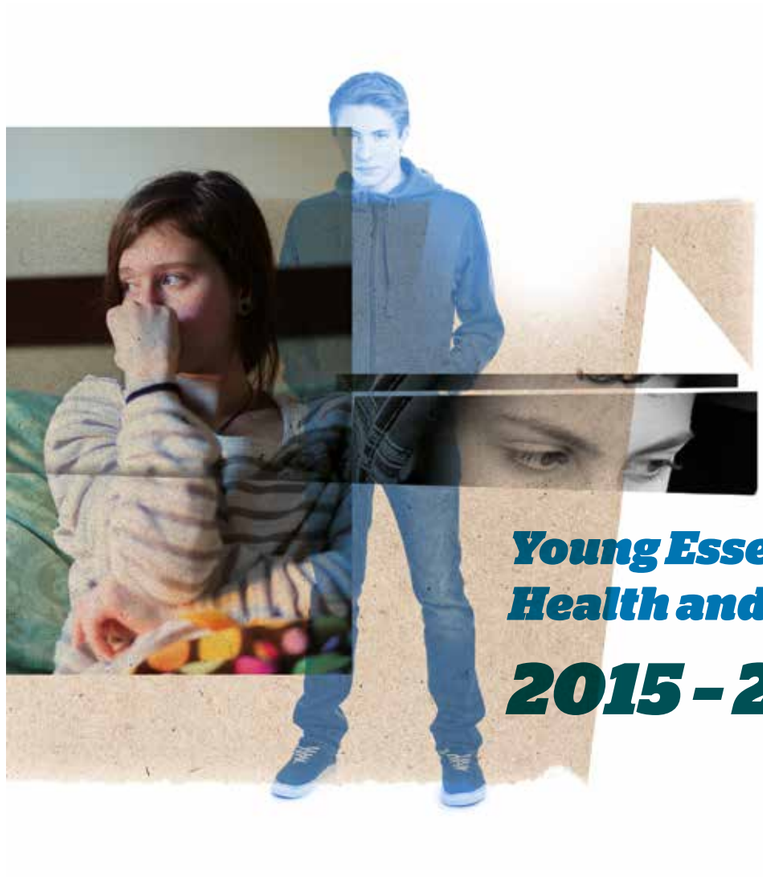
#EssexYEAH!

YEAH!2 report



# Young Essex Attitudes on Health and Social Care

# 2015 - 2016

Hannah Fletcher

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# Foreword

**By Jessica Valentine-Howard YEAH! 2 participant**

During my 3-week adventure attending NCS, Healthwatch Essex came to talk to me and my peers, which was helpful on many levels.

I particularly liked the format – the small groups made it easier to speak about personal experiences and not worry about what other people think.

It was also really helpful hearing information about the topics we spoke about, and so in that respect the experience was quite educational too.

With the increased workload and exam stress that pupils experience, anxiety and depression levels are sky rocketing in our age group – I know this just because I talk to people studying alongside me. Family life, deciding what to do after school, and the stresses of exams can all tip people over the edge. In my personal experience of talking to others, this is when people my age can turn to alcohol and drugs, or in some cases self-harm.

A topic that was discussed a lot, during the session I had with Healthwatch Essex, was mental health. I, and some of my peers, strongly believe that mental health is not spoken about enough. People need to be educated on mental health, and the services they can use to get help. This is something our group spoke about, and all agreed that this needs more attention.

These are the issues people my age are dealing with and trying to get through. Therefore it's important that young people know there are services they can go to, and people they can trust. Healthwatch Essex speaking about services I didn't know existed was helpful, and will go on to affect others.

I really liked the fact that while we were being asked questions, our answers were clearly cared about. We all took it a little more seriously, and some opened up more about their personal experiences, because we saw that sharing our experiences could go on to make a difference.

***A guide to health and well-being for young people***

***If you want more information visit our essexyeah website for a guide to health and well-being for young people***

***www.essexyeah.org.uk***

Design: www.lowenhoff.co.uk
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## Abbreviations

**A&E**
Accident & Emergency department
**CAMHS**
Child and Adolescent Mental Health Services
**CCG**
Clinical Commissioning Group
**EWMHS**
Emotional Wellbeing and Mental Health Services
**GP**
General Practitioner
**NCS**
National Citizen Service
**NELFT**
North East London NHS Foundation Trust
**NHS**
National Health Service
**OCD**
Obsessive Compulsive Disorder
**PSHE**
Personal, Social, Health & Economic Education
**SWEET!**
Services We Experience in Essex Today
**YEAH!**
Young Essex Attitudes on Health and Social Care

In March 2015, Healthwatch Essex published the first YEAH! report,[1] highlighting over 400 young people's lived experience of health and social care across the county. YEAH! went on to achieve local and national impact, showing the positive influence high quality engagement can have. Dr Lisa Harrod-Rothwell, Medical Director for the North and South Essex Local Medical Committees said of the YEAH! report:

***"Our members felt that greater GP awareness and reflection of the issues highlighted within the report could support changes in practice and improve the care and experience of children and adolescents. Therefore, the Committees recommended that this report be sent to all GPs in Essex for discussion within our Practices."***

# Introduction

The YEAH! report was also used to inform the 'Open Up, Reach Out' mental health transformation plan for Essex,[2] the Youth Select Committee's national inquiry into mental health services for young people,[3] and Healthwatch Essex's own online guide to health and well-being for young people: essexyeah.org.uk,[4] as well as being presented as evidence of best practice to the Health Select Committee. Following on from this work, Healthwatch Essex was approached by West Essex CCG to undertake a countywide scoping exercise on engagement around Child and Adolescent Mental Health Services (CAMHS), to inform the recommissioning of the new Emotional Wellbeing and Mental Health Services (EWMHS).

Recognising the impact the lived experience of YEAH! participants had, Healthwatch Essex returned to the National Citizen Service (NCS) in summer 2015 - this time focusing in more detail around our mental health and A&E findings. Having produced the SWEET! report,[5] we also decided to ask participants about their lived experience of social care.

Working in partnership with NCS providers for Essex, Essex Boys and Girls Clubs and Essex County Council, we engaged with 865 young people that were both geographically and socio-demographically representative of our county.[6] This has allowed us to form a snapshot of young people's lived experiences of mental health, social care, A&E, additional services, and how young people access health and social care information.

Our hope is that YEAH! 2 will continue to positively influence health and social care decisions in our county, while continuing to show the value of effective engagement with young people.

**1** Healthwatch Essex (2015) 'YEAH! report: Young Essex Attitudes on Health and Social Care.' Essex: Healthwatch Essex

**2** Collaborative Commissioning Forum for the Emotional Wellbeing and Mental Health of Children and Young People in Southend, Essex and Thurrock (2015) 'Open Up, Reach Out: Transformation Plan for the Emotional Wellbeing and Mental Health of Children and Young People in Southend, Essex and Thurrock.'

**3** Youth Select Committee (2015) 'Young People's Mental Health.' London: British Youth Council

**4** Healthwatch Essex (2016) 'A guide to health and well-being for young people.' http://www.essexyeah.org.uk

**5** Healthwatch Essex (2016) 'SWEET! report: Services We Experience in Essex Today.' Essex: Healthwatch Essex

**6** NatCen Social Research (2013) 'Evaluation of National Citizen Service.' London: NatCen Social Research: p. 20

In the first YEAH! report, Healthwatch Essex devised the **Explain, Empower** and **Enjoy** principles that we believe underpin successful engagement with young people. Here is how we adapted them for use in YEAH! 2.

# How we engaged

**Explain**
We wanted to ensure participants felt that sharing their lived experience with us would be worthwhile, and so we explained how Healthwatch Essex aimed to gather and represent their experiences in a meaningful way. We spoke about the impact the YEAH! report had already achieved, and how we would continue using young people's voices to influence positive change. We also explained why we had chosen to focus on the particular topics covered in YEAH! 2, allowing participants to understand why their lived experience around sometimes difficult topics were useful.

**Empower**
Making participants feel comfortable in sharing their lived experience was paramount to the success of our engagement. Therefore, we spoke to the young people in their NCS cohorts where they had already formed friendships and felt comfortable sharing their experiences. We also gave young people the option to share their experience privately through written feedback forms, which provided the quotes used in this report.

Sitting in circle formation meant everyone could be seen and heard, and we gathered the data that formed our statistics by counting a show of hands. These focus groups were informal, and when topics were introduced we spent as much or as little time on each topic as the young people wanted, allowing them to drive our discussions according to their own priorities. There was also scope for young people to talk about other topics important to them, such as GPs, hospitals and sexual health.

As YEAH! 2 had a focus on social care, we worked with our partners from the SWEET! report, Achievement Through Football (ATF), who are experienced in engaging young people around their social care lived experience. We partnered with NELFT, who provide the EWMHS service in Essex. This allowed young people to share their feedback on mental health services directly with the new service provider, as well as ask questions of what could be expected from the new service itself.

**Enjoy**
Engaging around topics which can be serious, and at times difficult, can still be an enjoyable experience for young people. Where we could, we sat outside on the grass or in the sunshine based on what the young people themselves wanted to do, and we also used creative activities such as mind mapping. The more the young people enjoyed the session, the more engaged they were, and it was important for us to show them we were interested in them and their lives, and did not simply view them as participants in our study. We ate lunch with them, spoke to them about their hopes for the future on GCSE results day, and made sure we were there to answer questions during and after sessions, as well as signposting them to relevant services for their queries or concerns.

# Key findings

**Awareness**

*The young people consistently felt they needed more information about health and social care topics and services, in order to manage their own care and to support others.*

**Although 7 in 10 participants had not received information on mental health, 9 in 10 participants felt being informed about mental health was important.**


6 in 10 participants wanted to learn about social care topics and services for a range of subjects such as abuse, disability, being a young carer and homelessness.

Participants told us that a lack of awareness created stigma around issues such as mental health and social care, which could lead to bullying or isolation. For many young people, this meant they avoided seeking support, but felt a raised awareness could help to overcome stigma.

***6 in 10 YEAH! 2 participants had used A&E, but less than 1 in 10 had used 111 or a walk-in centre, with most being unaware of these services.***

### Consistency and Compassion in Care

**Patient experience was key to how positively young people felt about their care, with young people placing great importance on feeling informed, listened to, and able to make choices about their care.**

Across topics, we learned that inconsistent care caused young people to feel that they were not listened to, or seen as important enough. This was particularly true of young people's experience of social workers.

YEAH! 2 participants seemed aware of increased pressures on those working in health and social care, and the impact this could have on the recruitment and retention of professionals. However, they recognised that consistent and compassionate care was crucial to them and their families in getting the best possible outcomes.

### Transition

***Across topics, YEAH! 2 participants expressed feeling that services did not fit the needs of their age group.***

Young people spoke about the anxiety of reaching the age of 16 or 18 and having to transition out of children's services before they felt ready, or without being sure of what care they would be entitled to.

Participants felt that services regarding them as children could be patronising, with professionals "speaking down" to them, or addressing their parents rather than them.

**On the other hand, participants felt that entering adult services could mean they felt treated as much older than they were, with professionals using complex terminology that could be confusing.**

# Recommendations


**High Quality Engagement**

YEAH! 2 has demonstrated the value of using a high quality model of engagement that young people find empowering and enjoyable. It was important that participants had the opportunity to discuss the topics that mattered the most to them, and felt their contributions were valued and taken seriously. This high quality engagement has allowed Healthwatch Essex to form a rich snapshot of the health and social care lived experience of 865 young people from across the county.

We recommend that commissioners and providers ensure young people's lived experience is embedded in the planning and delivery of services, through utilising the results of high quality engagement. The New Economics Foundation reports: **"Not all resources are financial. Children, their families, and their communities have time, knowledge, skills and networks that can play a vital role in designing and delivering services."**[7] YEAH! 2 found that young people have the time, experience and enthusiasm to engage with discussions on services, providing they feel confident their voice will be taken seriously, and used proactively.

**Raising Awareness**

Young people consistently expressed a need for more information across the range of topics we discussed. As services increasingly focus on the value of early intervention, young people are keen to be informed on issues and services in order to take steps towards managing their own health and social care. Equipping young people with the knowledge they want will enable them to seek support early on, supporting models of prevention and early intervention that services are moving toward. 'A guide to commissioning children's services for better outcomes,' says that **"By making the transition to a more preventative system, the UK will improve children's well-being, create a better and more just society, and support our economy by being less wasteful economically and making far better use of our sacred public resources."**[8] A key example from YEAH! 2 shows these issues at play: less than 1 in 10 had used a walk-in centre or 111, largely due to being aware of these services, yet 6 in 10 had used A&E.

YEAH! 2 participants wanted to access this information in school, or through credible sources. Healthwatch Essex worked with CCGs and services to produce an online guide to care for young people, based on the information they told us they wanted. Essex YEAH! can be found at www.essexyeah.org.uk.

Healthwatch Essex recommends that health, social care and education services take a joined up approach to raising awareness among young people around the topics they tell us they want to be informed about.

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**Investment in the Workforce**

Young people wanted to feel that their care was consistent, empathetic, and appropriate for their age. The largest contributor to a positive experience in health and social care was good patient experience with staff.

Participants recognised that there can be immense pressures on staff which could lead to inconsistent care. This resulted in feeling as though they weren't listened to, or that their problems weren't considered important enough. These feelings were exacerbated for participants with experience of Children's Services, who felt let down when social workers changed frequently, or couldn't visit very often.

Healthwatch Essex understands that health and social care staff face increasing pressures and workloads, which can lead to stress and dissatisfaction, and, in turn, result in vacancies arising within organisations. We recommend that professionals remain sensitive to the fact that the young people they work with may feel distrusting or disengaged due to experiencing a high turnover of staff working with them. We also recommend that commissioners and providers invest in solutions that recruit and retain staff who are passionate about providing high quality care to young people at a time when increasing pressure and workloads can discourage people from the sector.

YEAH! 2 also found that professionals working with young people, such as GPs and teachers, are not always aware of existing services that can be signposted to. Participants told us these professionals were often the first people they would approach about a difficult issue, but that they did not always get the outcomes they wanted or needed. We therefore recommend that commissioners and providers raise awareness among professionals of the issues young people can face, and the support that can be accessed.

**A Personalised Approach to Care**

YEAH! 2 participants commonly spoke about how services were designed for children or adults, which meant their needs were not always met. Young people often voiced frustration in feeling patronised by services, but also expressed anxiety about the uncertainty of transitioning into adult services before they felt ready.

The Youth Select Committee has acknowledged that "young people progress at different rates and will not always be ready to move to adult services at 18," naming good transition practices to include extending child services to age 25, deciding age of transition on a case-by-case basis, or providing services such as adolescent rooms for 16 – 18 years which bridge gaps to adult services, saying "we are clear that the outcome should be that no young person is forced to move to adult services until they are ready."[9]

QualityWatch says "A study on arrangements for the transition between child and adult services found that young people and their families often struggled with a lack of information, support or services available to meet their complex needs."[10]

We recommend that commissioners and providers consider taking a personalised approach to care where possible, acknowledging that every young person progresses differently. It seems that flexibility, as opposed to a definite "cut off point," would be effective in ensuring services suit the needs of the individual, and services should work with young people to ensure they are clear about the details of their transition and the support they can expect to receive.

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**7** nef (2015) 'A guide to commissioning children's services for better outcomes.' London: nef: p. 9

**8** nef 'A guide to commissioning children's services for better outcomes.' p. 1

**9** Youth Select Committee 'Young People's Mental Health.' p. 11-12

**10** QualityWatch (2015) 'Closer to critical?: QualityWatch Annual Statement 2015.' QualityWatch: London: p. 27

In the first YEAH! report, young people told us that mental health was a key priority for their age group, with 8 in 10 participants unaware of how to access support, or having ever received any information on the topic.[11] Therefore, we decided to return to mental health in YEAH! 2, to find out more.

# Mental health

We asked YEAH! 2 participants about their lived experience of mental health, and the information they wanted to receive. In this section of our report, we draw upon the Youth Select Committee's findings from their 'Young People's Mental Health' report that examines these themes at a national level.[12]

**Experiences**

Over 4 in 10 participants spoke about mental health issues that they, or someone they knew, had experienced. Most commonly, people told us about depression, anxiety and self-harm. Other issues experienced included stress, eating disorders, bipolar disorder, and schizophrenia.

"I have constantly, over the past year, fought suicidal thoughts due to simple things or objects being out of place. The mind set I have is of a perfectionist, and I have mild OCD [Obsessive Compulsive Disorder] making the situation worse. I have overcome this by helping a friend of mine cope with their own suicidal thoughts. I would never actually kill myself because my mind can't fathom the distress, mess and emptiness I would leave behind. I got over it in my own time with little need for outside help, but I wish the thoughts and OCD wouldn't occur."

7 in 10 participants who spoke to us about these mental health problems told us they had approached a service for support. Half of this number went on to receive treatment or support through counselling, medication, inpatient care or pastoral support in education, though for many we were told there had been no follow-up, referral or treatment.

While it should be encouraging that almost three-quarters had tried to access support for their mental health, it was clear that positive outcomes weren't always achieved.

**Accessing Timely Support**

The overarching feedback on mental health services was that they were too slow, from trying to get a referral through to accessing treatment. Participants sometimes had long waits to get support, or had to make numerous attempts in order to feel their problem was being taken seriously, and addressed.

"The support took far too long, and required too much work to get. It isn't given to everyone who needs it."

"My younger brother has depression, and is very lonely. He has had problems for ages and has been bullied. He no longer goes to school, and shuts himself in his room all day. He's had problems since he was a toddler, and things are only just getting sorted. I just don't think the services are good enough, or quick enough to help."

The concern was sometimes that during the wait for support or acknowledgement, a young person's mental health problems could become exacerbated. As some participants told us:

"I suffered from constant and regular breakdowns, I tried to get help but I'm usually ignored. In my eyes, this has led to a lot of issues in my life, currently."

**11** Healthwatch Essex 'YEAH! report.' p. 21

**12** Youth Select Committee 'Young People's Mental Health.'

"I was diagnosed with OCD, Tourette's Disorder, depression, anxiety and a sleep disorder. For a while I was not believed or taken seriously, which made it worse as well as harder to trust people. When I was finally admitted to a service it took a long time before treatment."

"Doctors and counsellors always make me feel like they have no time for me. Mental health gets overlooked and isn't taken seriously. It took 4 months to start therapy, and at that point I was suicidal."

These findings reflect national issues, as QualityWatch writes: **"Waiting times for outpatient children and adolescent mental health services (CAMHS) have increased, and young people and their parents have described "battles" to get access to this vital service."**[13]

YEAH! 2 indicates that it isn't the case that young people aren't trying to access support for their mental health, it's that they are often attempting to access support but aren't always getting the outcomes needed.

In the worst case scenario, an individual who does not access timely support could reach crisis point. 6 individuals spoke of a relative who had committed suicide, in some instances because they had not sought help for their illness.

"My dad had depression badly for the last 3 years of his life. He didn't get it treated or look for support; the result of this is he has passed away."

As the Youth Select Committee has said: "Untreated mental illness can have an adverse effect on young people's education, physical health, life-chances and life expectancy. In extreme cases, it can lead to self-harm, harming others and suicide – one of the leading causes of death amongst adolescents. A pilot study report in 2006 said that the majority of children who commit suicide have not had contact with mental health services."[14]

Therefore, it is important that young people take care of their mental health, and seek support when they need it. For them to do this, they need to feel assured that they will be listened to, taken seriously and can access timely support, or at least that their expectations of waiting times and referral criteria are managed.

**Awareness**

More than 7 in 10 participants told us they had never received any information about mental health.[15]

Of those who had, half had learned through classes, enrichment days or promotional materials in school or college. However, more than half of this number felt they still needed more information.

"A drama project ran some sessions about mental health after school, but only a few people got to go. I think there needs to be a lot more awareness about mental health so people know they're not alone, and know how to help friends who are struggling."

"Assemblies kept the school informed about mental health. Assemblies don't get people involved, however, and it's difficult to speak up without feeling embarrassed or ashamed."


Half of YEAH! 2 participants had read about mental health through their own online searches, with others getting mental health information through personal experience, or from fictional or non-fictional TV programming. Because this information is not guaranteed to be adequate or credible, young people need reliable access to the information they are looking for.

Almost 9 in 10 participants felt it was important to learn about mental health in school and college, with many feeling that school is where many mental health issues begin.[16] The young people often felt that their age group was particularly susceptible to stress, self-harm and eating disorders.

"I went through a very bad stage where I had feelings of anxiety which lead to crying every night, and self-harm. I had no one to speak to. So I think there needs to be more advice on symptoms of anxiety and depression, and more help without it being scary or patronising."

Participants often told us they knew someone with mental health issues, but did not know how to support them. This had been distressing in times of crises, such as self-harming, panic attacks and suicidal ideation.

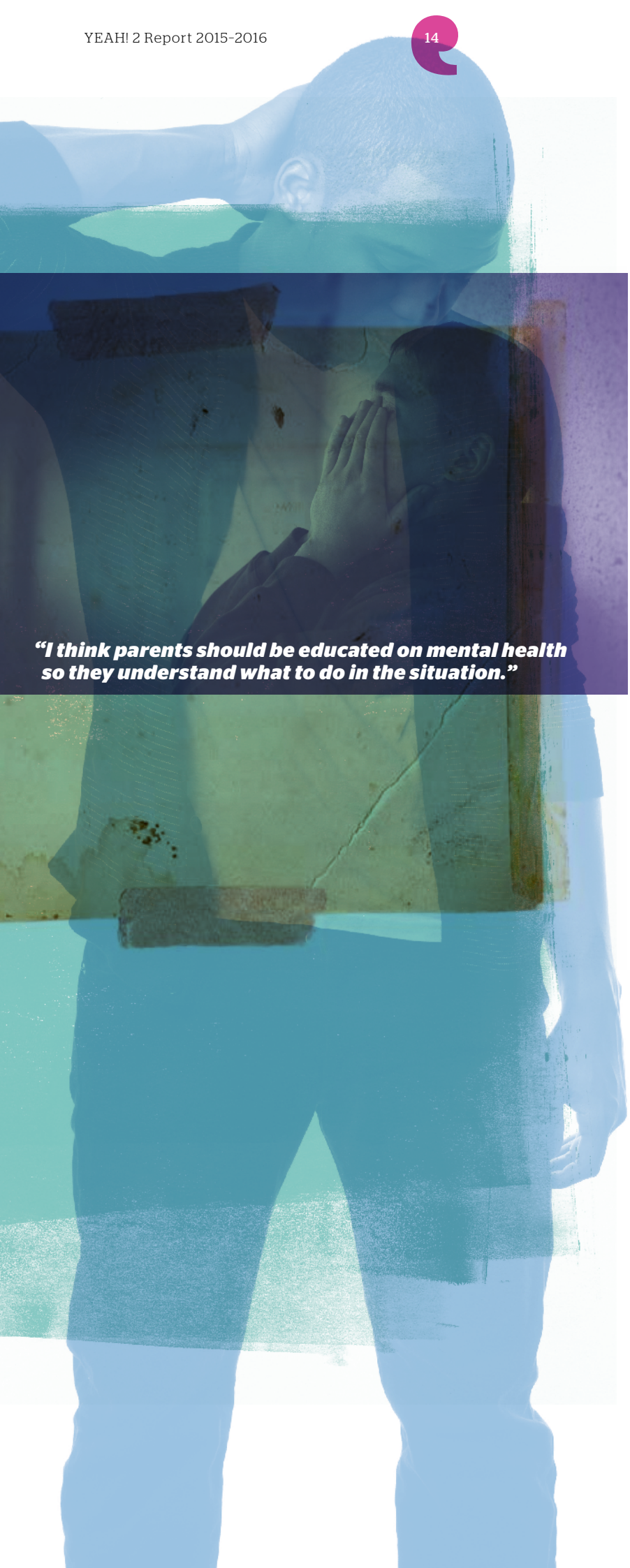
**"I have many friends who have mental health problems. I found that as a friend there was no information or help in order to understand what they were going through, or to support them. Only one from a large group was referred to a mental health service, and for others it wasn't considered an option."**

**13** QualityWatch 'Closer to critical?' p. 8

**14** Youth Select Committee 'Young People's Mental Health.' p. 19

**15** Healthwatch Essex 'YEAH! report.' p. 21

**16** The Youth Select Committee reports that "more than half of all mental ill-health starts before the age of 14." Youth Select Committee 'Young People's Mental Health.' p. 2




The Youth Select Committee recommends that **"Young people should leave school with a good level of understanding of mental health. This should include the ability to understand and develop their own mental wellbeing; how to support friends or family members; understanding that mental health is as important as physical health; and knowledge of how and where to seek help."**[17]

"I went through a really rough time and got really depressed. I felt really ill, sick and always upset. Then I opened up to some friends. But I didn't really have someone to talk to – I just didn't want to open up about my emotions. I wish I had known I could make my own appointment where everything I said would be confidential."

Some participants also wanted to know how to be proactive when a friend was experiencing crisis. Support from peers was valuable to young people, and often reported to be an influential factor in stopping harmful behaviours.

**"I've spoken to 3 friends who have self-harmed – for 2 I was the first person they told about it. I was able to talk to them, and it helped a lot. Both no longer self-harm (and the other one had received professional help which sorted it), and they thanked me for being there when they needed someone to talk to."**

Participants also wanted education for teachers, employers and parents on mental health. They wanted the adults whose care they were in to know how to spot mental health problems, and deal with them appropriately.

**"I think parents should be educated on mental health so they understand what to do in the situation."**

"Luckily, my friends told the school teachers who were informed about my family situation and got me help. I think schools should strive to be informed about their pupils' family situations and ensure anyone effected by someone's problems is checked and supported."

The Youth Select Committee has said:
"We also believe that those working with young people, chiefly GPs and teachers, need to have the appropriate level of training and guidance to support young people and signpost them to the right services."[18]

**Services**
Nearly 6 in 10 told us they did not know who they could approach if they, or someone they knew, experienced a mental health problem.

Those who had approached someone to discuss their mental health had most commonly contacted a member of staff in school, or a GP.

**Counselling**
Participants who shared their experiences of counselling told us it had been most helpful when they felt comfortable with their counsellor and gained effective coping mechanisms.

"I was referred to counselling by my school and it really helped build my confidence, although this help came late."

"My girlfriend lives in a foster home and finds counselling very effective when dealing with issues."

These young people valued feeling that services and professionals listened to them, and took their problems seriously.

Some participants told us their counselling sessions had been unhelpful, due to a number of factors such as feeling that Cognitive Behavioural Therapy (CBT) was not the right approach for them, being referred from one counsellor to another, and not feeling able to confide in their assigned counsellor.

"I went to counselling at 3 different places. It didn't really help because they didn't understand me."

"I've gone through a variety of therapists, and they all refer me on. I wish they hadn't kept passing me on, and had taken me seriously."

Perceiving services as inconsistent or impersonal often caused disengagement from services, and therefore a continuation or deterioration of the mental health problems young people experienced.

**Support in School**
Young people seeking help for mental health issues most commonly approached a GP, or a member of staff at school. Several participants told us of positive experiences of approaching school staff, feeling the person they spoke to did their best to help, took them seriously, and referred them to the relevant service.

"A student at our school started storming out of classes and having angry episodes. He'd come out as gay and his parents and other students had not received the news well, which caused him to become depressed. The head teacher made contact with his parents and they met together regularly. The boy was referred to counselling, which seems to have helped and has made him feel better."

**17** Youth Select Committee 'Young People's Mental Health.' p. 17

**18** Youth Select Committee 'Young People's Mental Health.' p. 2

"I self-harmed for 3 years and my high school was helpful... especially the head of year who made it clear who you could talk to, and that free counselling services existed."

However, some felt that pastoral care did not treat mental health issues appropriately which could mean being removed from the classroom, and treated differently to others. Participants said this could feel like being punished for having a mental health problem.

The Youth Select Committee has said: "For schools to deliver a whole school approach to mental health, the professionals working there must have a basic understanding of young people's mental health. However, the evidence we have received shows that the current level of understanding is poor and inconsistent ... The teachers who gave evidence said that 'mental health awareness very rarely happens' and 'we need more regular training on how we promote positive mental health.'"[19]

School counselling was sometimes perceived by participants to be more helpful than counselling taking place externally.

"My school counselling sessions allowed me to believe in myself, and tell those I love what's affecting me. It was great to feel listened to, and not intimidated."

"I used to self-harm, but I spoke to a teacher who got me counselling in school. It helped me talk about how I was feeling and the reasons behind it, which makes it easier to deal with."

However, some participants explained the feeling of being "stuck" if they didn't get on with their school counsellor, feeling there was nowhere else to access support. Others felt school counselling services could be "patronising," and not appropriate for their age.

The young people often told us that they were unsure if their school provided a counsellor or that their school had once provided a counselling service, but no longer did.

"My school counsellor helped until the sessions were cancelled."

"Someone used to be there to talk to about anything you wanted, but she isn't there anymore."

The Youth Select Committee has said: "the British Association for Counselling and Psychotherapy said that school-based counselling offered effective and accessible treatment to young people with mental health problems. They advocate for counselling services in every school to give pupils easy access to a trained and trusted counsellor."[20]

**Medication**

Some participants spoke about their experience of being prescribed medication for mental health problems. Interestingly, most of these participants told us they hadn't been aware of the side effects, and had stopped taking their medication when side effects presented.

"They should check the side effects before prescribing medication."

"I have ADHD [Attention Deficit Hyperactivity Disorder] and I'm on some tablets to help me concentrate more. It helps a lot, and helped me concentrate in my exams. I wish I'd been diagnosed earlier."

Some participants who wanted to try medication reported being told they were "too young", whereas others had reluctantly accepted medication after giving up on waiting to be referred to counselling. Some felt medication was presented as the only option:

"I was told nothing could be done apart from anti-depressants. I refused to take them, so I was sent home. There should be a better solution!"

It was interesting to discover that participants in general seemed to hold a negative view of medication as a form of treatment, with many claiming they would refuse a prescription. Medication is not the only form of treatment for mental health problems, but it seems there is a stigma attached to considering it as a solution. This was an area many young people were interested in finding out more about.

It seems a greater communication around medication, as well as other available treatments, would benefit young people who want to make informed choices about their treatment. Those who had not been informed about the side effects of their medication disengaged with treatment, which could mean their mental health problems continued, or could deteriorate.

**Inpatient Care**

Several participants spoke to us about their lived experience of needing, or knowing someone who needed, inpatient care for their mental health problems. For some, attempts to get into inpatient care had not been successful.

"I was referred to hospital with an eating disorder. My private information was lost, and I never heard back from them."

"A family member with severe depression could not be admitted for inpatient care because there was a shortage of beds. This was a risk to her health, and the private cost of inpatient care was unaffordable."

"The hospital did its best to accommodate our needs, but there was no room. Private healthcare is too expensive. I think there should be spare beds for emergencies."

Other participants who experienced care as an impatient told us they felt they were discharged before they had recovered, and that group therapy taking place in inpatient services was impersonal and unhelpful.

Another participant praised the kindness and efficiency of staff when his brother was admitted to a mental health ward, but felt that overall the service was under strain:

"My brother was diagnosed with psychosis and had to spend some time in a mental health hospital. The mental health section of the hospital was quite small, and seemed quite unorganised and understaffed. They acted very fast when my brother was taken in, and dealt with him well and with kindness."

Participants mainly told us that inpatient care was difficult to get into when needed, and discharge could feel rushed. Young people told us it was important that those who reached crisis point could get the treatment they needed, and be cared for in safety. The concern was that being unable to access this support could place the patient, and those around them, at significant risk.

**19** Youth Select Committee 'Young People's Mental Health.' p. 18

**20** Youth Select Committee 'Young People's Mental Health.' p. 20

***"I've been diagnosed with depression, but the first time I went to the GP they told me it was just hormones, and I didn't feel I was cared about. If it had been picked up at this point I don't feel I'd struggle like I do now."***

**Child and Adolescent Mental Health Services (CAMHS)**

In 2015, CAMHS was recommissioned, and is now known as the Emotional Wellbeing and Mental Health Services (EWMHS) in Essex. The experiences reported below took place before the new service went live on 1st November 2015.

7 participants told us CAMHS had been helpful for reasons such as teaching them to manage their mental health and building confidence.

"They've been so supportive, and have given me confidence in living with Tourette's. I only wish that more young people could have mental health treatment."

"CAMHS is very helpful and gives good advice."

We spoke to one person whose sister had entered as an inpatient into CAMHS voluntarily, but would be sectioned if she left. At the time of our study, the participant's sister was turning 16 and a conversation was approaching where professionals would determine if she would remain a CAMHS patient, or transition to adult mental health services. While the participant and his parents didn't feel his sister was ready to be discharged, he was pleased that CAMHS encouraged her to return home at weekends so she wouldn't become reliant on the service. He thinks that CAMHS is currently the best place for her.

Others felt the service they received had been inconsistent, with some feeling the service "left" them to cope alone.

"I was referred to CAMHS, but all they did was bring up my past and leave me again. Nothing was resolved, and they don't see you outside of sessions when you're having a "down" moment."

"I was referred to CAMHS for an eating disorder and found staff unhelpful, not understanding of me and discussing things irrelevant to my recovery. In the end I put the weight on by uncontrollably binge eating, and dealt with the depression and anxiety myself, feeling that no one could help."

We are pleased to say that NELFT, the new provider of EWMHS, took part in the YEAH! 2 study and listened to the participants' feedback about the positive and negatives of the former service, with the intention of embedding young people's lived experience in decisions made in the new service.

**GPs**

A GP appointment was the starting point for many young people in their attempts to access support for their mental health. We were often told that it felt as though doctors didn't take mental health in young people seriously, which had prevented some participants from accessing the support they felt they needed, which could lead to problems becoming more complex or exacerbated.

"I've been diagnosed with depression, but the first time I went to the GP they told me it was just hormones, and I didn't feel I was cared about. If it had been picked up at this point I don't feel I'd struggle like I do now."

Other participants felt their GP did not seem aware of the range of support available, which left them feeling there was nowhere to turn to manage their mental health problems.

"They could have given me a number to ring, or a place to go, if my depression got worse. They could have told me options to help me, like therapy. Because my issues are serious I felt they could have listened, and asked if I needed someone to talk to."

"My GP told me I was unlikely to get counselling. I feel like I was not told about medication, or any other support, nor was I diagnosed. I was not told about CAMHS, and the doctor struggled to tell me about other services that were available. In the end I paid for therapy."

Young people placed an emphasis on the importance of kindness and empathy from healthcare professionals. Mental health can be difficult to talk about, and young people felt they weren't always dealt with appropriately after taking the step to seek help.

"During the appointment I didn't feel the doctor was sympathetic to what I was going through. It was hard to deal with the fact I was prescribed medication and referred to a mental health unit. I think more compassion and empathy should be in place regarding matters of mental health."

"Doctors aren't approachable or easy to speak to. When I was getting referred to counselling the doctor made me feel like she was judging me."

As the Youth Select Committee have said: "A young person's experience of speaking to their GP is not just about the GP's professional knowledge but also about how they treat young people."[21] Negative experiences with healthcare professionals could prevent young people from seeking support in future.

Participants told us of positive experiences when a GP had provided effective medication, referred them to a relevant service, and explained their mental health in a way that helped them understand their issue.

"They listened to me when I explained myself, and helped me find what was best for me."

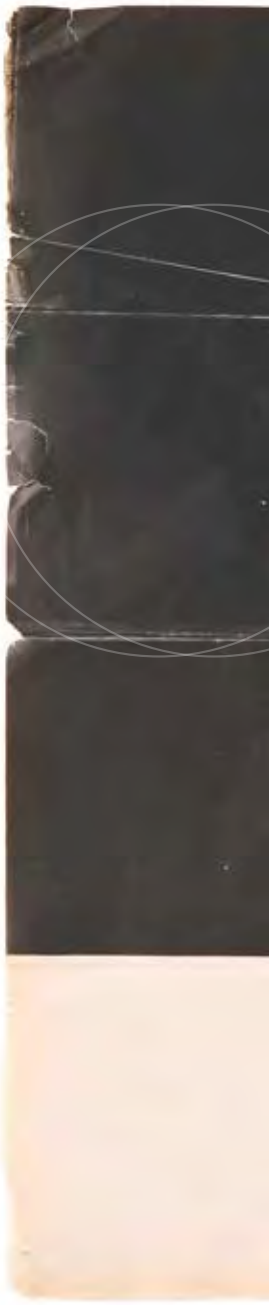
"I went to the GP to discuss anxiety; it helped me understand what was wrong and learn more about it, though it would have been good to have been offered other services to use for support."

As a visit to the GP is often the first step in dealing with a mental health problem, it is important to young people that they will be treated with empathy, and given the relevant information to help them decide the best course of action. The Youth Select Committee has said: "Approaching a medical professional for support with a mental health problem should not be a traumatic experience. GPs should be trained to recognise when a young person has a mental health problem and have the right knowledge to understand how to signpost them to the right service."[22]

**Peer Support**

It became clear that many young people rely on support from their peers when facing mental health issues. Through YEAH! 2 participants, we learned about unofficial peer networks the young people had set up amongst themselves, and the positive influence supportive friends could have on one another.

"My friend used to self-harm, but now she doesn't. We support her and she knows we're here for her!"



**21** Youth Select Committee 'Young People's Mental Health.' p. 13

**22** Youth Select Committee 'Young People's Mental Health.' p. 13

***"Doctors aren't approachable or easy to speak to. When I was getting referred to counselling the doctor made me feel like she was judging me."***

Participants discussed talking their friends out of suicide, supporting them to stop self-harming and trying to make friends feel happier. This could sometimes be a burden on young people, with one reporting he barely slept for a week so he could ensure his friend did not harm herself. As well as this, the young people were aware that the support they could give each other had its limitations, as they were not professionals.

"It was good I had others I could rely on, but it would have been better if I'd known I could approach my doctor."

"My friend has a mental health issue. All I can do is try to stop him thinking about it and try to make him happy. I think I helped him; he has stopped self-harming. It would be better if there was someone else for him to talk to."

The young people also told us that "mental health issues come in waves", and could often affect several in a friendship group as opposed to just one individual (for example, if one person began self-harming it was likely that others in their peer group would follow). Therefore, some cohorts of friends had set up their own unofficial support networks on a weekly basis to discuss their issues and support each other.

While the support of friends and family can have a positive impact, the level of care young people can provide to one another is not of a professional standard, and does not come with the necessary safeguards. Young people also described a "knock on effect," explaining that the suicide of a relative, or supporting a friend or relative with mental health issues, had negative consequences on their own physical and mental health. Therefore, while peer to peer support is valuable, young people need an awareness of the appropriate services, and the confidence that these services will treat them effectively, and with empathy.

The young people's enthusiasm around this topic, and willingness to help those they care about, is a great opportunity to inform them of services: not only so they can signpost their peers, but to alleviate the pressure of supporting someone with a mental health problem.

**Stigma**

A quarter of participants were concerned about the stigma surrounding mental health issues which could lead to bullying, isolation or accusations of attention-seeking. This stigma was often evident when self-harm arose in discussions, with some participants stating that self-harm was "a trend," or a method of seeking attention. For some participants, this meant hiding their mental health problem and avoiding seeking help.

"My mum died in front of me in a car crash. I get depressed, but my nan is strict and doesn't like the fact that I do, so I have to handle it myself."

"I have a mental health issue – depression. I decide to keep this to myself and my best friends as I do not have the courage to talk to anyone about it. I talk to my friends; they're the ones who help me and their service is appreciated, but it isn't professional. I don't believe things will be better."

This stigma could sometimes be greater for male participants, who told us it was more difficult for them to ask for help. This was attributed to pressures of being "masculine" and the expectation for males to conceal their emotions. They were concerned that asking for help would appear "weak," and lead to bullying and gendered/homophobic slurs.

"I experienced bullying at school, which lead to self-harm and other serious incidents. I had people in school I could talk to, but nothing serious happened – no action was taken against the bullying. When people found out about the self-harm and other things the bullying continued."

***"It was good I had others I could rely on, but it would have been better if I'd known I could approach my doctor."***

"I know friends and family who have mental illnesses. My friend self-harmed and many people didn't tolerate it thinking it was for attention. I think more advice could be given, as mental health has a stigma around it."

The impact this stigma had was evident, with participants often being concerned that their school would share a mental health problem with their class, or contact their parents. In some instances, this had been the case, which resulted in further disengagement and feelings of isolation. Participants were also concerned that stigma surrounding mental health issues would have an impact on their employability, as there was uncertainty about what they would be expected to disclose to potential employers – again having prevented some young people from seeking support.

Participants also cited stigma as the reason for using online resources to get information about mental health, because they could be anonymous.

Education was shown to play a part in breaking down the stigma surrounding mental health, as one participant recalled:

"In PSHE [Personal, Social, Health and Economic education] they encourage us to think about the issues that surround us. A lot of girls at school have mental health issues and it's important for everyone to understand and respect those issues. People say it's just attention seeking, but PSHE taught us it's more than that. A woman came in and taught us about self-harm and suicide. It was really informative, relevant and direct information."

Almost half of YEAH! 2 participants suggested an increased awareness of mental health would reduce stigma, and increase the number of people accessing support earlier. They wanted to see more promotion of mental health services they could self-refer to, a campaign targeted at young people, and a campaign specifically targeted at boys (that some suggested could be promoted by local football clubs).

Following on from Healthwatch Essex's SWEET! report, which gathered the lived experience of young people living in areas of recognised deprivation,[23] we wanted to understand the social care experiences of young people from across the county, and found that almost 3 in 10 YEAH! 2 participants had experiences of social care (such as intervention from Children's Services, housing services, foster care, and so on).

# Social care

Half of participants told us they had received no information on social care topics, with over half of those who had received social care information saying this came from personal experience only. Yet 6 in 10 participants felt it was important to receive information on social care.

Participants wanted information on a range of social care topics that included adoption and fostering, abuse, homelessness, disability and dementia. It was felt that an awareness of these topics, and the services existing around them, could help young people get the right support sooner.

"I was placed in a hostel. You don't receive any information until you get to crisis point, then you get so much that it's overwhelming."

"Young people don't know what social care services exist, and what support they can get."

These young people also felt that increased awareness would reduce stigma surrounding disability, being a young carer, and being in care.

"Knowing about adoption and foster care is important, and it's not something many people know about and some people joke about it. I'm adopted, and I don't know much about this topic or about social workers. I'd like to know how and why it happened, and why you sometimes aren't allowed contact with your birth parents."

"I went swimming with my disabled friend. We had a great time and the staff made us very welcome, although some of them did stare at my friend. They didn't understand."

**Children's Services and Family Life**

Just over 1 in 10 participants told us they had experienced contact with Children's Services, yet most of these participants still knew of Children's Services as "Social Services," which is reflected in their written quotations.

A number of participants felt that Children's Services had a negative reputation, with some saying they had only heard of them as **"people who take kids away from their families."** This was also a common perception amongst SWEET! participants,[24] which created a sense of fear and distrust of Children's Services, meaning the young people felt hesitant about making contact with services. Participants felt this could be counteracted by a raised awareness of positive examples of the work of Children's Services, and how the service works.

Participants who spoke about positive experiences with Children's Services told us that effective support had been put in place which, they felt kept young people safe.

"Social Services helped, due to my adoption."

"My boyfriend's parents weren't suitable – his mum's boyfriend was abusive so he was taken into care. He now has a better life with a foster dad."

Participants with a negative experience of Children's Services felt that services had either intervened too quickly, or not quickly enough.

"It was good that they wanted to protect my cousin, but they shouldn't jump to conclusions and should be understanding and compassionate."

**23** Healthwatch Essex 'SWEET! report'

**24** Healthwatch Essex 'SWEET! report.' p.19

"I recently made a disclosure about my father, and Social Services were not helpful beyond the first few weeks where they did house checks and held a few meetings. They've not been very supportive, and quite hard to contact. The police helped me the most: they were very helpful."

A sense of consistency was extremely important to the young people. Having a consistent social worker played a key role in influencing the young people's experience of Children's Services. Those who spoke of positive experiences appreciated social workers who were friendly, consistent and worked with the young person to put the right support in place.

"My experiences with social workers have always been good, as they've always been polite."

"My social worker comes very regularly to check our wellbeing and the safety of our home."

Several young people spoke about their frustrations when their social worker changed a lot, or they didn't feel they had been listened to, which was also a finding of the SWEET! report.[25] We also heard from some participants that social workers didn't visit often, or that it took a long time to get a social worker. In these instances, young people spoke about the difficulty in building trust, the frustration of repeating their stories, and feeling that social workers didn't have the time to help them.

"Social Services didn't look at the previous calls I'd made, or listen to the answers I gave to their questions. They just seemed interested in getting their job done quickly."

"My social worker was always off, and it really annoyed me."

As QualityWatch writes: "There are a number of indications that staff in both the NHS and social care services appear to face pressures that lead to work-related stress and high vacancy rates … Given the relationship between engaged staff and good-quality care, there is a substantial risk that the current staffing situation in both health and social care may be reducing the quality of care received by people who use services."[26]

Current pressures around funding and targets could also contribute to a higher turnover of social workers, which can result in the feeling of inconsistent care these participants reported. Action for Children found that over 4 in 10 social workers "have felt powerless to intervene in cases of child neglect, with nearly a third saying they lack the necessary time and resources…"

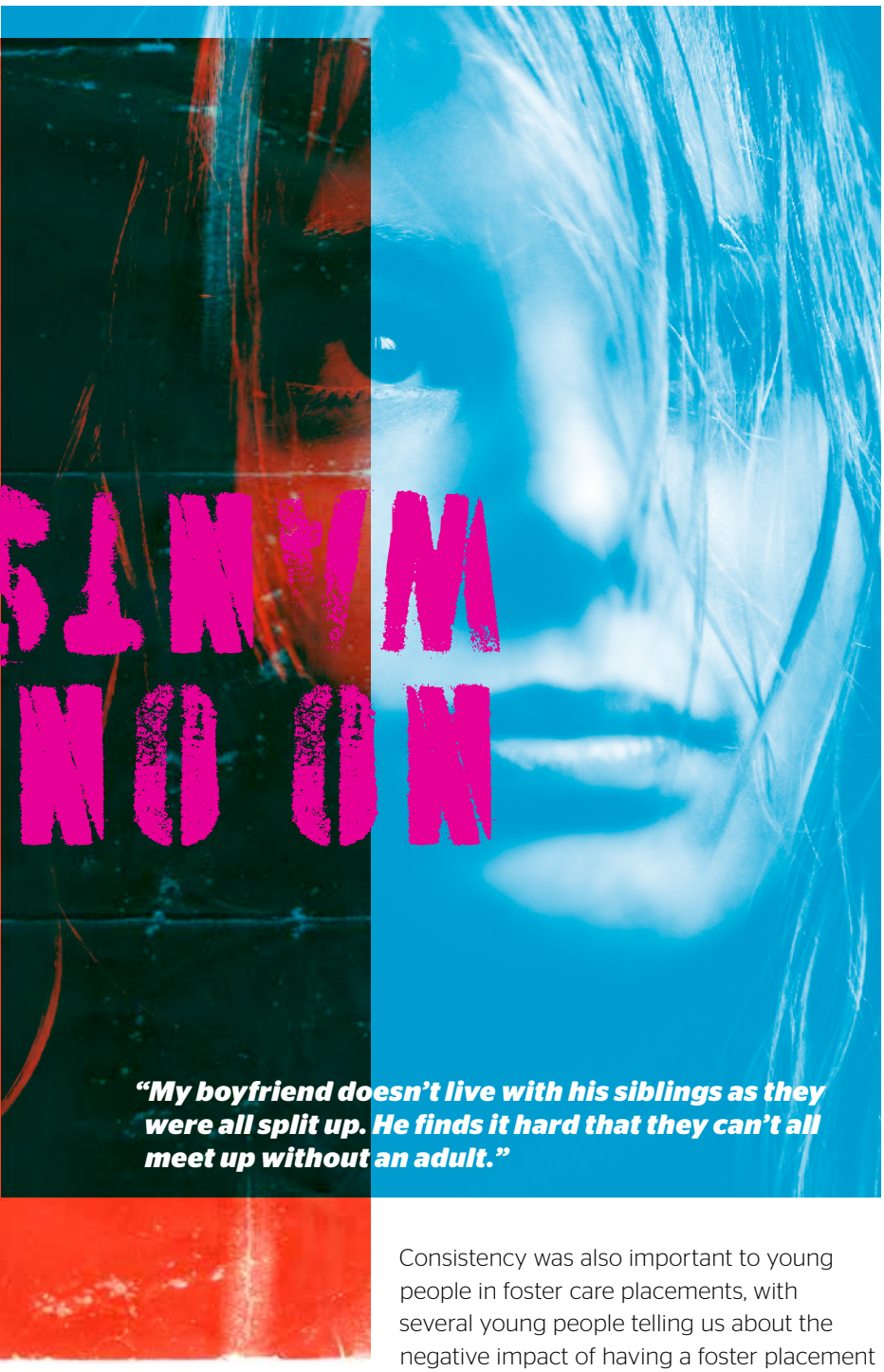
Sir Tony Hawkhead, chief executive of Action for Children has said: "We cannot go on like this. Limited resources, increasing caseloads and professionals feeling powerless are combining to create the perfect storm putting children in danger."[27] QualityWatch has also said that "Poor terms and conditions, coupled with demanding yet sensitive tasks, make social care a difficult area for retaining staff."[28]

An engaged and consistent social worker was crucial to young people feeling positive about the care they received from Children's Services, but with high workloads and other pressures, it seems this is not always possible. Participants felt that investing in the workforce, to recruit and maintain effective social workers, was key to improving their experiences.

**25** Healthwatch Essex 'SWEET! report.' p. 16

**26** QualityWatch 'Closer to critical?' p. 7

**27** Action for Children Media (2015) 'Overstretched and overloaded: social workers feel powerless to help neglected children.' London: Action for Children: https://www.actionforchildren.org.uk/news-and-opinion/latest-news/2015/march/social-workers-feel-powerless-to-help-neglected-children/




Consistency was also important to young people in foster care placements, with several young people telling us about the negative impact of having a foster placement break down. Moving placements often meant having to change job, school and social group, which participants described as causing them to feel "unsettled" and "unwanted."

Participants also told us that it was difficult being separated from their birth families, especially for long periods of time, with limited, or no, contact.

**"My boyfriend doesn't live with his siblings as they were all split up. He finds it hard that they can't all meet up without an adult."**

In keeping with these findings, Action for Children writes that a third of UK children have been separated from siblings when placed in foster care. The report goes on to say: **"Splitting siblings can ignite feelings of loss and abandonment which can affect emotional and mental health. They increase the risk of unstable foster placements and poor performance at school, as well as further problems in adulthood, such as difficulty finding a job, drug and alcohol addiction, homelessness or criminal activity."**[29]

Perhaps for this reason, many participants felt it would be beneficial for counsellors to visit young people in care placements to ensure they don't feel that **"no one wants them."**

As we found in our SWEET! report,[30] participants wanted young people to have more choice as to who cares for them, but also felt there should be classes for foster carers about the issues young people can face, and recruitment of foster carers who want to make a positive difference to young people's lives (as opposed to those who choose to foster for financial reasons). Some participants also wanted social events for young people in care placements to meet up and form friendships and support networks, based on their shared experiences.

A number of participants shared their concerns about turning 16 or 18, at which point they were aware they would transition out of Children's Services, but without an idea of what, if any, support they would transition into. This was a source of anxiety for these participants, who were unsure of the impact this could have across a range of aspects in their lives.

**28** Quality Watch 'Closer to critical?' p.21

**29** Action for Children Media (2014) 'One in three children split up from siblings in foster care.' London: Action for Children: https://www.actionforchildren.org.uk/news-and-opinion/latest-news/2014/september/one-in-three-children-split-up-from-siblings-in-foster-care

**30** Healthwatch Essex 'SWEET! report.' p. 18

**Caring for Others**

A number of participants told us they had caring responsibilities, and shared how these responsibilities could impact them emotionally, socially and within education.

"I was a young carer for my dad with a mental illness. It was hard at times, but I learned to deal with it."

"My friend is a young carer for her mum, her school attendance is really bad."

The Children's Society reports that caring "can cost young people dearly if they are not given the opportunities to participate in all aspects of life. They can miss out on a huge range of opportunities that so many other children and young people take for granted, from educational opportunities, to spending time with friends and having time and space to do their homework."[31]

Many of these participants knew about young carers clubs, and had mixed opinions on how useful these services were. Some told us young carers clubs had been good for getting support and information, as well as making friends. Others told us these clubs weren't always useful, and felt it would be more helpful for young carers to receive help in school.

"I went to young carer's club for about a year, but in the end it got less interesting and I got bored. Some sessions were fun when we did sport, or went out, but others were just sitting inside not doing much. I liked getting to talk to other people, but there could have been more activities."

***"My grandma with Parkinson's has been in hospital and a care home. They were unable to give her essential medication at the correct times."***

**31** Children's Society (2013) 'Hidden from View: The experiences of young carers in England.' London: Children's Society: p. 4

Some participants felt positively about the support they received from Children's Services, which could include home visits, days out, and putting paid carers and cleaners in place to help at home.

"I've been a young carer all my life, and have had constant support from Social Services. They've been good – with carers coming in, and cleaners to help, most days. I've been offered days out and a break from caring. It makes me feel less stressed, and able to enjoy myself more as a child."

We also heard that managing caring responsibilities when accessing mainstream healthcare could be problematic, with some participants feeling healthcare professionals did not understand how best to work with young carers and the people they help to care for.

"I was expected to know how to deal with my dad's emergency problem that resulted from his disabilities. This was at a young age, and I was the person who went with him in the ambulance. I was told to pack all of his medicines. I wasn't prepared, as I didn't know!"

"I go to the hospital with my mum so that if she misses something I can repeat it. I've found that instead of making it easier for her to understand, they speak directly to me and so she isn't able to lip read. Apart from that, the care is good."

Participants felt more positively when they were kept informed and supported when caring for someone.

"My grandmother had dementia, which meant doctors visited a lot and gave her medication. I was told about the options for her, and the doctors were open and kind."

Many participants also spoke to us about the experiences of older relatives who were receiving, or in need of, care. They spoke about their concerns when it was difficult to get this care, and the impact this had on members of the family.

"My grandad had dementia and Parkinson's, and had no help for 3 out of 4 years. My nan was struggling to care for him on her own, but there was no help!"

"My nan is cared for at home and the staff are sometimes very late, or don't come at all. This is a worry, as my nan can't walk."

"The staff at the care home treat patients badly, with no respect. Patients are often shouted at – particularly those with dementia."

"My grandma with Parkinson's has been in hospital and a care home. They were unable to give her essential medication at the correct times."

The young people we spoke to often played a role in the care of older relatives with dementia, and were informed about the struggles that came with finding effective, quality care. Many participants felt that this was an area that needed improvement, with many feeling the recruitment of more dedicated care professionals would improve standards of care their relatives received.


**Disability**

A number of participants identified as having a disability, and spoke about the support they received, or wanted to receive. The majority of these participants spoke about learning disabilities, but also mentioned physical disabilities and neurological conditions.

Autism was frequently discussed, and participants felt there appeared to be little support for those effected.

"Having knowledge on what care is available would help our family."

These participants also felt there was a lack of autism awareness among their peers, which could lead to isolation and bullying. One participant described school as being like "hell" for people with autism.

"Socialising can be difficult for me because of my compulsory anxious behaviour. It would be better if I was accepted all the time."

"It is important for young people at school to be more aware of people's different capabilities, so that we can help more and be understanding."

We were also told that being diagnosed could take a long time, which could delay getting the support required to help them achieve desired outcomes in school, social activities, family life and beyond. We heard from one participant that his brother, who has autism, had been told he would have a support worker for the past 8 years, but this had not yet happened, and we learned how stressful it could be for a person with autism, and their family, to be referred from service to service without getting outcomes.

"My father and brothers have autism and I don't know where to go to find out about the possibility that I have autism myself. I went to my GP, but they were no help. I still don't know if I have autism or not."

Having access to the relevant support in education had a positive impact for several participants. However, it seemed that it was not always possible to guarantee support throughout education, with participants reporting support had stopped, causing them to feel they had "been left," or that they were advised to perform badly in tests in order to secure the continuation of this support.

**Housing**

Homeless Link reports that "Nearly half of people living in homeless accommodation services are aged between 16 and 24 and without adequate support or early intervention, homelessness can go on to impact education, employment, health and wellbeing and is more likely to lead to homelessness in older age."[32] Yet participants who told us about their experiences of housing services often reported feeling support was slow, or unavailable.

"I was made homeless and called a homelessness charity 10 times across 2 days. I was told there was no one available I could speak to. It made me feel like there was no one there who cared or could help."

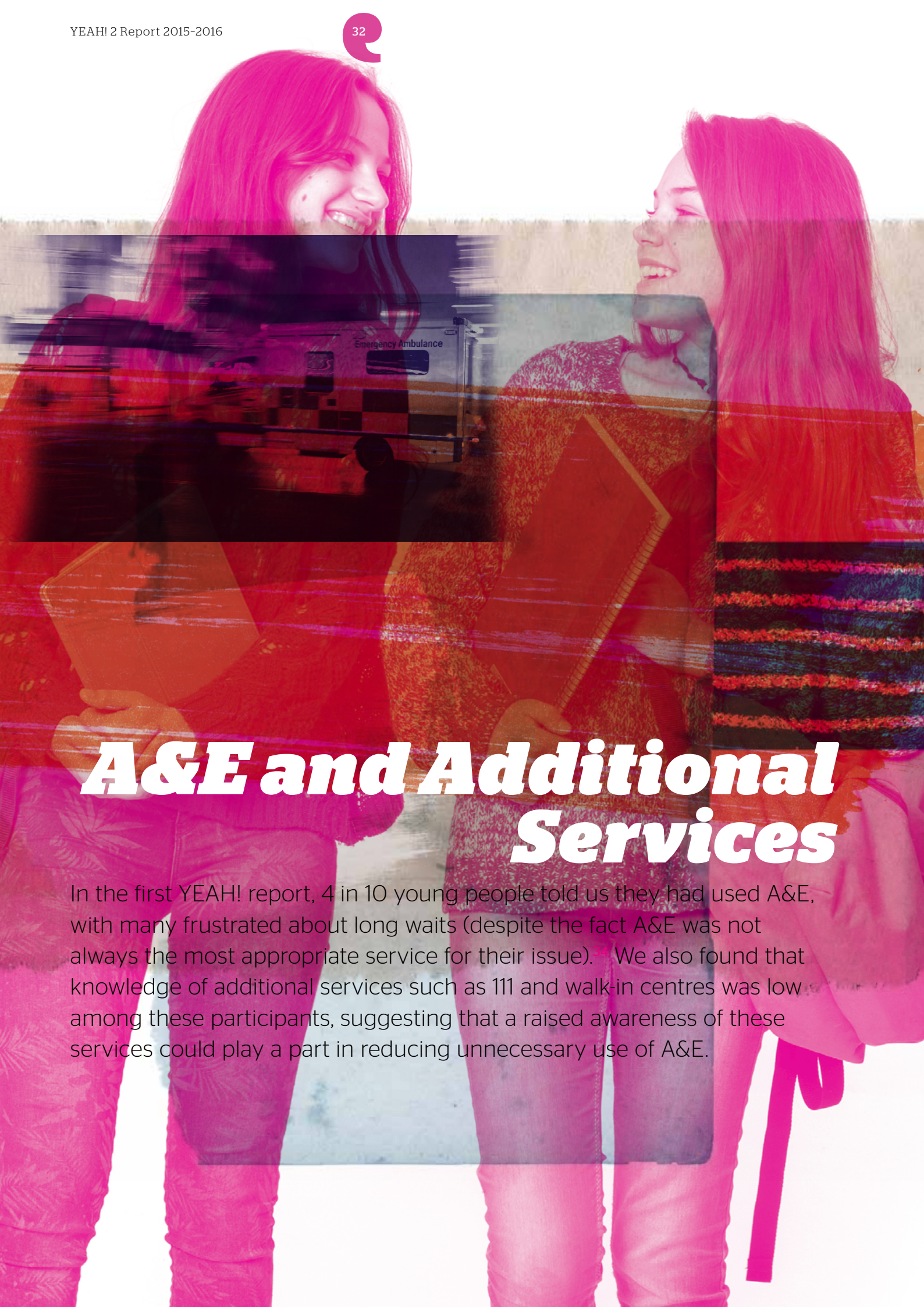
"My mum split from her partner and we had nowhere to go. We went to the council to get help, but as I was 15 and my mum worked full-time we weren't considered priority. We spent 6 months in a homeless hostel which impacted my school work."

We heard from participants who had been made to leave home, or knew a young person who had, that didn't know of any services that could be contacted. We heard that these young people had turned to "sofa surfing," or in other incidents "sleeping rough."

Some participants who were currently living in care placements told us they were worried that when they turned 18 they would be moved out of their care placements and into social housing. However, the Children and Families Act (2014) means that those in foster care now have the option to stay in their placement until the age of 21,[33] so long as this complies with the wishes of their foster carer. This is good news for young people concerned about having to leave their placement at 18, although participants were unaware of this legislation, suggesting a need to inform those in care about their entitlements.

**32** Homeless Link (2015) 'Young & Homeless.' London: Homeless Link: p. 3

**33** NSPCC (2016) 'Legislation.' London: NSPCC: https://www.nspcc.org.uk/preventing-abuse/child-protection-system/children-in-care/legislation-policy-guidance/




# A&E and Additional Services

In the first YEAH! report, 4 in 10 young people told us they had used A&E, with many frustrated about long waits (despite the fact A&E was not always the most appropriate service for their issue).[34] We also found that knowledge of additional services such as 111 and walk-in centres was low among these participants, suggesting that a raised awareness of these services could play a part in reducing unnecessary use of A&E.

For the YEAH! 2 report, we wanted to further explore how young people use services, and their knowledge of what choices they have in different situations – as well as their experiences of these services. We found that 6 in 10 participants had used A&E, compared to less than 1 in 10 who had ever been to a walk-in centre or called 111. 31 YEAH! 2 participants felt that too many people used emergency services when they didn't need to, which contributed to the strain these services are under.

"I've been to A&E many times and have always had to wait overnight for many hours. I didn't realise there are other services aside from A&E as nothing else was advertised, so we didn't have the necessary information."

"There were a lot more serious cases than me in A&E. Knowing about other services would have been good."

**A&E**

Most commonly, YEAH! 2 participants told us they visited A&E for a broken bone, a sprain or muscle injury, or a knock to the head. Severe issues included chest pains, car accidents and even gunshot wounds, but less severe issues included shutting a finger in a door, feeling unwell and getting a splinter.

Participants told us they sometimes used A&E when their GP surgery was closed or when they were unable to make a GP appointment, with others saying they skipped the GP altogether and went straight to A&E. Other participants told us they went to a walk-in centre to avoid A&E, only for the centre staff to refer them to A&E anyway:

"I was having bad headaches every day, and my family suspected it was because I'd fallen down the stairs around that time and had hit my head. I went to my GP who referred me to A&E for a scan, and A&E staff saw me quickly. I don't think I should have been referred to A&E though, as the problem was not that urgent."

Young people commonly expressed feeling that waiting times were too long, and that the service was unable to cope with demand. A report from QualityWatch echoes the experiences and expectations that young people voiced in our study, saying that "...people are spending longer in Accident & Emergency (A&E).... The decline has been consistent over several years, and there is no reason to expect that services will in future hold to the level of performance that they deliver today. Yet the public is clear that better access is expected."[35]

It was clear from our discussions that many participants were unaware of the average waiting time in A&E, and that expectations needed to be managed. Again, participants felt that having an understanding of 111 and walk-in centres could have saved them this wait.

"If I had been aware of other services my wait could have been shorter."

"I wish I'd known about other services instead of waiting for hours."

Patient experience in A&E largely revolved around how young people perceived they had been treated by staff. Participants praised staff who had been kind, helpful and respectful during their care. This was particularly valuable to patients who felt distressed or confused.

**34** Healthwatch Essex 'YEAH! report.' p. 36

**35** QualityWatch 'Closer to critical?' p. 7

"I tried to stop my friend getting in a fight and was beaten up, kicked and stamped on, which caused a bleed to my brain. I woke up in hospital not knowing what had happened. The staff were very pleasant and helped me get through it."

"My dad had a heart attack in the ambulance. It really freaked me out, but the paramedics were brilliant at keeping me and my mum calm."

When young people felt that staff had been "judgemental" or uncaring, they felt they felt negatively about their experience, which reduced their confidence in using services or discussing their care with professionals. While they did not want to be patronised, they often reported that it had been confusing to understand details of their care as explained by professionals, which caused them to be dependent on adult relatives who could help them understand. Others told us professionals always addressed their parents, instead of them, which discouraged young people from attempting to manage their own healthcare.

"They were very polite but didn't really explain what was happening to me. They could explain better to children, not just to adults."

"Explanations of conditions could be better, then I'd feel like I knew more about it."

It was important to participants that they felt empowered to manage their own healthcare, which would also encourage resilience and self-management as they grow older. Yet several participants told us that "young people aren't listened to."

"I felt so isolated, because it felt like I wasn't taken seriously."

Young people often reported feeling that services did not fit them, with professionals either explaining things in complicated language, or patronising them and causing them to feel they weren't taken seriously. Many participants said they would feel both comfortable and confident if staff were aware of how to treat people in their age group.

"Health services need to be better suited to teens."

Participants were aware of the strain that A&E was facing, through their experience of long waits in crowded waiting rooms. Many felt it was obvious that more staff were needed, and felt that a lack of such resources caused A&E to be unorganised.

"There should be more staff in A&E."

"Ambulance services are overstretched – I believe more staff are needed to reduce waiting times."

Participants sometimes felt the pressure staff were under could lead to mistakes, as we heard examples such as misdiagnoses, the wrong medication, a cast being placed on the wrong arm and the wrong test results being given. One participant was discharged after being told she was fine, but was later told she would have died if she hadn't decided to go back. Another young person told us she sustained lasting damage after being discharged with a broken ankle that she was told was not broken.

"When I broke my leg, I was told it wasn't broken. 3 days later, A&E reassessed my x-rays and I had to go back. I'd been walking round on a broken leg for 3 days!"

"When I broke my wrist, A&E told me it was a clean break and I didn't need surgery. The next day they told me I needed to have an operation. It would have been good to have found out the first time."

YEAH! 2 provides a snapshot of a service already under strain sometimes used by young people who are unaware of more appropriate services for their issues. While national conversations highlight a need for improvements in A&E resourcing, equipping these young people with knowledge of additional services could also contribute to alleviating the strain.

**Additional Services**

We wanted to understand the services young people knew they could use outside of their GP surgery, aside from A&E. We found that 4 in 10 had heard of walk-in centres and 111, and under 1 in 10 knew they could speak to a pharmacist. We wanted to gather young people's lived experience of using these services, and form an idea of what they use them for.

**111**

Although 4 in 10 participants knew of 111, fewer than 1 in 10 had used this service. 72 participants told us that although they'd heard of 111, they were unsure what the service was for, and when it was appropriate to use.

Over 6 in 10 of those who had used 111 reported positive experiences, most often because they found the service had been helpful (including sending ambulances, and preparing one participant's sister to deliver her baby at home if the ambulance did not arrive in time).

"I was babysitting my 4 year old brother when he got a high temperature and looked ill. I couldn't get hold of anyone I knew, so called 111. They talked me through how to help him – they were very helpful."

A high number of participants claimed that calling 111 was easier than trying to make an appointment at their GP surgery, and saved unnecessary journeys to other services.

"The 111 service was reliable, encouraging, and quick to help me."

"Using 111 I was able to get an emergency appointment at my local hospital where I was seen straight away."

Some participants did feel that 111 had been too slow, with one reporting a wait of 3 hours to hear from a doctor about her partner's breathing difficulties. Another said that when her grandma fell over a neighbour called 111 who said an ambulance would be sent, but after several hours of waiting they called 999 who came straight away.

"I passed out and hit my head on a concrete floor. The school told me to go home and sleep, but I felt very unwell and was being sick. We called 111 who said they'd send an ambulance, but 45 minutes later it had not turned up. As I'd had a relatively traumatic head injury my parents drove me 20 minutes to the hospital where doctors rushed me through for a scan and kept me in for a couple of days."

Several young people felt that 111 asked too many questions, and had told one they couldn't help her because she did not know the postcode for where she was staying. These participants felt that the service would be improved if call operators had an opportunity to expand their medical knowledge.

Overall, participants felt that 111 was a convenient service that they would be interested in using now they were aware of it. They felt that a raised promotion of this service would encourage uptake by young people, improving their patient experience and reducing A&E use.

"More people should use the 111 number to free up time in A&E for emergencies."

**Walk-in Centres**

Although 4 in 10 participants were aware of walk-in centres, only 43 participants had used them. Several participants told us they knew of walk-in centres, but their nearest one had closed down, meaning they went to A&E instead. Others said they weren't sure what they could use walk-in centres for.

"The walk-in centre was fast, but it's closed down now."

"I'm not aware of walk-in centres or out-of-hours doctors. These should be better advertised."

Those who had used a walk-in centre told us they used it when they were unable to get a GP appointment. The vast majority of participants reported positive experiences, claiming the waiting times were good, it was easier than trying to get an appointment with their GP, and that staff were helpful and friendly.

"I was seen by a doctor really quickly, who prescribed me some medication for an infection that my own GP wouldn't do for me."

"I went to a walk-in centre for a persistent fever I'd had for a few weeks. The doctor gave me useful advice and effective treatment."

A minority of participants felt that walk-in centre waiting times took too long, or that the staff were not helpful.

"We went to the walk-in centre as it is open later than my GP surgery. I was told to go home and rest, and that I'd feel better. After a week of not feeling better, I went to my GP who diagnosed me with a chest infection and tonsillitis and told me I should have had antibiotics from the start."

As with 111, the young people responded well to hearing about walk-in centres, and felt positive about knowing they were an option. Although some walk-in centres these young people knew of had been closed down, it seems it would certainly be worth promoting those that are still active.

**Pharmacies**

YEAH! 2 participants had mostly visited a pharmacy to collect a prescription, and were rarely aware of other services pharmacies offer. Only 19 participants told us they had used their pharmacy for advice, but told us this had been a positive experience.

"We went to the pharmacy on a Sunday when my GP surgery was closed. They were helpful and able to diagnose me, as well as give me the treatment and medicine I needed."

***"I'm not aware of walk-in centres or out-of-hours doctors. These should be better advertised."***

"The pharmacy was quick, organised and helpful."

The young people who had used their pharmacist for advice had found it positive, and with the majority of those who had collected a prescription from a pharmacist reporting a quick and friendly service, it seems this is currently an untapped resource that could benefit young people if they were aware of it.

Through the course of our discussions, participants seemed to realise that emergency services could be improved if people knew the other options that existed.

"People should be more aware of services for milder problems. This is because I have always assumed you just go to A&E in these scenarios."

Almost 8 in 10 participants felt they needed a greater awareness of services that could be used outside of their GP, when to use them and where to find them.

"I would strongly suggest we are given information on what to do in different situations."

# Getting Information

As with the first YEAH! report, we found that participants unanimously wanted more information on health and social care issues and services. They felt that having access to more information would empower them to manage their health and social care, as well as give them the insight to address issues earlier.

"More information is needed for teenagers."

"I didn't learn any of this information in school that I have learned in the last half an hour."

We asked YEAH! 2 participants how they got their information about health and social care, but also about social activities happening near them.

Perhaps surprisingly, given the common assumption that young people gather all of their information digitally, over 6 in 10 participants named school as being their preferred method of accessing information. This ranged from messages spread through assemblies, classes, and workshops through to word of mouth and peer to peer information sharing. These participants often told us that school or college was where they spent most of their time, and so this is where it seemed both natural and convenient for information to reach them.

Participants who wanted to receive this information wanted to learn in school and college, stating:

"Schools can give kids more help than anyone else."

"We spend the majority of our time in school."

Half of participants told us they used websites or social media to search for, or receive, information. However, discussions often covered the difficulty in finding an online resource that provided up-to-date and reliable information, and it was decided that searching for information online could be risky.

While the majority of participants used apps, they told us these weren't used for finding information, but for entertainment purposes instead, and they were not interested in downloading information or service based apps.

"Have classes on it, or more websites fit for certain age groups."

"With health & social care there are lots of places you can go, but nowhere to find the information easily if you don't know the website or number. If you don't take specific classes you don't know about it, and you never know when you might need it."

Other participants said they get their information from TV or the media.

In order to improve young people's access to information, it is important to engage with them to develop understanding, as well as ideas. It can be easy to assume that in the digital age young people want interactive apps, but YEAH! 2 participants told us they wanted information to be accessible in school, and through credible online sources.

# Concluding Thoughts and Next Steps

Many of our findings are in keeping with national conversations around health and social care, such as growing waiting times and a strain on both mental health and emergency services,[36] that are experienced across all age ranges. But YEAH! 2 also helped us understand issues unique to the experiences of young people, such as the difficulties around transitioning between child and adult services, the impact mental health and social care issues can have on education and socialising, and what information young people want (as well as how they want to receive it).

We encourage health and social care commissioners, providers and frontline staff to recognise the findings of the YEAH! 2 report, and apply them to their role in any way they can, to play a part in positively changing young people's experiences of health and social care. Investing time and resource in young people early on equips them with the knowledge and confidence to manage their own health and social care in future, and may prevent presenting issues from becoming exacerbated. As QualityWatch has said **"It is well established that events in early life affect health and wellbeing later in life, with associated increased care needs. Prevention and intervention in the early years is believed to produce significant future cost savings, which means that investing in services that improve the health of children and young people has the potential to deliver long-term social and economic benefits to the nation."**[37]

Healthwatch Essex continues to gather the lived experience of young people in our county, and will return to NCS in summer 2016 to begin YEAH! 3 (with a public health focus). We have also undertaken engagement with young people living in areas of recognised deprivation in Tendring, which will form the SWEET! 2 report.

**"It's great that Healthwatch Essex is committed to engaging with young people. It can sometimes feel as though young people are the group that are forgotten about: too young to be seen as adults; too old to be called children. If no one asks us for our views we feel ignored, as though we aren't cared about or valued. But there are so many young people across Essex with lived experience of health and social care, as YEAH! 2 highlights. If our opinions aren't represented, or considered, there's a huge gap that needs to be filled in order to look at providing services that young people need. This is why YEAH! 2 is crucial and valuable; it could potentially lead to improved versatility of services that can cater for all people, and empower Essex's young people."** Kemi Biyi, Young Ambassador, Healthwatch Essex.

**36** As reported by Quality-Watch 'Closer to critical?' p. 7

**37** QualityWatch 'Closer to critical?' p. 23

# Acknowledgements

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