

Listening to Children and Young People: Your Experience of Health and Social Care

An independent voice for the people of Wiltshire

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Note:

A young carer is someone under 18 who helps look after someone in their family, or a friend, who is ill, disabled or misuses drugs or alcohol. For more information: https://carers.org/about-us/about-young-carers

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About Healthwatch Wiltshire

Healthwatch Wiltshire is the independent champion for health and social care in Wiltshire. It has an important role in assessing the quality of health and social care services today and influencing the design of services for tomorrow. We want to make sure that the people who use these services have a say in how they are shaped and that their overall views and experiences are heard and taken seriously.













Foreword

Healthwatch Wiltshire has been delighted to work with Youth Action Wiltshire on the Young Listeners project. Through the project we have seen an absolutely inspiring, engaging, and enthusiastic group of young people get stuck into some really valuable work. In their own time they have gone out to listen to other children and young people about their experiences of health and care services. I know (because they have told me) that the project has helped the individual Young Listeners to learn new skills and develop their confidence. The project has enabled us to reach out to a wider group of young people and some key messages have come out of the work. We were delighted to learn that the project was shortlisted for a national award. We are also encouraged that the commissioners for health services have welcomed the messages. There are plans afoot to deliver improvements especially in the area of mental health. We plan to work together to build on this work in 2017. Watch this space!

Chris Graves, Chair, Healthwatch Wiltshire

It is great to see the work that has been done by HealthWatch Wiltshire's Young Listeners. The Young Listeners gave a powerful presentation at the recent HealthWatch Wiltshire conference on the theme of mental health. Improving support for young people struggling with their mental health is a priority for commissioners and we are working with young people, schools and the specialist Child and Adolescent Mental Health Service to transform mental health services. Improvements will only be made if commissioners listen to what young people are telling us. I look forward to hearing more from the Young Listeners in 2017!

Julia Cramp - Strategic Lead for Children's Commissioning (Wiltshire Council and Wiltshire Clinical Commissioning Group).



Children and Young People NOW! Awards (shortlisted for the Youth Volunteering and Social Action Award)

Introduction

Children and young people can often feel that they don't have the opportunity to share their experiences of using health and care services. The views of children and young people are just as important as those of adults.

Healthwatch Wiltshire wanted to find out what children and young people living in Wiltshire felt about using health and care services.

Nationally we know that more and more young people are trying to get help from mental health services ¹, but that many children and young people are not getting the help they need or have to wait a long time to see a mental health professional ².

It is also nationally recognised that medical professionals should be aware of Young Carers and their needs and that Young Carers are given the extra support they need to enable them to continue in their caring role. School nurses should be there to offer support to children and young people³ in a familiar environment.

Key Messages

- Children and young people want to be seen as individuals and treated with respect.
- Many young people felt that the waiting time for an appointment after being referred to Child and Adolescent Mental Health Services (CAMHS) was too long.
- Young people felt that they weren't being listened to and said that they found it unhelpful seeing different mental health professionals each time.
- Some young people said that they did not know where to go for advice on either physical health or mental health in schools.



¹ https://www.theguardian.com/society/2016/oct/03/quarter-of-a-million-children-receiving-mental-health-care -in-england

² http://www.childrenscommissioner.gov.uk/sites/default/files/publications/Children's%20Commissioner's% 20Mental%20Health%20Lightning%20Review.pdf

³ http://www.youngcarer.com/sites/default/files/health care pros booklet 2012 low res.pdf

What we did

Working with Youth Action Wiltshire and Community First's Community Organisers we trained a group of 10 young people (aged 16 - 18) to become Young Listeners. They carried out training in listening skills, community organising skills and safeguarding and were supported to carry out listenings with other children and young people. The Young Listeners worked together to develop questions that they would ask, focusing on 3 areas:

- Young Carers
- Children and young people with Special Educational Needs (SEND)
- Emotional Wellbeing and Mental Health

They were supported to visit youth groups and clubs run by Youth Action Wiltshire to listen to the views of young people. They chose their listening style to suit the ages of those they were listening to for example, having a conversation with older young people and by creating a board game to play with younger children and encouraging them to draw pictures of their experiences. After each listening, the Young Listeners had a chance to reflect and report on what they had heard.



The Young Listeners listened to 174 children and young people (aged 5-18) in total.



74 Young Carers



48 Children and Young People with Special Educational Needs and Disabilities (SEND)



52 Young People about Emotional Wellbeing and Mental Health.

What we found

1. Children and young people wanted to be treated as individuals and have a choice. Feedback from young people about dentists and opticians was largely positive and many young people said this was directly linked to having a choice in who they saw.

"We want to be treated as individuals by people who support us with our health"

Young Person

"My Optician was good....they speak directly to me and the waiting time is quick"

Young Person

2) Young people said that they would like to have the choice about whether healthcare staff address them or the adult who is with them when they are at an appointment. This has an impact on the experience of the young person. Young carers particularly found this challenging as medical professionals usually address the adult when the young person is normally the carer and involved in making the decisions.

"The doctor was nice and she made me feel safe. She spoke to me and my mum"

Young Person

"I broke my arm in two places the doctor didn't explain to me what was happening, they put me to sleep and I didn't know why. They should have explained more to me".

Young Person



3) Several young people aged from nine upwards said they felt that they had not been listened to and this was linked to their age. Many said that they felt patronised or didn't feel that they had been taken seriously.

The experience of a young woman (aged 18) - as told to a Young Listener
She went to A&E after tearing her hamstring during a dance class. She was in a lot
of pain and so went to the local A&E. When she got to A&E they provided her with a
wheelchair so she could get from the car to the hospital. After letting the
receptionist know what had happened she sat in the waiting room for an hour and a
half without any help or assistance. People who had come in after her were
prioritised which made her feel worse about herself and the situation. The waiting
room was dull and boring with not much to preoccupy her. When she did get help
she spoke to a nurse who offered her some pain killers before going to see a
doctor. She told the nurse that she had already taken some pain killers before going
to A&E but the nurse was insistent on her taking some. It was only after she
stressed that she had taken some only a few hours ago the Nurse stopped. She
was then seen by a Doctor who was helpful and gave her ways to make the
recovery process quicker and some crutches to use until she was able to walk
again. As an overall experience, she wasn't happy with the help that she had
received.

Where to go for support when in school was raised by many of the young people. While some young people thought the school nurse was helpful and approachable, others had no idea where to go for help and support about a physical or mental health issue in their school. Some young people also described their school nurse as unapproachable or unfriendly.

A young person's experience of her school's matron (aged 16) - as told to a Young Listener

She was having a bad asthma attack in school and went to her school matron, the school are aware of her asthma and therefore she thought they would be able to help her. When she went into the Matron's room she didn't feel comfortable talking to the Matron as she is quite blunt and unapproachable. She seemed like she wanted to be somewhere else rather than helping her, making her feel self-conscious and vulnerable. When she told Matron about her asthma attack the Matron didn't seem to believe her and told her to 'just deal with it' making the girl feel upset and alone. The Matron then left her in a room for what she thought would be a short time however, the Matron had forgotten she was in the room and so she was left in the room from 11am-3pm with no help. The girl only left the medical room after noticing that it was the end of school and went home, not having received any help. This experience has made her not feel comfortable going back to the school Matron even when she feels like she really needs help.



65% of the young people asked said they felt respected



5) Many young people had experience of using CAMHS. They felt that the waiting time for an appointment after being referred to CAMHS was too long. In some cases young people were waiting 8 weeks for an appointment after being referred by the GP. Young people felt that they weren't being listened to and felt that medication was being offered instead of counselling or therapy that could help them work through their problems. Young people also said that they found it unhelpful seeing different mental health professionals each time, and found re-explaining life events traumatic.

"It has taken the specialist five months to give me an appointment for my ADHD diagnosis. No other support has been offered to me whilst I have been waiting"

Young Person





Another concern of many young people was the transition from children's mental health services into adult mental health services. Young people were concerned about the change from CAMHS to Adult Mental Health Services, with many having older siblings who had experienced a lack of continuity. This led to them worrying about their own transition and if they would get the support they needed.

"I used to have support from CAMHS but because of my age there is no support through sixth form and university...I don't know where to go...I feel like any support I had is going away."

Young Person



A young man's experience of mental health services (age 18) - as told to a Young Listener

This individual was hesitant to share his views on the mental health system. He started by telling me miscellaneous complaints about long waiting times and he didn't think he had anything relevant to say. Eventually he opened up about his situation with adult mental health care services. Due to his age, he can't see a paediatrician anymore and so he has no way to get support. He doesn't know what to do, where to go or how to get support because he has slipped away from the children's mental health system and into the adult one and the support is going away. He feels he will struggle throughout sixth form and university because of this lack of support. He also believes that now that he's an adult, there is no team of health professionals specialising in long-term support. This 18 year old feels that GPs don't specialise in mental health and that a solution to this could be long-term help that's readily available to his age bracket.

7) Young people of all ages felt that waiting times for appointments with healthcare professionals were too long.



49% of the young people asked expressed how unhappy they were with waiting times

- 8) Many young people spoke about their experience of using the ambulance service, either having to call for themselves or someone they cared for. All of the young people that spoke about this said that they were made to feel safe and reassured, even though the journey in the ambulance itself might have been scary.
- 9) The young listeners found that many young people would seek advice from someone in person, but that increasingly more young people were seeking advice and information online. While they recognised that there is increased awareness around mental health and emotional wellbeing, they were worried that this may have become glamorised and those that need support may not be confident enough to ask for help.

"I broke my arm at home when I fell down the stairs. It hurt a lot but I felt safe once they put me in the ambulance and explained what was happening"



75% of the young people asked, felt that they could get help confidentially



A key element of the success of this project was the fact that young people were given the opportunity to share their experiences with their peers, and this led to the Young Listeners gathering feedback that perhaps a young person would have been less likely to share with an adult.

"It has been so good having someone to come and listen to us like this. I wish they offered it for all sorts of things around Wiltshire so that young people can have our voices heard around more"

What we will do next

We will work together with the Young Listeners to share what they have heard with the commissioners and providers (the people who plan, pay for and run services) of services so that the voices of the children and young people who spoke to the Young Listeners can help shape services in the future.

The Young Listeners will also carry out further listenings looking at some of the key messages that were heard. These will focus on:

- Health in schools
- Mental health and emotional wellbeing

Thanks and Acknowledgements

Healthwatch Wiltshire would like to thank all the children and young people who took the time to share their experiences and views with the Young Listeners. Thanks also go to Youth Action Wiltshire and Community First, and finally huge thanks to the dedicated Young Listeners who gave so much of their time to allow other young people the opportunity to be heard.

FIRST





Supporting community engagement and action











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