

Young Listeners Project

Sharing young people's feedback to improve the health and social care services they use.

November 2021





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Introduction

About us

Healthwatch Somerset is the county's health and social care champion. We listen to your experiences of using local health and care services and hear about the issues that really matter to you. We are independent and impartial, and your feedback is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need.



As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared.

Background



In our 2019-2020 work plan, we made a commitment to improve how we interact and engage with young people in Somerset. This was based on insight gained from several of our previous projects and reports which highlighted the lack of support for young people's health, both before and during the ongoing Covid-19 pandemic.

Impact of Covid-19

In a critique of the Government's Spending Review for 2020, by the National Children's Bureau (December 2020), it was noted that a rise in child poverty has led to services for children and young people to be 'poorly prepared for the pandemic'. The report goes on to discuss the impact that successive lockdowns have had on the health and wellbeing of young people and the toll this has taken on the health and social care services that were already struggling.¹

Young People's mental health

Young people's mental health and wellbeing has been a particular area of concern in Somerset over the last few years. In 2018, the Somerset Children and Young People's Health and Wellbeing Survey questioned 1,918 Year 8s (age 11-13) and 1,818 Year 10s (age 13-15). When asked if they were 'feeling happy with life at the moment', 23% responded 'not much' or 'not at all', up from 19% in 2016. The percentage of young people who responded more positively with 'quite a lot' or 'a lot' decreased from 62% in 2016 to 59% in 2018.

¹ National Children's Bureau: Whatever it takes (report, Dec 2020)

² The Somerset Children and Young People's Health and Wellbeing Survey 2018

Somerset did see significant improvements made to the mental health services available for children and young people, mainly due to increased investment from NHS England as a part of their Five Year Forward View policy directives.³ This can be seen through the introduction of the Trailblazer project which looks to establish dedicated mental health support teams in schools throughout Somerset, as well as the Big Tent Programme which aims to bring together and deliver young people's mental health and wellbeing services under one umbrella, through the voluntary and community sector. However, Somerset has simultaneously seen increasing demands on Children and Adolescent Mental Health Services (CAMHS), social care, hospitals and schools during an historic low level of investment in these services in Somerset.^{4,5,6}

Valuing young people's views

A large part of the foundations of the Young Listeners Project was an understanding that young people have had little opportunity to share their experiences and ideas, and they feel that the decisions about the services they use are being made by those who are not in the know. The Somerset Children and Young People's Health and Wellbeing Survey 2018 found that only 35% of those questioned felt that they were asked for their ideas and opinions within the community. Similarly, only 37% stated that they thought the opinions of young people make a difference to decisions in their community.



The Young Listeners Project was introduced by Healthwatch Wiltshire in 2018. Acting on previous research, both in-house and from external services, Healthwatch Wiltshire recruited, trained and supported young people in the area to talk to other young people about the health and social care services they used. They found that this method of engagement and information gathering was incredibly effective, so the project was rolled out to Healthwatch Somerset, Dorset and Gloucestershire.

We know that to help young people it is of the utmost importance to include them in the decision-making process. They are the ones using the health and social care services, and they know what issues they face and what changes they would like to see. Consequently, we wanted to include young people at every stage of the Young Listeners project.



³ Somerset Children & Young People Health & Wellbeing: <u>Improvements to CYP Mental Health in Somerset</u> [Sept 2019]

⁴ Local Government Association: CAMHS - facts and figures

⁵ Community Care: <u>How cuts are affecting social care performance</u>: <u>what the data says</u> [Nov 2019]

⁶ The Health Foundation: <u>Urgent call for £1bn a year to reverse cuts to public health funding</u> [June 2019]

What we did

Recruiting our Young Listeners

At the beginning of 2021 we recruited nine young volunteers from across Somerset, aged between 12 and 18, to be our Young Listeners. We wanted our Young Listeners to represent the diversity of our community and our county, taking into account location, background and service use among other factors. We promoted the opportunity widely to all young people aged 11 to 24 living in Somerset, via social media, press and radio, and through our local networks. We also contacted every secondary school and college in the county.

During what was already a challenging year with the pandemic, especially for younger people, the fact that nine young people gave up their free time to help their peers shows just how dedicated our Young Listeners are.



Training our Young Listeners



Our Young Listeners, with guidance from our Youth Engagement Officer, decided what training they felt would help them with the project and with their futures.

Between March and July 2021, our Youth Engagement Officer led them through a comprehensive 12-week training programme. This included AQA sessions on topics such as communication skills, equality and diversity, safeguarding, and planning engagement activities, alongside mindfulness sessions to support their mental health and wellbeing. All training was conducted online due to the Covid-19 pandemic.

Planning the project

Focus areas

As Covid-19 restrictions had eased by July 2021, we were able to meet some of our Young Listeners face-to-face to start planning the project. They were clear about the areas of young people's health and care services that they wanted to investigate:

- Mental health
- GP access
- LGBTQ+ problems when accessing support.





Questionnaire

The Young Listeners designed a questionnaire to guide their engagement with other young people to help them gain a better understanding of young people's health and social care services in Somerset. This included questions to gather feedback on the specific issues they were interested in, as well as more general questions to make sure that they did not disregard feedback from young people who were not facing those issues. The questionnaire was checked by a youth group at the Cheddar Methodist Hall to make sure the questions were easy to understand by young people of all ages (see **Appendix**).



Delivering the project

Community events

During August and September 2021, our Young Listeners attended several community events across Somerset and online, from Glastonbury to Yeovil, Minehead to Frome. We attended events hosted by third parties, including Strode College Freshers' Fair and Richard Huish's EnRICH afternoon, and we held our own events.

Online meetings

We also carried out online meetings for young people who were not comfortable meeting face-to-face due to the pandemic.

Online survey

We also created an online survey which we published on our website and promoted widely, including on social media and at youth clubs and health centres.





Who we spoke to

By the end of September 2021, our Young Listeners had engaged with 65 young people aged 11 to 24, through the online survey and in-person listenings.

Our initial goal was to conduct 100 'listenings', but it became clear this would be difficult to achieve due to the Covid-19 pandemic.

Demographics

Our 65 respondents came from a variety of age ranges, genders, backgrounds and locations.



Figure 1: Age of young people

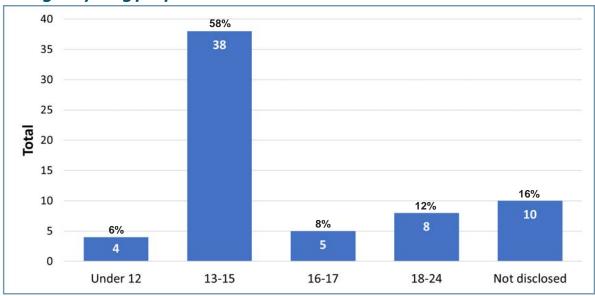


Figure 2: Gender

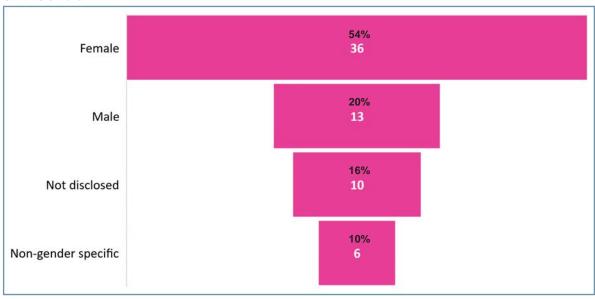


Figure 3: Sexual orientation

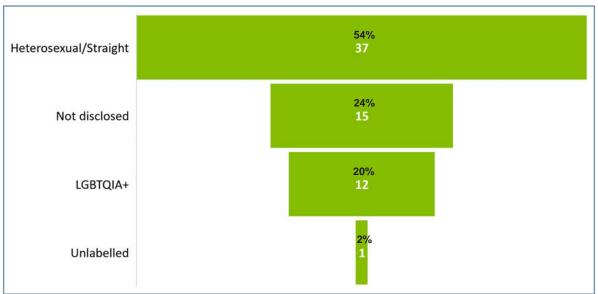
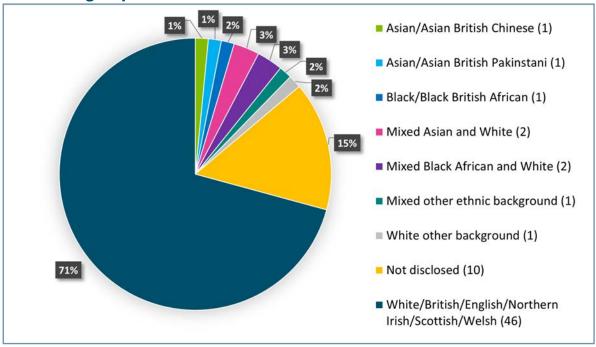


Figure 4: Ethnic group



Location by district/area

• Mendip: 1

• Sedgemoor: 3

Somerset West and Taunton: 23

South Somerset: 17

Devon: 1

Not disclosed: 20



Key messages

- There is a lack of communication between services about young people's health and wellbeing.
- Services are not communicating effectively with young people, and they often feel left in the dark.
- There is not enough information or education about health and social care in schools, so young people have to find information online.
- Many services do not promote themselves in a way that is accessible or inclusive of young people.

What people told us

Poor communication between services

41% of young people said they had to repeat their symptoms and backstory to each service they used, even if they had been referred by their GP or another service.

While some understood that this helped each service gain an understanding of the patient, there was confusion about why their details had not been passed on, with many feeling like they were not being listened to. A repeated theme was that young people found it "annoying" having to constantly repeat their problems and did not understand why it appeared as though the various services were not communicating with each other.



"Frustrating to keep repeating myself."

Within the responses, young people stated that it was also quite harmful or distressing having to repeat themselves, particularly those who were discussing mental health problems, as having to bring up the same memories each time was "really tough."

One young person spoke of an interaction with their GP in which their symptoms were discussed in depth, leading to the proposal of an MRI scan. However, when they were contacted by the MRI clinic, they were asked to repeat their problems despite the referral from the GP.

"It wasn't triggering or anything like that, I just felt that the notes should have been passed on."

Another stated that they were "sent to the wrong service as a result" and this made them feel unheard and that they would be less likely to contact their GP in future.



Young people said they would like to see more communication between services, and this would make patients feel more cared for and also save time.

Lack of communication with patients

One of the strongest themes young people noted was that the services they were using tended to suffer from a lack of communication with the patient.

Young people spoke of how they often felt that they had been forgotten.

"I had to wait to hear back about appointments; that felt like I had been forgotten." | "...nearly too long and I almost gave up."

A repeated topic was that young people's treatment was cut short without their consent and often before they were ready. This led to distrust in the service they were using and, on occasion, the wider health and social care systems on offer.



In particular, there were four young people who spoke about their transition from child to adult services, specifically social care. They talked about their lack of inclusion in decision making processes. One young person said: "I consented to it, but I had no control. It was never 'Would you like to try this or this?' it was 'Are you ok doing this?' and I wasn't going to say no." They also said that they had to "actively search" for more information, that they received no emails or calls and often "felt alone" as they struggled to keep themselves informed.

"I never felt like I was in the loop with anything." | "At the end I did feel better, but it was stopped before I was ready." | "After a GP laughed at me it took me a long time to recover and feel confident in going to healthcare staff with a problem."



Young people stated they would like to see services make more of an attempt to contact their patients, even if only to apologise for the waiting time or to let them know that they were still working on the patient's case.

Lack of information at school, college, or university

More than half of those who fed back stated that there was not enough information and education about health and social care services available at their school, college, or university.

Another prevalent theme was the lack of education. One young person stated: "At school we don't really learn new things about health etc., they just go over the same thing." Many others responded with notions that teachers need to be "more open about offering you and directing you towards support." One young person said that even when they did reach out to teachers "they had no information to provide", so they had to find the information they needed by themselves, which was not easy "when you're in an unhealthy [mental] place."



"I felt trapped alone and judged and school wouldn't do anything." I don't think enough awareness is spread around."

Young people talked about how their school's usual response was to tell them to see the school nurse, "... but that's not really good enough", especially as their school nurse didn't seem to have much information on the wider services on offer and so couldn't give worthwhile support or offer ongoing treatment.



Young people would like to see more information and education at school, college, or university. In particular, they would like to see more information about the services they can access outside of school, and they want staff to be aware of these services so that they can help signpost young people in the right direction.

Make services more accessible for young people

Young people said that services do not present themselves in ways that are inclusive or accessible for young people.

When asked about the barriers and difficulties young people face when accessing health or social care, a consistent response was around the lack of awareness among young people, meaning "they don't know how to access the services if they need them."

Young people also expressed concern about the lack of advertising of services for young people on relevant platforms. As young people increasingly use the internet to find out about services, particularly as information in schools is lacking, this means it is difficult for young people to find the answers and information they are looking for. One young person said that services should: "Use apps like TikTok and hire someone young to actually appeal to teens properly." This sentiment was seen several times, with young people urging services to take another look at how they are interacting with their target demographics.



matter of finding

the support."



Young people would like services to promote themselves using methods that are more appropriate and accessible to young people.

Treat young people as equals

Young people were asked what advice they would give to the people in charge of services, and they said they wanted to be treated as a person rather than as a child.



Throughout the responses young people talked about not being taken seriously, commenting on how this often made them not want to go back to services through fear of being condescended to again. One young person stated: "You should be led by the young person, it's a conversation not an interrogation." This sentiment was backed by other young people.

"I was offered a referral to a specialist, but only after a GP literally laughed out loud when I said I thought I had a certain condition." | "Felt like being a minor made me not listened to." | "Ignorant adults putting it down to hormones."



Young people would like to feel listened to and recognised as having an understanding of their health concerns by professionals, not talked down to or disregarded.

Lack of information held by GPs on wider services available

Although only raised by a few young people, it is worth mentioning that they talked about the lack of information on wider services offered to them by their GPs.

A consistent theme was that young people said their GP was often their first point of contact if they were experiencing health problems, particularly the younger respondents, and that often it seemed like the GP was unable to give information about other health care providers.

"I feel like I'm banging my head against a wall!"



Young people would like to see an increased level of awareness of other services among GPs.

Lack of communication when moving between services

Four of the 65 young people who shared feedback were social care leavers. Asked about their experience of moving from children's to adult social care services, they spoke about a lack of communication between the service and users.

Two young people felt they were not given enough time to prepare for the transition to adult services and were rushed into circumstances they were not comfortable with. One described how they were "given no options, put into shared accommodation which affected my mental health negatively as there wasn't the right support staff around", and they suggested that a "settling in period would be much better", to allow time to adjust to the new setting.

"No emails (or) calls, I felt left alone." | "Have a basic understanding of care leavers. Respect my history, have some discretion."





Young people in care would like to see more communication between services and themselves, particularly when transitioning between children's and adult social care services.





Recommendations

Based on what our Young Listeners heard from other young people, we recommend the following to help improve young people's health and care services in Somerset.

1. More training should be provided for all school staff around mental health and wellbeing awareness and the support that is available locally, so that they can signpost young people to the correct services.



- Within the next 12 months, young people would like to see school staff given training to improve their knowledge of local health and social care services.
- 2. Health and social care services should re-evaluate how they communicate with each other and their patients, to reduce confusion and feelings of abandonment.
 - Young people recommended that services have a centralised system where patient's notes are shared.
 - Young people also suggested services make more frequent contact with patients, particularly if they are waiting for feedback, to avoid feelings of abandonment.
- 3. Services that support young people should promote themselves in ways that are appropriate and accessible for young people.
 - Young people suggested recruiting younger staff to deliver communications as they might relate better young people's views and experiences.
 - Similarly, younger staff will have a better understanding of the platforms used by young people to find information online (e.g. TikTok, Snapchat).
- 4. Schools and services should promote the need to ask questions and reduce stigma around health and social care issues, encouraging young people to seek information and answers from professionals.
 - Within the next 12 months, young people would like to see services make a concerted effort to reduce stigma around seeking health and social care, perhaps through targeted ads for young people or school workshops.
- 5. Health and social care services should involve young people more regularly in decision making processes, as well as in planning for projects concerning young people.
 - This project has shown that young people are willing to give their time and views, and that
 continued interaction with young people would provide significant value to health and
 social care services going forward.
 - We will work with young people to set up a Young Listeners' Reading Panel to review outgoing communications, checking they are accessible and appropriate for a younger audience.

Next steps

We will work with our Young Listeners to share what they have heard with the commissioners and providers of health and social care services in Somerset (the people who plan, pay for, and run services). We will make sure that the voices of the children and young people who spoke to our Young Listeners are used to help shape services in the future.

We will set up a Young Listeners Reading Panel to review outgoing communications for Healthwatch Somerset and health and social care services that want to take part, to make sure they are appropriate and accessible to young people.

Stakeholder responses

Fiona Phur, Partnership Business Manager at Somerset County Council



"The Participation & Engagement team at Somerset County Council were pleased to support this project from its inception, and promoting the opportunities it offered to young people. Young people's voices should be at the centre of all our decision making and the findings from this project are powerful and give direction to future service planning.

"Well done to Max and the young people and everyone who supported them."

Becky Applewood, Deputy Director for Women's and Children's Health at Somerset Clinical Commissioning Group



"The insight from this report shows just how important is to ensure children and young people are at the centre of the work we do and that we really listen to their experiences and observations. Our services need to properly meet the needs of children and young people, not the organisations and this can only be achieved by working with and listening to them.

"The report also shows how, when we deliver any of our health services, we have to think about the child or young person holistically, considering both their mental and physical health so we achieve the best outcome for them.

"It is really important that we join up our health and care services so that children and young people in Somerset are able to easily access what they need; making sure that early help is available before things worsen.

"The principles outlined in the report have informed our Somerset's Children's and Young People's plans. They will also influence the way that we design our services so they are developed collaboratively with those that may need them and using feedback to ensure we are getting things right.

"This commitment is evident in the successful and continuing development of support for children who have Special Educational Needs and Disabilities (SEND), and for those that may need an autism, ADHD or neurobehavioral support. Children and their families have been actively engaged throughout the process, ensuring that the pathway for these services work.

"Working with organisations like Healthwatch, who can form honest and trusting relationships to understand experiences and coordinate and represent their views is essential. This will help us to understand how we can best deliver the NHS Children and Young People's Transformation Plan, which looks at how we can further improve the accessibility and quality a whole range of paediatric services in the county."

Thank you

We would like to thank the young people who took time to share their experiences and views with our Young Listeners. We would also like to thank the many organisations who helped promote the project so that our survey could reach as many young people as possible. Finally, a huge thank you to our Young Listeners who dedicated their own free time to give other young people an opportunity to be heard.



Appendix

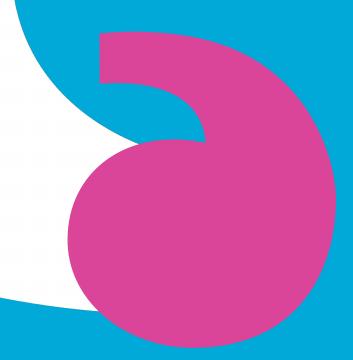
Survey questions

- On a scale of 1-10, 1 being no knowledge, 10 being very knowledgeable, how knowledgeable are you
 of available health and care services in your area? For example, GP, Mental Health, Sexual Health or
 Accident and Emergency.
- 2. Any comments on why you gave the above score?
- 3. Are you currently using a health/social care service, or have you in the past? For example, visiting a GP, dentist or mental health service.
- 4. Would you be happy to answer questions about an experience you have had with health and care services? This may be the most recent, or could be an experience which is particularly important to you.
- 5. Were you offered a range of support services?
- 6. Is there anything you would like to say about the range of services you were offered?
- 7. Did you have to go to/were you directed to different services before you knew what the problem was?
- 8. Is there anything you would like to say about how you used different services before the problem was found?
- 9. Did you have to repeat your background story/symptoms to multiple people?
- 10. How did you find repeating your background story/symptoms to multiple people?
- 11. Which support services did you use?
- 12. Did you find the staff helpful?
- 13. How helpful was the treatment?
- 14. Were you offered ongoing support? If so, was it useful?
- 15. What did you like about the service?
- 16. What didn't you like about the service?
- 17. How was your overall experience of the service?
- 18. Would you go back/recommend the service?
- 19. Do you know where and how you can access more support if you need it?
- 20. Did you not use a service because you couldn't access the services, or because you felt that you did not need the service?
- 21. If you needed to access any health or care support, where would you find the information you needed?

- 22. If you have experienced a medical emergency (physical or mental health), how easily was the information about your next steps available to you? Skip this question if it is not relevant to you.
- 23. Have you experienced transition between children's and adult services? For example moving from a young person's mental health service to an adult mental health service.
- 24. Are you happy to answer some questions about the transition between children's and adult services?
- 25. Which services were involved in the transition?
- 26. Did you get any say in how your transition would work?
- 27. What worked well with your transition between services?
- 28. What could be improved for transitioning between services? This is the final question about the transition between children's and adult services.
- 29. If you are in school, college or university, is there enough education and information available about health and social care services?
- 30. Have you previously had difficulty accessing services, support or information?
- 31. Please tell us about the difficulty accessing services, support or information that you experienced.
- 32. Has this previous experience or difficulty accessing services, support or information put you off seeking help in the future?
- 33. Can you tell us more about how and why it has put you off seeking help in the future?
- 34. What are the current barriers/difficulties for young people accessing the information and services they need?
- 35. What advice would you give to the people in charge of the services you have talked about so that they can better support young people in the future?
- 36. Is there anything else you would like to say, which you haven't had the space to elsewhere on this survey.

Why not get involved?

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