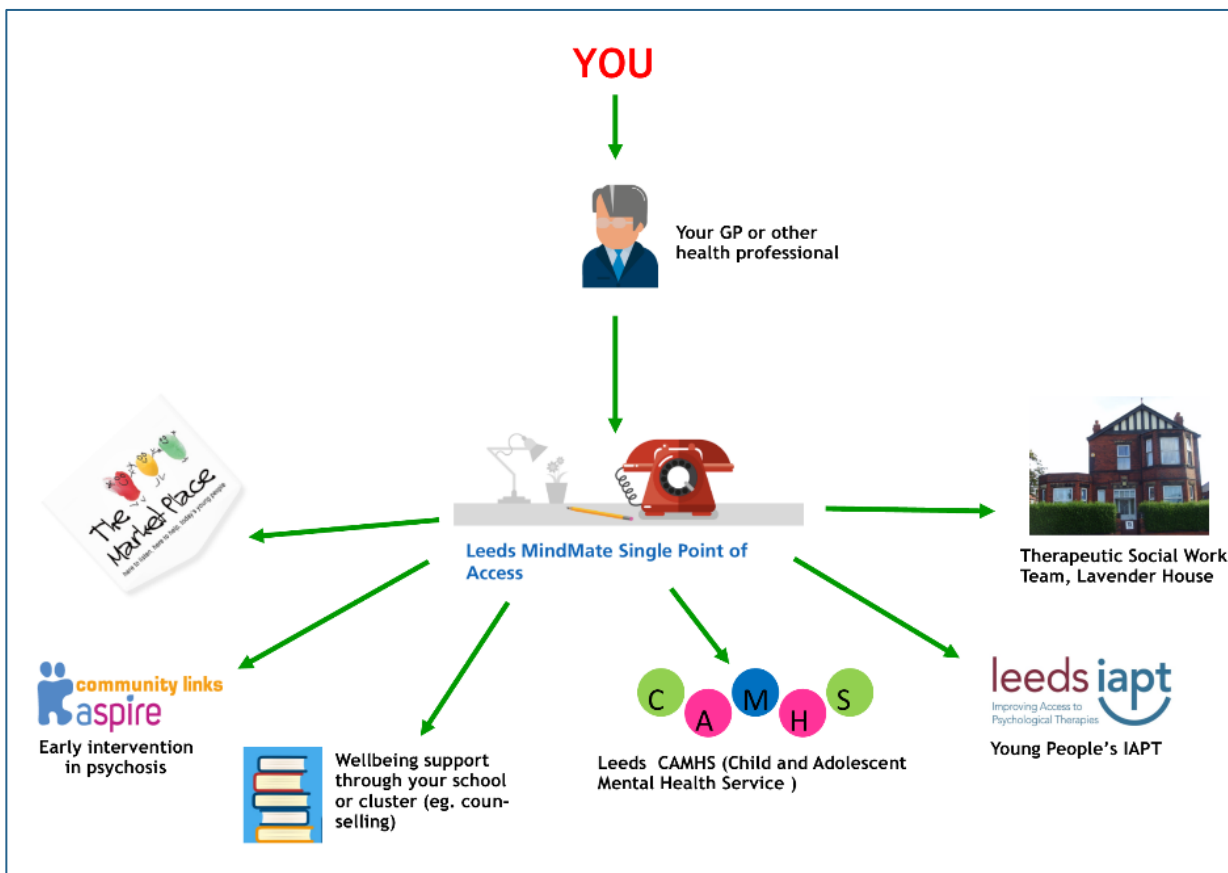
in touch, SPA said someone would be in touch within around 2 weeks, it's now been 8 weeks and we're still waiting.” (parent)

What do you think would have made your experience of MindMate SPA better (parents)?

“Explain the process better. Felt that no-one really explained the process - either GP or SPA. Felt like there was this assumption that I knew what was going on. Doctor gave me a leaflet, but wasn't very clear in explaining what would happen. Would have been really useful to have a follow up letter in writing of what was going to happen and also a number for SPA, at the moment I have no way to contact them if the service they said they referred my son to doesn't make contact.” (parent)

“A tick box for children who don't have clear cut diagnoses, and appropriate services to support them” (parent)

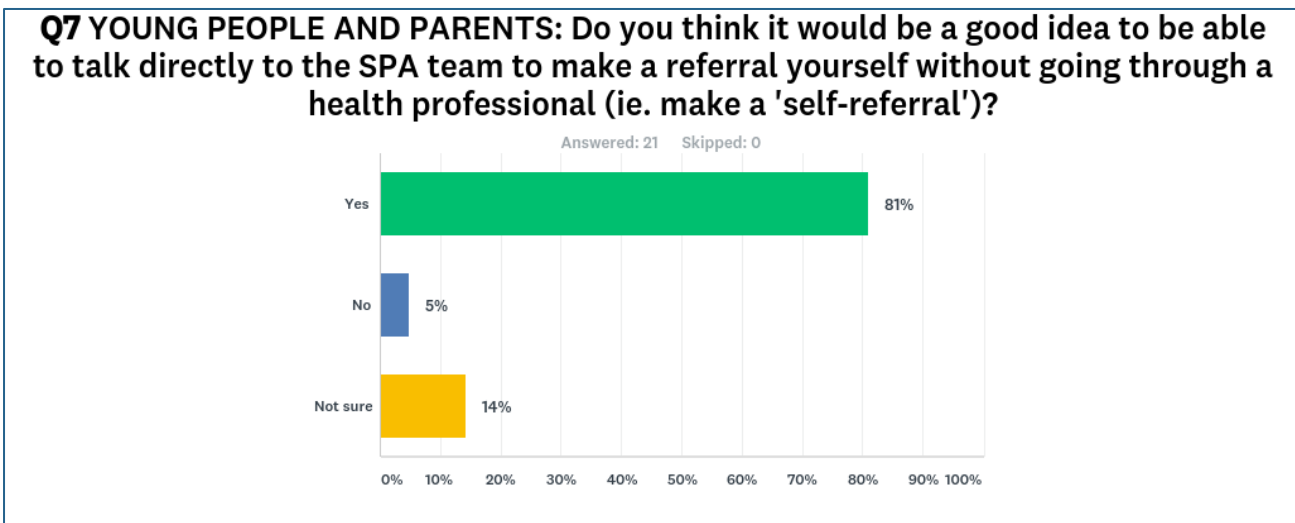
“Would be useful to have a diagram like this [one used on survey] in the leaflet.” (parent)



What young people and parents told us about self-referral

The majority (81%) of young people and parents supported the idea of a self-referral option into MindMate SPA.

“Self-referral is a very positive step forward in helping young people access the support they need.” (parent)



People gave several reasons why they liked the idea of a self-referral option. These included it being a quicker, easier process which would be likely to have a more appropriate response.

“It may be a more comfortable form of discussing your issues.” (young person)

“It makes it so much easier for people to get what they need... likely to be quicker, more simple” (young person)

“I don't think the GP added anything to the process, I could have done it myself. Would make it quicker, and one less thing to do to have to go via GP as it's difficult to get a GP appointment sometimes. Also you would then have a direct contact with SPA if you need to chase something up.” (parent)

“Parents have instincts and, when acted upon, generally prove to be a powerful and effective measure. Children in crisis need help quickly, by self-referring the process may be quicker.” (parent)

“This could result in a speedier process to receive the help required and prevent further distress.” (parent)

“Get things done faster...It took 2 weeks to make referral ...Had first panic attack, referred from school took five months to actually see the counsellor ... maybe if I could self-refer I could have waited less time ...also wasn't the best place to go...also had been so long they'd lost my paperwork” (young person)

Several young people and parents talked about how they didn't always find it easy to talk to their GP or other health professional.

“Some people get intimidated talking to doctors. It would be good if it didn't feel intimidating. You can never fully put it into words with a GP... It's important that professionals work to not make people feel judged and to talk plainly. Big words can be really intimidating. Professionals often forget this.” (parent)

“not all GPs are good with kids, e.g. talking to them and getting them to open up.” (parent)

“I am worried that the GP will dismiss my concerns” (young person)

“Because some people are scared to talk to GP” (young person)

In addition some people felt that to talk first hand to the right team would mean the information shared would be more accurate, and you would be more in control.

“I can explain problems first hand, better to tell my own story” (young person)

“As a parent you know more about your child than anybody.” (parent)

“People who may be afraid to seek help from others will have the chance to seek help for themselves instead.” (young person)

“It is the best way for people who is suffering from the mental health or anything connected to health to express themselves.” (parent)

“GP may misinterpret things” (young person)

“GP is a filter. My child talks to me, story gets filtered through GP and different professionals. I wouldn't have to tell story multiple times to different professionals.” (parent)

“Could work for kids as well if they were able to self-refer. They might not want to go through parents if relationship not good with them. Going to the GP can be another hurdle for young people when accessing help.” (parent)

Some young people expressed concern about how self-referral might work and it being fair and timely for the children and young people in most need.

“There will be a higher demand for services and therefore some people who need this may not have places as there are too many people.” (young person)

“It's a tricky question because at times a self-referral might be made due to more situational circumstances - e.g. Upset and a bad day rather than mental health. However, at times referrals from a health professional aren't the best way since you can sometimes be ignored or not taken seriously.” (young person)

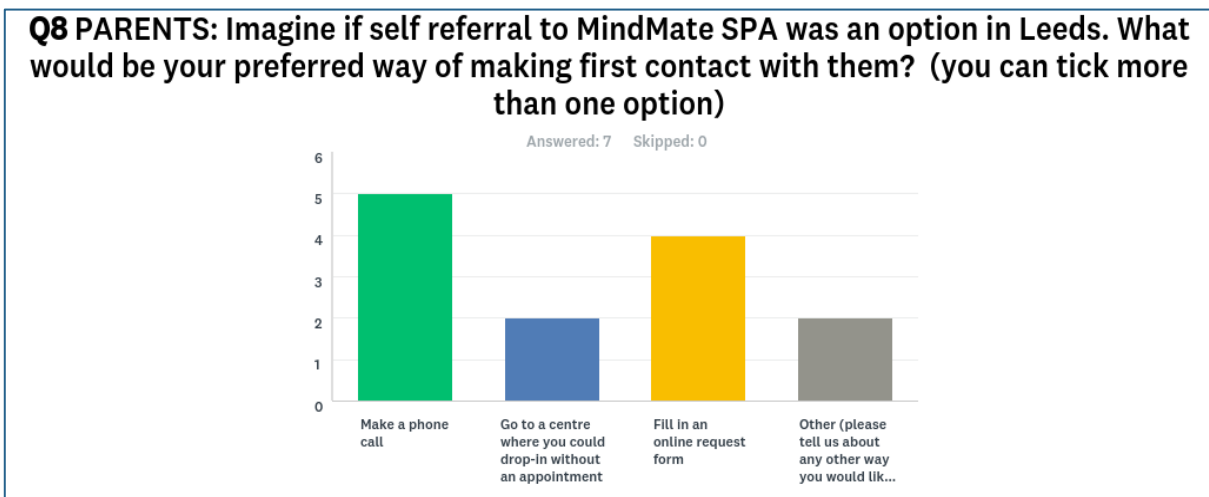
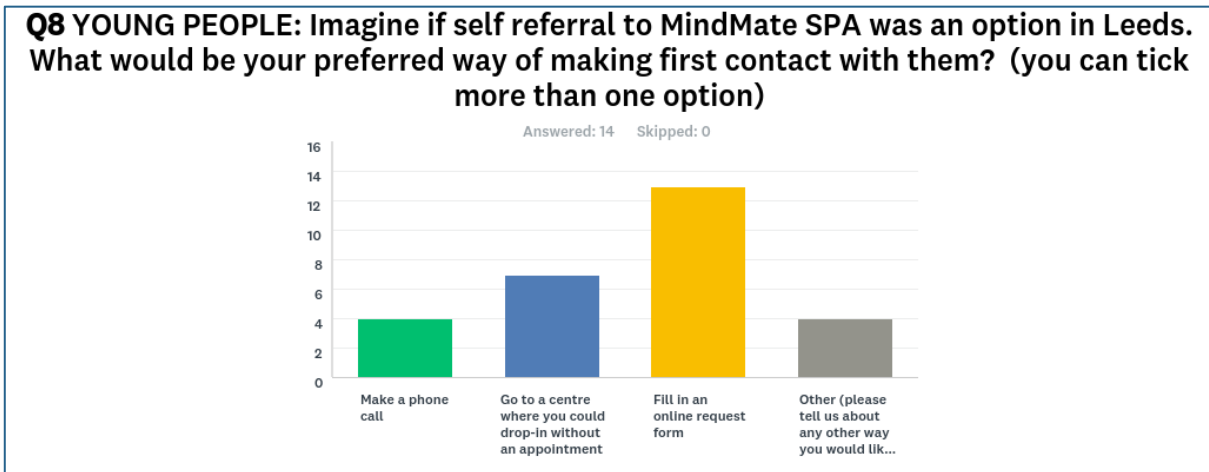
Two parents spoke about their positive experience of being referred by a health professional:

“It worked ok for me getting referred through health professional. Felt like they would make a good decision for me. It was very confusing when child has multiple health needs as there were lots of referrals.” (parent)

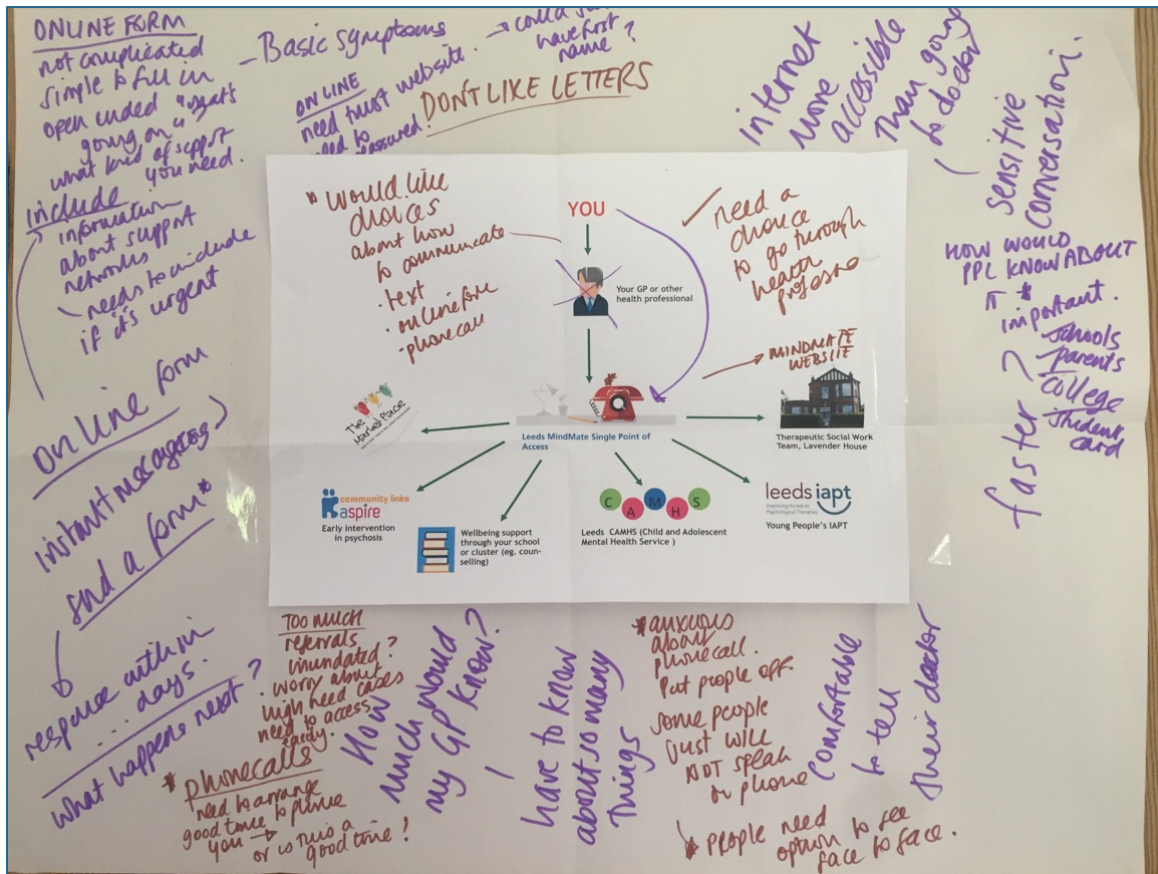
“As a parent I had a good experience of referral from a paediatrician who knew family well but it's not like this for everyone.” (parent)

Ways to self-refer

We asked young people and parents about the best ways they might want to communicate and engage with a SPA team if self-referral was an option. The most popular answer for young people was ‘fill in an on-line request form’ (13 of 14 who answered chose this as one of their options). For parents, the most popular options were to make contact by phone or online.



For young people, we found a recurring theme about anxiety related to making phone calls, especially when needing to speak about sensitive issues. Online communication felt more anonymous and less ‘daunting’.



"As for me this task [online] would have the least anxiety attached to it and therefore I would be more likely to do it." (young person)

"The internet is more accessible than going to the doc for a sensitive conversation." (young person)

"I'm anxious about meeting people/speaking to people I don't know so I'd rather make myself known online first." (young person)

"[online] considers people who get anxious over phone calls" (young person)

"I think that some may find it difficult to speak directly to a person about their issues and so it may be easier to speak briefly about their issues by filling out an online form where they may open up more." (young person)

*"...doing it on paper or online can be a little easier to speak freely."
(young person)*

"Some people I know don't like filling in online forms as they think they'll be judged by their spelling." (parent)

Young people also told us that there needs to be a range of options which include ways of being supported to complete a referral if you need it. It was clear from parents' answers too that it was important to have a range of options as some people preferred person to person contact, whereas others expressed preference for an online option. Two young people and one parent also suggested 'live chat' as another way they would like to get in touch.

"...making a phone call directly should also be an option as it is a quick and easy way to talk directly to someone about your issues." (young person)

"Preference would be an online form, but I would like a variety of options." (young person)

"how about.. you have one form but different ways of filling it out - you can do it online on your own or you could be supported to fill it in somewhere in a centre, face to face with someone supporting you to fill it in?" (young person)

*"Phone best personally but good to have other options available."
(parent)*

"Prefer to deal with people. Wanted to get it sorted there and then. With an online form, it's taken out of your hands. More peace of mind knowing it's being dealt with if it's person to person." (parent)

"[online] Time to think about questions and how to respond without being surprised by them by phone / in person." (parent)

"Can be done from a mobile device [phone, online]." (parent)

“Drop in option at school so people know about it” (young person)

Young people and parents said that the self-referral would only be effective if young people know about it.

“...needs advertising on social media... search key words across different mental health issues” (young person)

“Also good to have a really informative up to date website about SPA, how it works and other information about what to do if you need help.” (parent)

Young people also said that they are likely to worry about confidentiality and the sharing of personal information. They said that the process should be clear and sensitive to confidentiality.

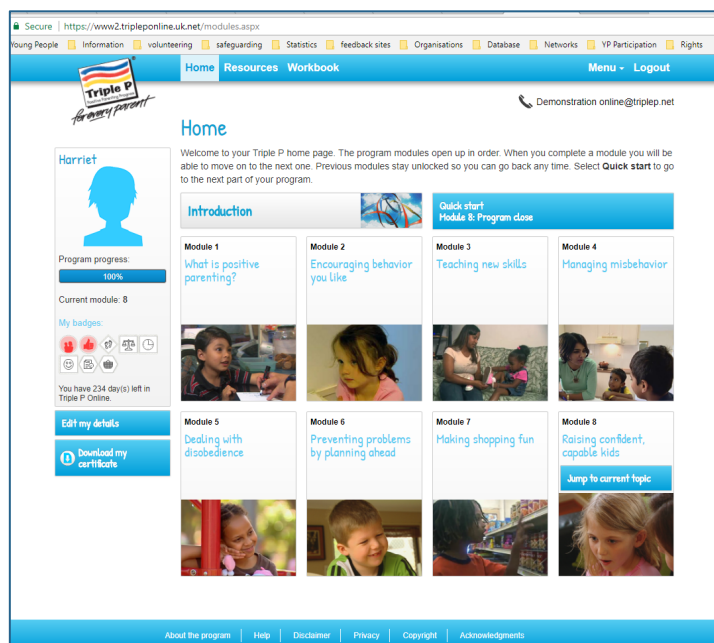
“An online form needs to be through a trusted website - need to be reassured.” (young person)

“Could it be quite light touch? ...even just give first name in the first instance - people will be worried where this is going.” (young person)

“It should have a message when you submit e.g. ‘thanks for your form, we’ll get back to you in ... days - and this information will be shared with... and what will happen next...’ (young person)

“Need a confidential way of asking the SPA whether you need something more or what the options were without needing to disclose to parents or school nurse or GP first ... someone to help you work out how serious it is. Or they might just point you in the direction of some resources, e.g. ‘use these coping mechanisms’” (young person)

Triple P Online



We offered the trial of Triple P to three out of the seven parents. Of these, one said it was something they'd like to try. Reasons that parents were not offered Triple P were because:

- They filled the survey in online and we were unable to show them the programme
- They said their children had, or thought they had a learning disability or were on the autistic spectrum, in which case the general version of Triple P online would not be appropriate.

The parent who expressed an interest in Triple P had had a previous positive experience of doing a parenting course as part of group. She said that the online course would be good as she wouldn't have to take time off work, but mentioned that access to support with the course would be an important factor.

“Online course might be useful but would be important to have opportunity to have support and someone to ask questions about own individual circumstances.” (parent)

Reasons that parents who didn't want to trial the course gave were: lack of confidence on computers, worries about security of an online course and preferring face to face interaction.

“I have done a parenting course before as part of a group - I enjoyed being in the group, it was fun and enjoyable and good to share experiences. I think online would be useful for some people, but personally I don't like it. I'm not that good at computers and some people think that websites can be unsafe. I prefer face to face where someone can see my child and help me.” (parent)

The issue of parents feeling that they are being blamed for a child being ill also came up.

“I think that offering a parenting programme can make it feel like it's saying it's your fault that your child is ill. Mental health is an illness. Not all children with mental health issues have behavioural problems as well. It's not a one size fits all. Offering it at the same time feels as though you're being accused of bad parenting. May make people less likely to come to you again for help.” (parent)

It is difficult to come to any concrete conclusions about Triple P online because the sample size of people we talked to was so small. But here are some of our thoughts, both from hearing people's views and our own experience of completing the online programme.

- Triple P online is not “a one size fits all” - it's not going to be appropriate for everyone. In which case, what other support is available for parents whilst their child is waiting to access services is a key consideration.
- The programme requires a level of commitment, headspace, time and confidence in IT. It relies predominantly on self-motivation to complete the course.
- Ongoing support from a professional (e.g. a weekly telephone call, group support etc) will be key to completion and getting the most from the course.
- Consider when might be the best timing to make the Triple P online offer. Is first contact with MindMate SPA the best time to do this?

Our messages / recommendations

- Use the comments in this report as a basis to explore how self-referral for parents and young people can be built in as an additional option to the referral pathway for MindMate SPA.
- Ensure that any future self-referral process allows for a choice of

communication modes, to include as a minimum online and phone options.

- Ensure that SPA offers a consistent collaborative approach in which parents and young people feel involved.
- Ensure that realistic, appropriate and up to date information about services is given to service users of MindMate SPA both verbally by phone and in a follow up letter. This should include accurate waiting times and what they can do if services do not contact them in the timeframe given.
- Involve service users in refreshing the [leaflet about MindMate SPA](#) making it more clear that SPA isn't delivering a support service but is a 'gateway' to other forms of support.
- The MindMate SPA leaflet states: *"If you want to get back in touch with the SPA while you are waiting, we will tell you how you can do this"*. Ensure that there is a robust system in place so that during their initial phone call, and in subsequent letters, all parents and young people are given a way to contact SPA.
- Further work needs to be done on considering carefully when and how Triple P online is offered to parents, and ensure that those who take up the offer are given appropriate support during the programme.

Commissioner Response

"Reports that provide us with direct feedback and ideas from the children, young people and parents are incredibly valuable. We are currently refreshing our Local Transformation Plan and our priorities going forward. The findings of this report will be reflected in the content of the MindMate SPA section."

Jane Mischenko, Lead Strategic Commissioner: Children & Maternity Care, NHS Leeds CCGs Partnership

Next Steps

This report will be shared with the Future in Mind: Leeds Strategic Board, as well as the Leeds MindMate SPA team.

We will agree with them 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

Thank you

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

Many thanks to Kieran Burke and the MindMate SPA team for working with us to help us make contact with parents who had used the service. Also thank you to Chris Lake (Leeds CAMHS) and who helped run the consultation workshop with young people.

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

Appendix 1 - Introductory information about Triple P Online used in interviews with parents

Introduction

We'd like to offer you the opportunity to take up an online parenting programme called Triple P '*Positive Parenting Programme*'

What is Triple P?

Triple P is an online parenting course which helps parents and carers in many different circumstances. The overall goal is to increase the knowledge, skills and confidence of parents and carers to help reduce problems for their children and teenagers.

Helps parents to learn different ways of dealing with difficult situations and to manage child's behaviour.

It is an 8 module interactive internet programme with video clips, interactive exercises and suggested homework tasks. The benefits of the course are that it can be completed at home and at flexible times.

There are two different programmes depending on the age of your child: 0-12s programme and 12+ programme

Leeds MindMate SPA have bought some licences to run a pilot. The course wouldn't cost you anything, although places are limited.

Triple P online is supported by a solid evidence base. In trials, **Parents who completed Triple P developed much greater confidence** in managing behaviour and had far fewer incidences of stress, conflict and behavioural problems in their children.

Is the course right for you?

It's totally your choice whether you take up the course. Here are some things to think about to help you decide;

- The course isn't suitable for children with a learning disability or autistic spectrum condition (there is a more tailored course for this which we aren't able to offer at the moment).
- The course **takes around 6-8 weeks** (spending around one hour per week online) and also asks you to apply some of the content to

everyday situations and try out some new techniques. So it's good to be realistic - could you set aside time to do this?

- You'll need **broadband internet access and use of a device and be confident in using a computer** (preferably a laptop or PC or tablet)
- Be patient! At first, the course might not feel relevant or you might not be able to relate to the examples shown. But stick with it - research shows really good results from the Triple P programme and you are likely to find some of the elements helpful. It also gives you a chance to take some time out to think proactively about how to help you and your child. The more you engage with the activities the more beneficial it's likely to be.
- You can work together with your spouse, partner or supporter on the course, or as a single parent
- **Support** - Phone call within 48 hours of logging on and then weekly phone calls of up to 30 mins offered. Support offered by clinician at MindMate SPA
- **Confidentiality***

REMEMBER

All parents can improve their relationships with their children and learn positive ways of responding to them, especially when things feel unmanageable. This is a chance to strengthen what you already do.

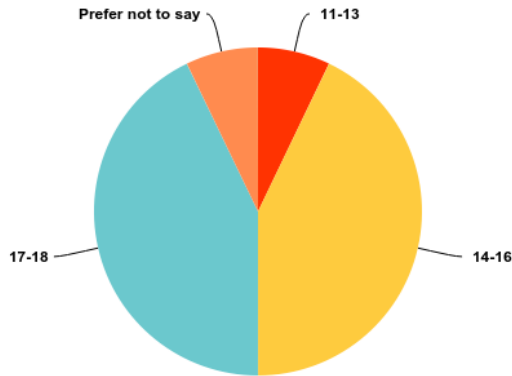
* to be clarified and communicated

Appendix 2 - Monitoring Data

Child/young person's age

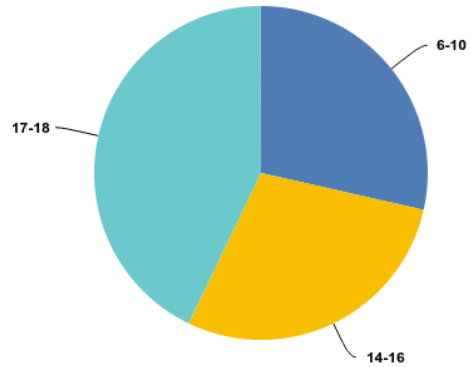
Q2 YOUNG PEOPLE: What is your age?

Answered: 14 Skipped: 0



Q2 PARENTS: What is the age of your child that is getting support with their mental health?

Answered: 7 Skipped: 0



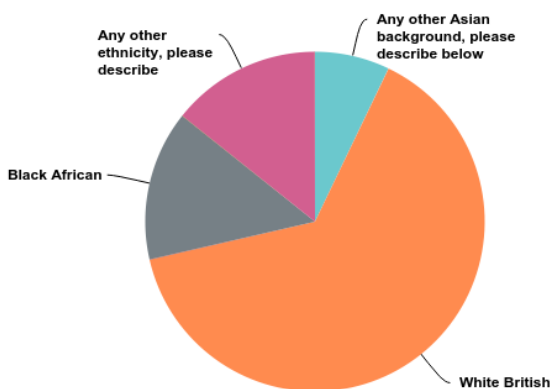
Gender

All parents we spoke to were female. 12 of the young people were female, one male.

Ethnicity

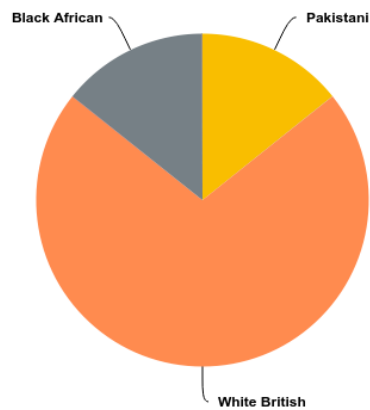
Q15 YOUNG PEOPLE: How do you describe your ethnic origin?

Answered: 14 Skipped: 0



Q15 PARENTS: How do you describe your ethnic origin?

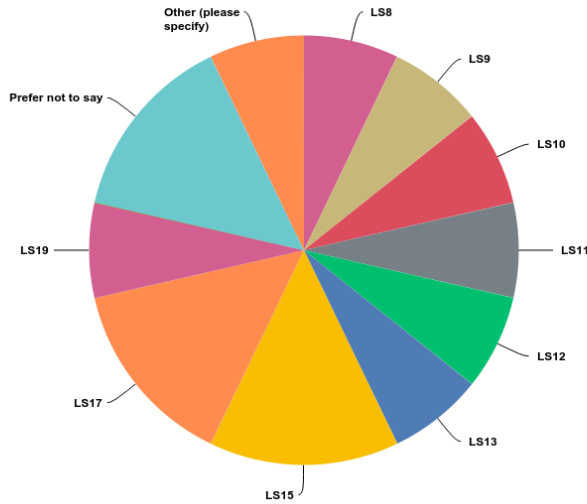
Answered: 7 Skipped: 0



Postcode

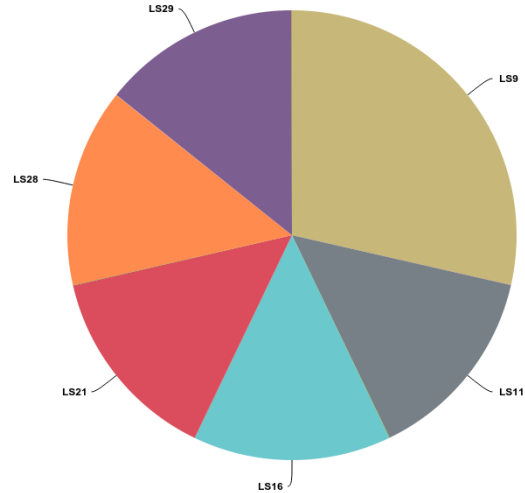
Q18 YOUNG PEOPLE: What is the first part of your postcode?

Answered: 14 Skipped: 0



Q18 PARENTS: What is the first part of your postcode?

Answered: 7 Skipped: 0



Disability

One out of the seven parents who completed the survey identified as being disabled.

Two out of the 14 young people who completed the survey said they were 'unsure' if they identified as being disabled.

Sexuality

All parents who took part in the survey identified as being straight/heterosexual.

11 young people identified as being straight/heterosexual, one identified as bisexual and two preferred not to say.

Other

None of the young people stated that they were the main carer for someone else.

One of the 14 young people said that they were or had been in care or looked after by the local authority.

