



# Minding Us

Improving services for young people  
at greater risk of mental ill-health





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## Key Findings

Between September 2016 and March 2017, we talked to 92 young people aged between 10 - 23 years, who may be at a greater risk of mental ill health because of additional life challenges they are facing. This is what we learned.

### What young people told us

- Waiting times for CAMHS can be long with worsening mental health whilst waiting.
- It is hard to know where to turn in a crisis.
- They had mixed opinions as to how well therapy worked for them.
- Appointments can seem too infrequent once in therapy.
- Healthcare workers did not always seem to understand mental health issues.
- Going to the GP for mental health concerns felt too daunting for some.
- Many did not know about existing mental health services, including new services like NHS 111, option 2.

### How young people would like things to be

- The majority preferred the option of face to face counselling.
- 70% of them would go to a trusted adult for more information about mental health.
- More flexibility in the times and locations of counselling appointments.
- They would like easier access to services, with more self-referral and drop-in options.
- Therapists need to be friendly and non-judgemental.
- Parents and teachers need a better awareness of young people's mental health.

### What staff told us

- At the time of discussion, there was a lack of provision for young people aged 16 to 18 years. They can fall between the age for children's services and adult's services and may not meet the raised thresholds for referrals. The age limit for children and adolescent mental health services (CAMHS) has been raised to 17 and up to 18 for young people with learning disabilities or complex health needs.
- Some staff suggested it would be helpful to have more open-ended appointments for young people with more difficult life challenges, to avoid re-referrals and extended waiting times.
- There are some specific issues within certain groups which are highlighted in the report under staff feedback.

Overall, amongst the young people we spoke to there seemed to be little understanding of mental health or where to go for help.

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## Introduction

Healthwatch Cambridgeshire and Peterborough\* is an independent champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.

The Minding Us project was funded by Cambridgeshire and Peterborough Clinical Commissioning Group (CCG). They asked us to speak about mental health with young people who have extra life challenges and experience greater health inequality\*\*. Children and adolescents' mental health services (CAMH) are undergoing changes based on a framework of care called i-THRIVE. This is an integrated, person centred approach to providing mental health services for children, young people and families.

As part of Minding Us, we visited ten young people's groups in Cambridgeshire and Peterborough, including young carers, young people who had been sexually exploited, and young lesbian and gay people. The groups we visited support young people who are more vulnerable in terms of their exposure to trauma, prejudice, isolation, abuse and disability. This is not an exhaustive list and there are other young people that we haven't spoken to who may have similar vulnerabilities.

At each group, we ran a session with the young people to encourage them to:

- Talk about their opinions and experiences of mental health and the services available.
- Give information about services and resources available in their area.
- Think about how they use and understand language related to mental health.

This project follows on from our Thriving report, published last year, where young people told us they wanted mental health support that is meaningful and relevant to them. This included:

- More information about mental health
- More education about mental health
- To fight stigma about mental health
- To share their own experiences of mental health

Whilst we were running the Minding Us project, we also ran a separate project called Being Happy, Being Me. This had the same overall aims; asking the same questions in four schools in Cambridgeshire and Peterborough. The Being Happy, Being Me report was published in May 2017.

Some of the findings of these two reports do overlap as they were looking at similar themes but this report focuses on the specific needs of young people who may be at a greater risk of developing a mental health problem.

\*This was a joint project between Healthwatch Cambridgeshire and Healthwatch Peterborough who merged on 1st April 2017

\*\*Children and Young People's JSNA< Cambridgeshire County Council, 2010

<http://cambridgeshireinsight.org.uk/currentreports/children-and-young-people>

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## How we met the young people

Many of the young people we wanted to talk to as part of this project had difficult life challenges. Arranging to meet them was not always easy. Our chosen method involved going through a trusted group that they were already supported by. We spoke to young people at six groups in Cambridgeshire and four in Peterborough. These were:

- SexYOUality, since renamed 'The Kite Trust', (lesbian, gay, bi-sexual and transgender - LGBT), Cambridge
- Spring Common Specialist School for Learning Disabilities, Huntingdon
- Link to Change (Sexually Exploited Children), St. Neots
- Deaf and Hard of Hearing Children, Cottenham School, Cambridgeshire
- Young Carers, Cambridgeshire and Huntingdon Support Group 1, Huntingdon
- Young Carers, Cambridgeshire and Huntingdon Support Group 2, Huntingdon
- Young People who have offended, Youth Offending Services, Peterborough
- Clare Lodge Secure Unit for Women, Peterborough
- Gypsies and Travellers, The Voyager Academy, Peterborough
- Looked After Children, Care Leavers, Youth in Localities Team, Peterborough

In addition to the group meetings, we also developed a survey for young people to fill in when having a discussion group was not possible. This helped us capture their views in another way. It was also useful for the young people who felt they could not share their experiences in discussion but could write them down anonymously.

In each session, we talked about mental health and discussed the stigma associated with it. We discussed language around mental health, including being respectful about words used in relation to people who may have mental health issues. We did the 'gapped-out' exercise from Young Minds where they had to try to fill the word gaps giving an overview of mental health. Young people were also asked to fill in our survey at the end of each session.

Some young people have complex life situations which made sitting down together to have discussions about mental health too challenging. The staff who work with these young people helped them fill in surveys on a one-to-one basis, instead of working through in a group.

As part of each session, we provided young people and the organisations with our information sheets about local mental health services. This included services like NHS 111 option 2, any local drop-in clinics, KOOOTH online counselling service, Shelf Help in some libraries, Keep Your Head website etc.

Within some of the groups, the staff also gave us useful feedback about how they view the mental health services and how that is affecting the young people they work with. These have also been noted later in the report under staff feedback. We gave all the young people involved a £5 voucher, which can be spent in many high-street shops, as a 'thank you' for taking part.

Feedback was collated for each group visited and fed back to the CCG. This report is a summary of all the responses.

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## What these young people told us

The following data has been collated from the surveys and discussions from all ten groups visited. Some of the questions were multi-choice. Not all of the young people answered every question, so the graphs will only show a trend in choices.

### Understanding of the words used

We asked young people what they understood about some of the words used to describe how you promote and develop good mental health, in particular the words thriving and resilience.

Generally, the word ‘thriving’ was understood by most, although 28% did not know what it meant. There was little or no understanding of what the word ‘resilience’ meant. Generally young people found it hard to define mental health, with some exceptions. Sometimes, young people would refer to mental health in relation to trauma or a difficult event such as a death in the family. There seemed little understanding about the spectrum of mental health and the fact that we all move along this in our daily lives.

Some of the comments about mental health were:

- ‘Emotional slump’
- ‘People being ill’
- ‘Death in the family’
- ‘Angry with family’
- ‘Being trapped in your own thoughts, feeling isolated, and feeling like no-one seems to understand and provide the help needed’
- ‘Sadness because of family problems’
- ‘How I feel in my head’
- ‘Your state of mental well-being - how you are coping with stuff in your brain’
- ‘Mental health means how mentally healthy you are’
- ‘It means helping people who are struggling!’
- ‘The way your brain works’
- ‘Mental health is when people struggle with liking themselves’

### Experience of mental health services

One in three (33%) of the young people told us they had used mental health services before. 45% said they had not used mental health services before. Not all young people answered this question.

## Making services better

We asked all of the young people what would help to make their experiences of using mental health services a positive one.

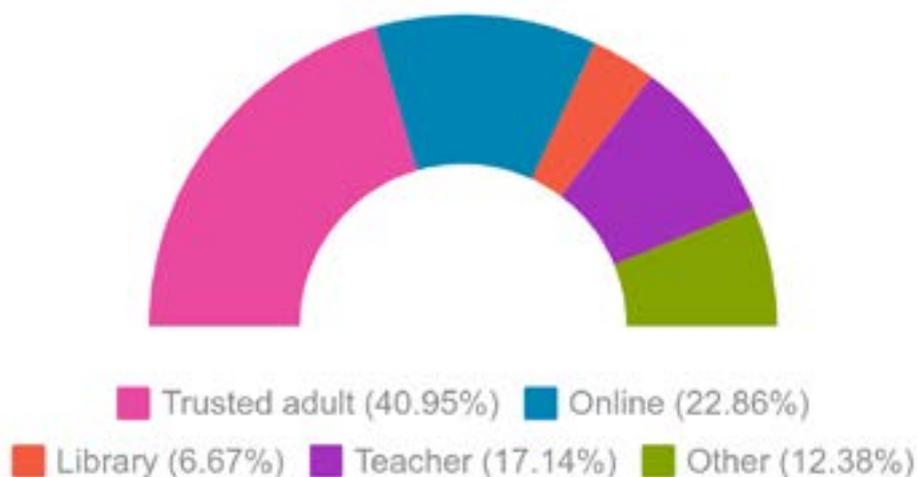
- ‘Have kind and knowledgeable staff - talking in a technical sense or layman’s terms.’
- ‘Getting help and access to services I needed.’
- ‘Being able to have someone I trust with me to be introduced to a new service.’
- ‘Get to know the person first.’
- ‘If I were to use mental health services, I would try my best to follow instructions and put in the effort to get the right help.’
- ‘Talk to someone positive, safe and approachable. Also, with patience in what they want to say.’
- ‘If I felt that I could say any troubles and be listened to without the other person judging me.’
- ‘An activity while I have my sessions because I find it hard concentrating - colouring, playing cards.’

## Where to go for information

We asked young people where they would like to go to get information about mental health. Strikingly, many young people would go to a trusted adult, including a teacher. Together with ‘other’, these made up over 70% of the responses.

Choices from the ‘other’ option were: Dad, my dealer, NHS, CAMHS, Mum, support worker, school nurse, friends, doctor and Link to Change.

### Where the young people went for information

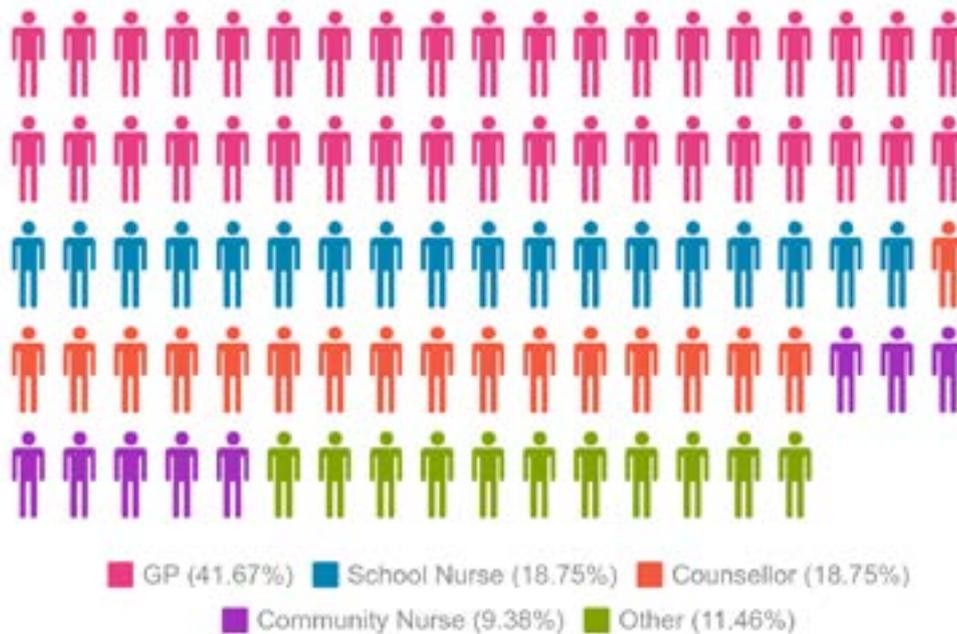


## Where to go for help with a mental health problem.

We asked young people where they would go for help with a mental health problem. Most young people would go to their GP (42%).

The next most stated options were the School Nurse (19%) and a Counsellor (19%). Some of the 'other' comments as to where to go for help with a problem were: CPN, crack-den, Supported Living Worker, Mum, Google, Parents, best friend, young adult carer worker, teacher, therapist, family.

### Who the young people spoke to for help

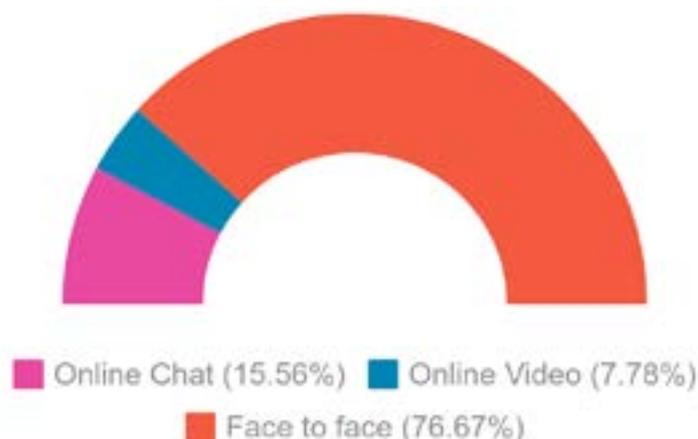


## Where to go for counselling

Face to face counselling was the most popular option (77%). However, some young people were also interested in support via online chat or video (23%).

Other suggestions included: Doctors, hospital, school, quiet room away from other people, home, café, in the community, near sixth form, drop in clinics, CAMHS, somewhere I can be creative, park, community centre, Oak Tree Centre, College, Counsellor's office, somewhere I feel comfortable.

### Where the young people went for help



## NHS 111 option 2

We asked young people if they had heard about NHS 111 option 2. This is a mental health crisis service launched in October 2016. One in five of the young people we spoke to had heard about this service (22%). The remaining young people had not.

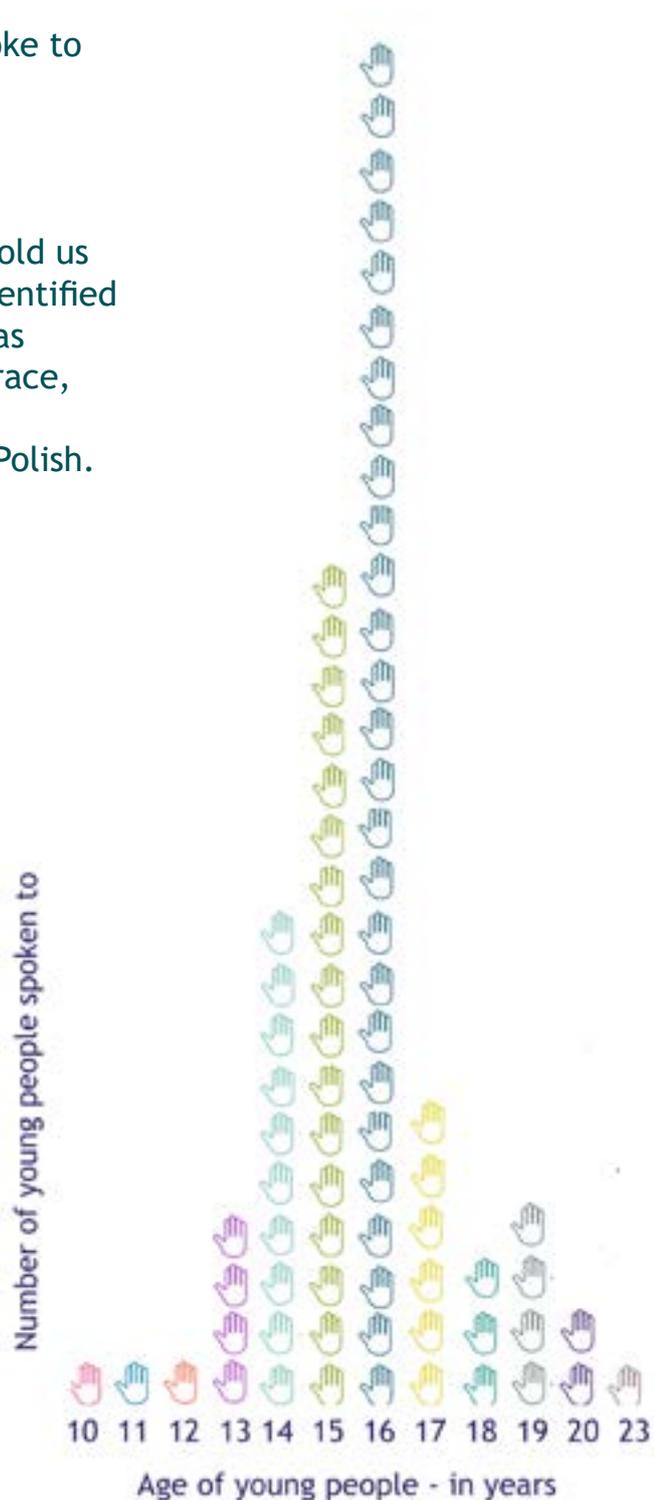
### About the young people

We spoke to young people aged 10 to 23 years. Over half were aged 15 or 16 years.

Just over half of the young people we spoke to (56%) identified as female, a further 42% identified as male. One young person did not identify as male or female.

Not all of the young people we spoke to told us their ethnicity. Of those that did, most identified as White British. Other people identified as Roma Gypsy, Pakistani, Slovakian, mixed race, Indian, Bangladeshi, Afro-Caribbean, White Asian, White Caribbean and White Polish.

### Ages of the young people we spoke to



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## Themes

### Education around mental health

Many of the young people found it very difficult to define what mental health is, although they might know that it is related to the brain or trauma. Mental health was often seen in a very negative light. When asked what it meant, young people would sometimes mention that it was related to a death in the family or some traumatic event, therefore it was only seen as a negative mental state. Comments that one either has mental health or not, were heard quite often. More education is needed to help them understand what mental health is and how to nurture it. There is a wide range of packages and online resources available to help with this.

### Knowledge of mental health services

Young people generally did not know about mental health services, unless they had been seen by Children and Adolescent Mental Health Services (CAMHS). Very few knew about any new mental health service changes. Only a few had heard of NHS 111 option 2. Only a few had heard of KOOH, an online wellbeing and counselling platform. They usually found this information out through their schools.

No-one told us they had heard about Keep Your Head, the local children and young people's mental health and well-being support website. Like other services, this is relatively new.

### Language around mental health

Many young people found the words 'thriving', 'resilience' and 'mental health', difficult to define, although there were some exceptions.

Some of the young people we spoke to had missed education because of complex issues such as difficulties at home or mental health problems. Some had a learning disability. One young person said they needed simple language to be used for questions.

It is important to make sure that the words used to talk about mental health are easy to understand, with information available in easy to understand terms.

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## Access to mental health services

Many of the young people reported good relationships with CAMHS. However, long waiting times were often a problem. Sometimes, young people experienced worsening mental health whilst they waited for an appointment. The exception here was for the young people at Deaf CAMHS where the wait was two weeks. In one group where the young people often have complex life circumstances, waiting could be three months to a year. The added complication of missed appointments could make the wait even longer.

Some staff said that it would help certain young people to have more flexibility with access to appointments. This could help them avoid a too early discharge from services followed by a rapid need for a re-referral.

Some young people wanted services near home. They wanted the option to have someone with them, particularly at the first appointment. Some thought there was a lack of self-referral options for mental health services.

Without knowing about the new service options, many young people would choose to go to their GP for help, but some felt this too daunting. They suggested more drop-in clinics to discuss mental health issues informally and flexibly.

Therapy options away from the home area were asked for by some young people. Privacy was a big issue for some.

The difficulty of accessing counselling in secondary school in a discrete way was mentioned. Young people said this needed to be set up in such a way as to be more private for the person involved.

A few young people told us that it was sometimes difficult to know where to turn to in a crisis.

## Feedback about therapy

Sometimes, appointments were felt to be too infrequent. Some young people needed more frequent support whilst in therapy.

There were mixed responses about how helpful therapy was. From one group of very vulnerable young people, four out of nine of them said they found their therapy unhelpful. However, young people in other groups told us therapy was positive when they finally gained access.

Young people wanted time to get to know and trust the person they were seeing.

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Interestingly, two young people told us they would like to try a more creative therapy. Having other therapy options available, other than talking therapies was of interest. Comments from both service users and non-service users included the wish for positivity, flexibility and a friendly and non-judgemental approach in therapy. Some of the young people feared being judged for having mental health problems.

A couple of comments were made about wanting their therapy to be fun and having an activity to do whilst in sessions due to having poor concentration levels. A few felt this could be useful to them.

Young people made a variety of suggestions for where they would like to get counselling, including a public place like a café or a private place such as at home. This depended on their circumstances, but overall, this shows that they would like other options than formal therapy rooms.

Face-to-face counselling was the preferred option choice in all groups. This was quite striking in an age group who use social media and the web so widely. In all of the groups however, there were always one or two young people who would try online counselling, which shows that having both options available to them is the ideal.

### **Finding information about mental health**

When needing to find information on mental health, a trusted adult was the preferred choice for many of the young people, which, again, was quite striking, given the wide online use in this group. A surprisingly small number would go online, as seen in all groups.

There was concern that Google can bring up too much information and that it is not always easy to know what is correct. Widely advertising websites like Keep Your Head and Young Minds, for example, are so important to enable young people to access accurate information about mental health.

One young person raised the issue of the fear of looking up information for what they might find out about themselves.

The young people in one group said that it would be helpful to have adverts about how to look after your mental health on social media sites that they used.

Young people suggested the involvement of well-known Youtube personalities and TV adverts to promote mental health understanding. It was felt that these options may have more influence on young people than having a teacher teach about mental health in the classroom.

The idea of visually attractive eye-catching posters about mental health in school might be useful for school age children.

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## General Practitioners and Healthcare Staff

Responses about GPs were mixed, with some experiences being very positive and others not. In one or two groups, there seemed general disappointment with GPs, mostly due to the lack of time on their part due to NHS pressures and maybe not understanding youth mental health issues well enough. Some felt going to the GP was very daunting.

Cognitive Behavioural therapy (CBT) seemed to always be the option open to them and some felt this was not always beneficial.

Young people told us about difficulties in making urgent mental health GP appointments on the day when they felt they needed to be seen.

There were also comments about other healthcare workers not really understanding youth mental health and gay issues very well. One young person's sexuality was referred to as 'a phase' by a healthcare professional, which was not beneficial to the young person's mental health.

## Parents and Teachers

Some young people do not feel that parents are able to help them with mental health problems due to them not knowing enough about the issues involved. Some feel that teachers do not know enough about youth mental health problems and therefore would not approach teachers for help. More mental health information for parents and teachers may help with this lack of understanding.

Some young people said that starting education about mental health at an early age, might help the situation.

The lack of awareness of youth mental health problems in the general population was discussed.

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## The staff feedback

### Young People who have Offended Service

The young people this team support have far higher rates of emotional / mental health, neurodevelopmental and learning issues. Often, they have social, safeguarding and substance misuse issues too. Many of the young people's behaviour can be better formulated as trauma and attachment driven rather than simply a behavioural issue.

Staff told us that more information needs to be available to young people on problems such as how to deal with aggression, anger and sexually abusive behaviour. The information available is often targeted towards anxiety, depression and self-harm. Whilst these are relevant, young people need information on a wider range of issues. Eight out of nine of the young people from this group noted on the survey that they would like more information on anger management.

The young people in this group often have complex social circumstances that make it difficult for them to access traditional CAMH services. They would be helped by a greater flexibility with appointments to avoid early discharge from services, avoiding the need for re-referral.

### Link to Change (Sexual Exploitation of Young People)

Staff commented that with some CAMH services to young people, the visits for therapy have been too infrequent.

Alongside this, young people can feel that communication can be difficult with repetitive questions and difficulties with trust and forming relationships with therapists, maybe partly due to visits being too infrequent.

Waiting lists can be long, e.g. six to seven months in the Fens. Link to Change work with young people whilst they wait for their CAMHS appointments.

### Young Carers

Youth workers continue to incorporate mental health awareness and well-being into their work. Questions in the statutory carer's assessment look at the impact of caring on the carer's own mental health as well as physical health.

In the one-to-one sessions carried out with 16 to 25-year-old young adult carers, they discuss the individual's own mental health needs, often identified through the young carer's star assessment tool.

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## **Deaf and Hard of Hearing Group**

The Deaf CAMHS waiting time is two-weeks. However, it would be helpful to have more flexibility with appointments with a more open-ended service for this group, making sure there is time after the last appointment to see if issues have resolved, so that the young person can return to Deaf CAMHS without re-referral.

There does not appear to be a texting service for NHS 111 Option 2. This is very important for the deaf community.

## **Spring Common Learning Disabilities Group**

The staff are addressing mental health issues with individuals. They are involving other agencies as needed, e.g. social workers, support workers etc. They have been working on incorporating several ideas around mental health into their curriculum.

## **Clare Lodge (young women's secure welfare placement unit)**

Making sure young people have a good transition when they leave Clare Lodge is a challenge. Ideally, they would like to have the capacity to help build young people's relationships with new services/workers, perhaps even working in an outreach way for a period after discharge. The other barrier to a good transition is that often they will not know when a young person is going until the last minute. This leaves little time to plan a more supportive transition.

There is a real tension at Clare Lodge between the importance of not keeping young people in a restricted, locked environment for longer than they need and the desire to ensure a good period of transition.

Outreach support for the young person would help but they don't have the resources to do this.

## **Roma Gypsies (The Voyager Academy, Peterborough)**

Staff report that getting access to mental health services has always been difficult due to long waiting lists and increased thresholds for referrals. They also have the dilemma of their post-16 students who neither fit into young people's services nor adults' services, hence there is a gap in provision.

It is important to make sure the present work on mental health continues over a long period and that it is not a short-term injection of interest.

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## What has changed since our visits

### Young Carers

They will continue to incorporate mental health into their work with young carers all the time, as they had done previously.

### Deaf and Hard of Hearing Group

The Hearing Centre are trying to make sure that lots of deaf children can come together from all over the county to increase support for one another. The Hearing Centre and Cottenham School are taking steps to connect with The Kite Trust to help support their LGBT students, some of whom are deaf.

### LGBT (Cambridge)

Since our visit, the youth leader now makes time for people to talk about any mental health concerns they may have. She often asks the young people to describe their emotional state as if it were a weather map, e.g. happy might be sunny, upset might be thunder clouds, etc. The young people seem to find this very useful and this gives the youth leader a chance to assess their well-being.

### Spring Common Learning Disabilities Group

The staff are addressing mental health issues with individuals and involving other agencies as needed, e.g. social workers, support workers. This term they have been focusing on the impact of healthy and unhealthy relationships on mental health and wellbeing. This included a performance of Tough Love. Tough Love is a theatre project that raises awareness around coercive control and domestic abuse in teenage relationships. 25 students were involved in this.

They took eight students on a five-day cultural awareness trip to Belgium in March. This has had a huge impact on their self-esteem, well-being and personal development. The year 10 and 11 students have had some workshops around mental health with the support group Centre 33 as part of their Healthy Lifestyles accreditation.

Lastly, the young people we spoke to had a great day in Cambridge during World Book Week, using the Love to Shop vouchers we gave them. They used the guided bus to get there. The day was a boost to their health and well-being!

### Clare Lodge (young women's secure welfare placement unit)

They are discussing introducing education workbooks around physical and emotional self-care that all young people could begin to work on when they arrive at Clare Lodge.

### The Roma Group - The Voyager Academy, Peterborough

Staff said our discussion group was very useful for the young people who took part and has helped improve their understanding of mental health.

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## What we have learned

It is so important to listen to young people from all backgrounds about their needs and wishes and try to integrate these into services. Young people have some great ideas about what could work well for their age group in terms of mental health therapy and education, which should be heard.

### Education

A whole-school approach in educating young people, teachers and parents in mental health would be ideal. It would be useful to:

- Provide more preventative, age-appropriate learning around mental health from an early age. With many mental health problems starting prior to the age of 14/15 an early start makes sense.
- Include how to maximise keeping mentally well with regards to lifestyle choices, appropriate social media use and behaviour.
- Tackle the stigma around mental health.
- Normalise talking about mental health.
- Encourage young people to seek help early for mental health issues.
- Make sure new mental health service information is advertised widely amongst young people as it becomes available.

### Parents and Teachers

- Give school staff mental health awareness training to help them spot the early signs of mental health difficulties in young people. It will give them confidence in how to support children.
- Parent training and educational websites such as MindEd, Young Minds and Keep Your Head need to be well advertised to help parents to better understand young people's problems.

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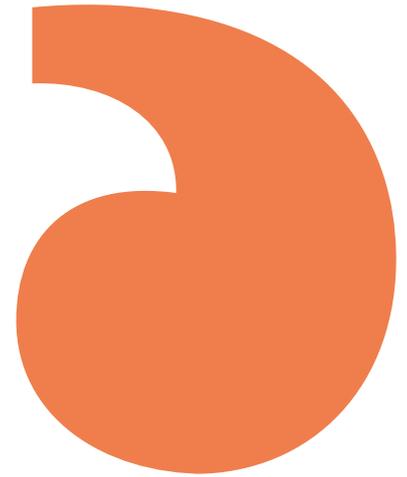
## Services Access

- Mental health service changes need to be distributed to primary and secondary schools, colleges and minority/support groups, who could help in turn to promote them to parents and young people.
- Waiting times for CAMHS are often too long with often no provision of services to fill the gap.
- Appointments are sometimes felt as not being frequent enough.
- Open-ended appointment systems could work better for some young people in more challenging social situations to avoid re-referral and more waiting times.
- It would be useful if there could be strategies in place for enough counselling options available for young people, including those waiting for appointments with CAMHS and for those in transition from children's to adults' services, aged between 17 and 18.
- Using discretion and privacy around access to counselling appointments in schools is important. Some young people do not want others to know about this.
- Young people want a flexible, friendly, casual, face to face approach to therapy and help. The drop-in clinics offer these qualities of service. It would be important to ensure these are widely advertised so young people know that they are available.
- Young people wish to have other therapy options other than talking therapies.
- We would encourage trying to tackle the problems with services that have been highlighted by the staff of groups we have spoken to.

We will be looking to see how this learning is used in the re-design of children and young people's mental health services.

## Acknowledgements

It has been a pleasure to work on this project with these young people. We would like to thank them all very much for their wonderful contribution and honesty within our discussions and in answering our survey questions. We appreciate it very much indeed.



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