

Mind's Eye

Seeing mental health from the view of a young person

An overview of a service design project with young people

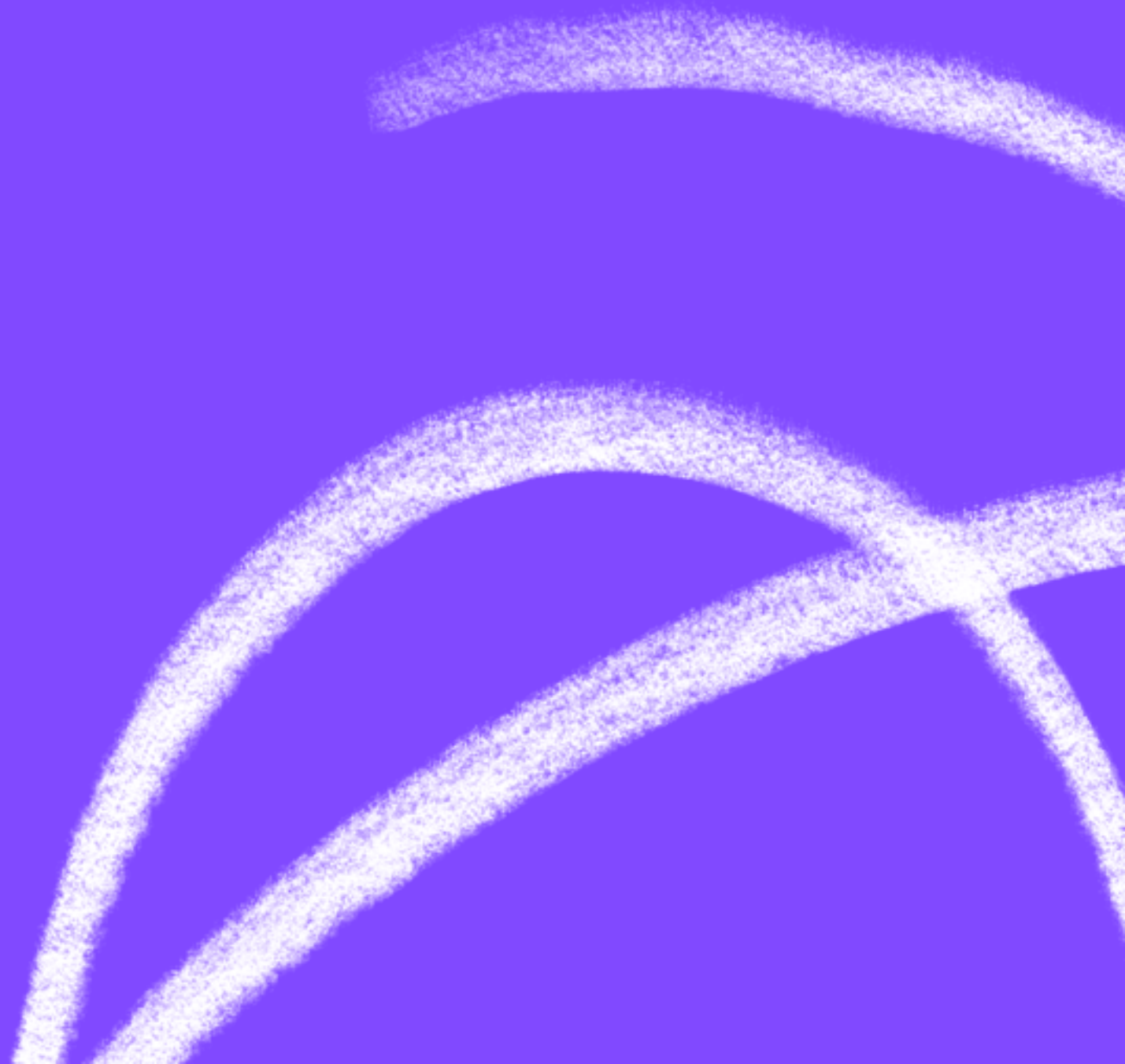


Contents

- Introduction
- Gathering research
- Young people's stories
- Our findings at a glance
- Designing a new service
- Outcome of our work



Introduction



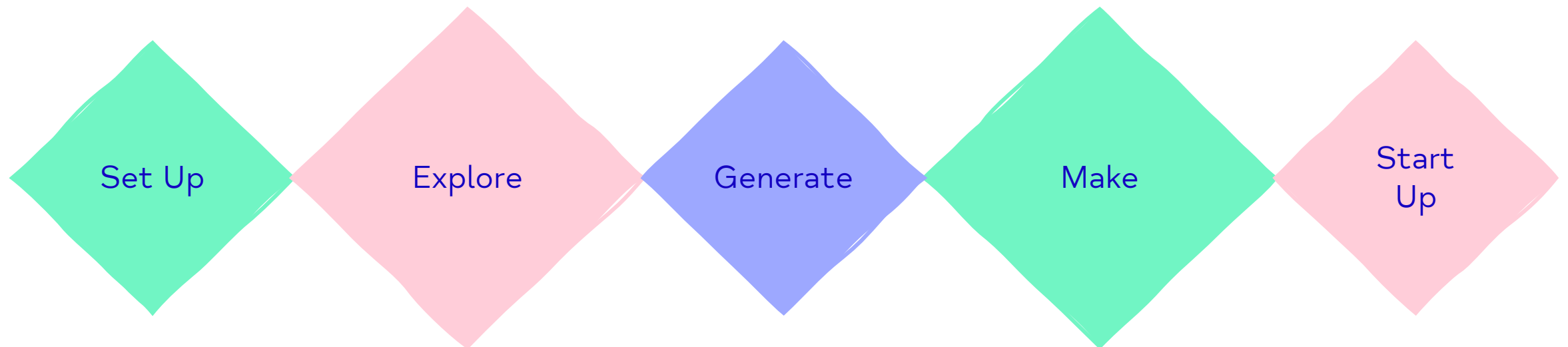
The prevalence of young people experiencing mental health problems in the UK is growing. NHS Digital reported that one in six 6 – 19-year-olds experience a mental health problem. This is up from one in nine in 2017 (NHS Digital, 2021). Research from Mind (2021) found that young people feel the current mental health support system is complicated and inconsistent. Young people often feeling the burden of responsibility to navigate through a system that feels like it prioritises adults. (Supporting Young People, Mind, 2021)

The growing body of research on young people's mental health highlights the need for increased and improved support. With this in mind, Teesside Mind committed to funding a service design project with the aim of co-designing a new service to support young people (aged between 11 – 25) in Teesside to understand, improve and maintain their mental health and wellbeing.

Service Design process

National Mind developed a Service Design Methodology to support local Minds with designing services, strategies, policies and systems which are effective, efficient and desirable.

This methodology enables us to create a service rooted in the needs of the young people in our community who would like support with their mental health and wellbeing.



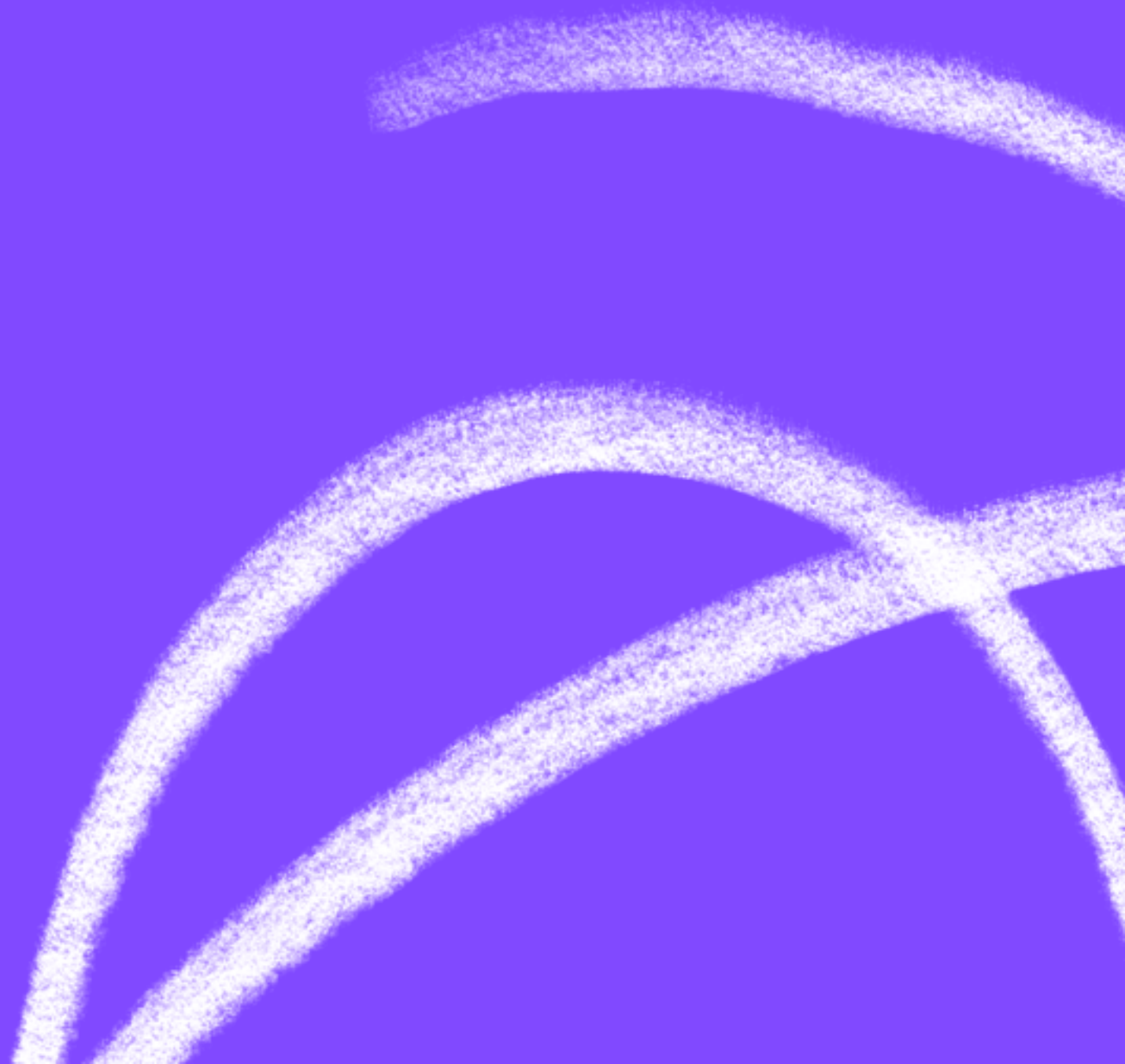
Five stages of Service Design

Service design team

A core element of the service design process for Teesside Mind is to involve people with lived experience from the start of a project. Therefore, Mind's Eye recruited two young people as peer designers, both of whom were involved with the project from the beginning and supported in guiding the direction of the project and informed the overall design and development of a new service.

The team also included five Teesside Mind staff members, all of whom had either experience of supporting young people or experience in service design.

Gathering research



Research methods

Over a period of two months, the service design team carried out research to gain an insight into the stories and experiences of young people

During that time, we did:

- 11 in-depth interviews with young people
- 15 interviews with stakeholders
- 15 reflective diaries
- 3 in-depth surveys
- 58 short surveys

and had insightful conversations with young people attending a youth group and a focus group.

Each interview, diary, survey and conversation was reflected on individually to identify the insights that should influence our next steps. From this we were able to identify our research themes and insights and develop a plan for progressing the design project.

The identified themes which are shared in this report are the foundations from which a new service for young people will be designed.



“I don’t want to be a burden to people”

“I don’t think I have anyone that I would openly tell everything too. I’m scared of judgement and the fear of someone not believing what I’m going through.”

“My boyfriend is the person who listens most and does his best to always understand and asks me what he can do to help rather than assuming he knows best.”

“I am very family orientated and would always speak to my parents or one of my sister. However, my parents would unknowingly brush things aside and don’t fully understand.

“I’ve been told I’m ‘too anxious’ for help.”

“I haven’t really spoken about my mental health to many people because I didn’t know how to.”

“I was told when I was 16/17 that I was attention seeking and told to just get a handle on things”

“You aren’t kept in the loop about who is getting your information, and after seeing doctors’ records, a lot of what professionals write is not what you have said to them.”

“When I first started to really struggle, I went to a professional and they talked down to me and made me believe that this was all in my head. They didn’t believe me and their response to me was “everyone feels sad” so that made me not want to speak out.”



Overview of young people we spoke with:

	In-depth interviews n = 11	In-depth surveys n = 3	Short surveys n = 58	
Gender	Female: 8 Male: 3	Female: 2 Male: 1	Female: 39 Male: 15 Non-binary: 2	Prefer not to say: 2
Age range	15 - 18: 2 19 - 21: 6 22 - 25: 3	11 - 14: 2 19 - 21: 1	11 - 14: 13 15 - 18: 18 19 - 21: 13	22 - 25: 13 26+: 1
Ethnicity	Mixed: 1 White: 10	White: 3	Mixed: 1 Black: 3 White: 53	Prefer not to say: 1
Lived experience	11	3	49	

Overview of who we spoke with:

Demographic information from the reflective diaries or informal conversations with young people was not gathered, however there was a mix of genders and ages involved.

We also interviewed twelve stakeholders including parents, mental health professionals, local organisations that support young people and youth group workers and volunteers.

The information shared in this report primarily focuses on the voices of the young people we spoke with, however the information gathered from our stakeholders has all be considered and has helped to influence our research.

Young people's stories



“It feels like sometimes, no matter how many times you tell people how big of an issue it is, they can still talk smaller of it.”

“I think it’s such a big thing where people are always scared to get mental health support in case they aren’t validated. If you don’t feel validated, then you’re not going to feel welcome, and then you won’t feel comfortable talking about your feelings”

“I would love to go to group therapy. Just a bunch of people chatting about their issues and validating each other.”

Chloe, aged 21

Anonymised story gathered from our research



Chloe's story

Chloe has both mental and physical health difficulties which significantly impacts her day-to-day life. Due to her health conditions, Chloe has had to withdraw from her university course and is unable to work. When she is finding things particularly challenging, she will find leaving the house difficult.

One of the ways in which Chloe's mental health impacts her is through overthinking, and for her, a good day would be one where she doesn't overthink. Chloe has learned some coping techniques for her mental health including distraction, positive thinking and being physically active, but these don't always work.

Chloe has tried to get support through various avenues in the past but has found it challenging. When she was in school, Chloe found engaging with support difficult due to feeling that she didn't have any privacy as everything involved her parents. When she tried to get support through her GP, she struggled to contact them before 9am to make an appointment due to her physical health. Even after explaining her circumstances to the GP surgery, no alternative solutions were offered.

From Chloe's experience, any support she has received relating to her mental health has been because she was able to advocate for herself and kept pushing to get the support she needed. If she hadn't been able to push for support, she feels that she would have been dismissed.

While Chloe has had some positive experiences, there have also been many times when Chloe has not felt validated by the mental health professionals who were supporting her, and she often feels belittled by people not understanding what she is experiencing and the impact it has on her. This causes Chloe to feel frustrated.

“It’s like a rollercoaster. I can have really bad days and really good days, and days when I’m angry and days when I’m just fine.”

“I went to an art college. Everyone’s not the same – you know what I mean, the school was a bit different.”

“The private counsellor, they’re enthusiastic. They actually wanted to see an outcome. I think with CAMHS they just want to get paid.”

Daniel, aged 20

Anonymised story gathered from our research



Daniel's story

Daniel first started struggling with their mental health in secondary school where the overall stress of school triggered them to start self-harming. At the time, Daniel did not share with anyone how they feeling, but people at the school noticed the signs of self-harm and reached out to Daniel's mother.

School did offer support in the form of a pass card which meant that Daniel could leave class if they were struggling with their mental health, and while it was helpful, the downside was that the only place for Daniel to go when they left the class was the isolation room where there was nothing to do except stare at the wall.

Daniel does find interacting with other people their age difficult, which was part of the stress at school. However, when they started art college and met people with similar interests who they were able to connect with, it reduced Daniel's urge to self-harm.

Daniel was initially referred to CAMHS for support. During their time with CAMHS, Daniel often felt like they were treated and spoken to like a child and felt like they were just 'one of many' for the mental health practitioner where the focus was just on outcomes, not the person. Daniel left CAMHS and opted for private therapy where they noticed a considerable difference. With private therapy, Daniel felt more in control within the sessions, with the therapist willing to work at Daniels speed and within Daniels comfort levels.

“I have to remind myself that people don't hate me sometimes. And sometimes it's easy to immediately assume from a single social cue that someone doesn't like me.”

“I'm sat here waiting for support. It's like, what am I meant to do? I'm still not doing great. I still haven't changed.”

“I've been told by my parents that 'since you're a very strong-willed person, it can be hard for people to realise that you're having issues.' Because I'm a relatively like, I'm a smiley, I'm a confident person.”

Liam, aged 15

Anonymised story gathered from our research



Liam's story

Liam has experienced anxiety from a young age, but for majority of that time he has kept it hidden from those around him. Liam only spoke about how he was feeling after he reached breaking point which led to him needing support from the crisis team.

Liam continues to find opening up about his mental health difficult, especially to his parents as he worries about how they are going to react to what he tells them. Liam therefore prefers to let them know how he's feeling via text message or writing a note so that he doesn't have to see their immediate response.

Liam has tried to get support from mental health services but is always met with hurdles. One service wanted to primarily speak to his parents about his mental health and not him, which meant that Liam would have to converse through his parents how he was feeling, which he wasn't comfortable doing. Another service said they'd refer him for emotional support and after a period of time where he didn't hear anything back, he followed up only to find out he hadn't been referred at all.

Liam is on a waiting list for support now but has been told that the waiting list is long, and he doesn't know when he will be offered the support he needs. Liam has tried to find his own coping techniques such as talking to someone he trusts or finding some hobbies to distract him, but it's hard sometimes when he's having a particularly bad day.

“People talk about having down days and depression and they want to stay in bed, but that’s not me – I can’t. Well, I can if I wanted to, but I’d rather be up and sad than in bed and sad.”

“Apparently, I opened up too much to them for them to think that I had an issue... I was too open! They were used to kids that wouldn’t open up in the first session and that’s why they wouldn’t take me.”

“I want to be there for everyone, I like to be there for everyone. But at the same time, I’ve got to be careful of what triggers me.”

Sara, aged 24

Anonymised story gathered from our research



Sara's story

Sara was initially diagnosed with anxiety when she was a teenager. A few years later she was also diagnosed with depression. Sara's mental health problems affect her every day, and while she tries to not let it disrupt her daily living too much, it does stop her from doing lots of things that she would love to be able to do.

Through her lived experience, Sara does have a good insight into the things that impact her mental health, and she has learned some helpful coping techniques to help her manage during difficult moments. However, she also acknowledges that she does have some unhelpful traits that can exacerbate how she is feeling at times.

Sara has tried to get support from different mental health services both as a young person and as an adult. As a young person, her mental health difficulties were initially dismissed because of how open she was about how she was feeling. Sara feels that had she been believed and got the support when she first reached out, she would not still be struggling with her mental health now.

Sara has had mixed experiences with adult mental health services. With one service Sara was made to feel ashamed if she hadn't done the assigned between session work whereas another service were more flexible and worked with Sara to find coping techniques that worked for her and her circumstances – those are the coping techniques that Sara continues to use now to support her during difficult times.

Our findings at a glance



Communicating need for and feeling worthy of support

Insight: Young people are aware of the language to use around mental health, but don't always understand and can't always describe how it impacts them personally. Young people often feel that their mental health concerns are dismissed due to a lack of understanding and empathy from adults – especially when the adults struggle to understand it themselves. Despite having a need for support, young people don't always feel worthy of that support.

“Other people knew I needed help, I knew myself, but I didn't know what to say. When my family said I needed help I was relieved.”

Real quote from our research



Communicating need for and feeling worthy of support

Opportunity	The issues	The needs	What's working
<ul style="list-style-type: none">• To help young people better understand mental health and communicate how it's impacting them.• To demonstrate that everyone who would like support with their mental health is worthy of that support, regardless of perceived severity• Support adults, including parents and teachers to better understand and communicate with young people around mental health.	<ul style="list-style-type: none">• Young people can't always communicate how they are feeling. This can sometimes result in their feelings being dismissed or the young person not reaching out for help.• Young people get told that "other people have it worse", leading them to believe that they must reach a certain level of distress before they can access support.	<ul style="list-style-type: none">• Adults who understand, are willing to listen and will acknowledge the experiences of young people.• Young people not to feel judged for experiencing poor mental health and needing support.• Young people knowing how to start the conversation with someone about mental health, and how to communicate the way they are feeling and the impact it's having.	<ul style="list-style-type: none">• Young people talking to each other about their mental health. Talking to their friends is the way that most young people get support with their mental health.• Services that aren't time-limited with the support they provide, giving the young person time to build trust and confidence with sharing how they are feeling and what they are experiencing.

Barriers to access & engagement

Insight: There is an evident need for support, however young people face many barriers which impact their ability to access & engage with support. One of the biggest barriers is waiting lists for support, with many young people becoming more distressed when they did not have someone to speak to when they needed it. Lack of support from school and lack of flexibility from the services supporting young people creates further barriers.

“I would like more accessible services. I cannot speak over the phone at all, and the current text services don’t work for me sometimes.”

Real quote from our research



Barriers to access & engagement

Opportunity	The issues	The needs	What's working
<ul style="list-style-type: none">• To provide support that is immediately accessible to young people as and when they need it.• To have a flexible approach to support that gives the young person choice over how and when they engage based on their needs.• To be a consistent presence in the community and be there for young people when they feel that other services or organisations aren't.	<ul style="list-style-type: none">• The amount of effort and time it takes to access much of the support that is available feels too overwhelming for many young people and their families causing further distress and mental health problems.• Many services are focused on outcomes / KPI's and not the individual sitting in front of them and their needs. This leads to disengagement from services.• Services not communicating with young people effectively when they are on a waiting list and not updating them on progress. Young people feel left in limbo not knowing whether they will be getting support or not.	<ul style="list-style-type: none">• Services to fit with the lives and needs of the young person and not expect the young person to fit with the timelines and expectations of the service.• Services to have a better understanding of the young people in their community and how they would best engage with support – it's not about what's easiest for the service, but what is most accessible and beneficial for the young person.	<ul style="list-style-type: none">• Services that have various ways of engaging – e.g. phone calls, text messaging etc.• Services that are transparent about any waiting times and what they offer.

Ensuring the right support is available when needed

Insight: Young people had better experiences of support when they were referred to the right service for them at the right time and were able to get support quickly. Young people did not have good experiences of support when:

- They were not kept informed about the progress of the referral
- The service was not suitable for their needs
- There was no clear explanation of how the support would be beneficial
- Childhood traumas were not addressed.

This sometimes led to young people no longer trying to seek support.

“When people don’t explain why something will help, I don’t see the point in doing it.”

Real quote from our research



Ensuring the right support is available when needed

Opportunity	The issues	The needs	What's working
<ul style="list-style-type: none"> • To nurture a trusting relationship with young people by being transparent about what support is available, how the support will be beneficial, what (if any) waiting times there are and regular updates / check-ins. • To be accessible to young people when they need the support, not having lengthily waiting lists. • To help young people understand the various services that are available to them and what the service can / can't support with, reducing number of inappropriate referrals to services. 	<ul style="list-style-type: none"> • Young people are often expected to go along with whatever treatment / support is offered to them without it being discussed with them as to why they are being offered it and how it might help them. • Referrals to services often get rejected without any explanation as to why they have been rejected. • Due to time constraints, many services just focus on the present and don't consider or explore how past experiences may be influencing current difficulties. • Scattergun referrals with the hope that someone might offer support, even if it's not the most suitable at that time for that young person. 	<ul style="list-style-type: none"> • More holistic support that recognises the impact that past experiences can have on current difficulties. • Longer-term support to allow time to fully explore MH needs and challenges • Better / clearer communication from services especially when there is a waiting list for support to help manage expectations. • Better / clearer communication from services when a referral is rejected as to why it's not being accepted. 	<ul style="list-style-type: none"> • Multiple organisations coming together to discuss referrals and identifying the right service and most accessible service for young people.

Lack of person-centred care

Insight: Young people don't always feel listened to or believed when they are seeking support for their mental health. Young people don't always feel that they are acknowledged as an individual and often feel that the support they are provided is decided by what the professional wants rather than what the young person wants, or what feels important to the young person.

“The service didn't really want to know what was going on, they just wanted to fix me or stop me behaving badly.”

Real quote from our research



Lack of person-centred care

Opportunity	The issues	The needs	What's working
<ul style="list-style-type: none">• To fully include young people in any discussions around their support and care.• To give young people an equal voice in the conversation.• To involve young people in the development and growth of services to better understand how to include them effectively in their care, considering use of language, communication methods and service provision.	<ul style="list-style-type: none">• Young people are spoken down to by professionals or adults who often believe that they know best.• Young people are expected to go along with whatever they are told by professionals / adults, and if they don't, or if they question why, they are the ones considered to be at fault.• Young people feeling that services & professionals see them as just another number and not as an individual.• Professionals deciding what issues they are going to support with based on their skill-set / service and not always considering what the young person wants to be supported with.	<ul style="list-style-type: none">• Young people to have an equal voice in the support they are offered and provided.• Young people to be empowered to identify the issues that are impacting them the most and ultimately decide the direction of their support.• Young people to be supported to speak up when they feel the support they are being provided isn't meeting their needs and for that information to be listened to, accepted and actioned.	<ul style="list-style-type: none">• When young people are included in their support plan, and are given some choice, they are more likely to engage with services.

Designing a new service



Generating ideas

As with our research stage, engaging with young people for the generate stage was our key focus. For each research theme, 3-5 open questions were identified, the answers to which would provide ideas for a new service and solutions to the current challenges faced by young people in Teesside.

For this stage, we engaged with 28 young people who shared their answers to our questions in different ways, including online responses, guided conversations and drawing. We also engaged with 15 stakeholders who answered the same questions.

Generate themes

Strong themes emerged from the questions that were asked to young people during our generate stage. These themes will be the foundations to the service that is designed:

- **Be flexible** – to the needs of the young person.
- **Be available and accessible** – when they need the support.
- **Be comfortable, safe and welcoming** – including the staff providing the support and the environment in which support is provided.
- **Be believing** – of what the young people tell us.
- **Be trustworthy** – follow through on any actions we say we will.
- **Be clear** – help young people to understand their mental health by clearly explaining what they might be feeling, why they might be feeling it and how different tools and techniques might help them.

**Outcome of our
work**



What we have designed....

...and are in the process of setting it up to be piloted in the coming months.

It is a

Drop-in service that will be consistently available

For

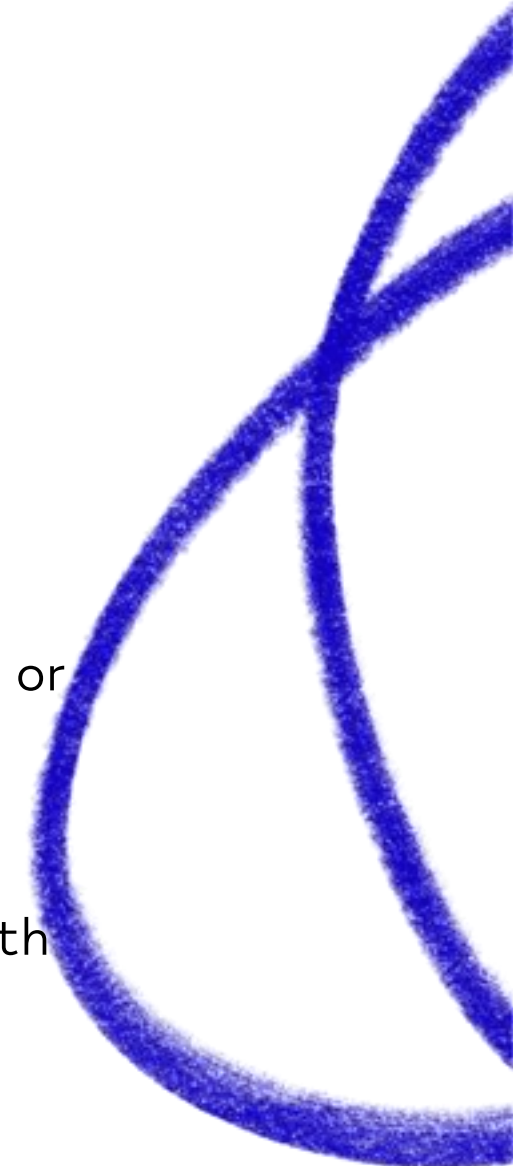
Young people who need a safe space, need a listening ear, need a distraction or need information about where to access support

That

Is there when they need it, helps them develop the skills and resources needed to manage mental health, builds peer support and connects them with relevant services

To

Ensure they feel heard, build their trust with services and mental health professionals, and be there while they might be waiting for therapeutic support.



Teesside Mind
The Mind Centre
90 – 92 Lothian Road
Middlesbrough
TS4 2QX

