

"So here's the thing"

A video diaries project by young people about their mental health



Contents

About us	
Summary	4
Introduction	
Method	7
Findings	8
Recommendations and/or next steps	144
Responses	
Acknowledgments	157
Appendices	177
References	177



About us

Healthwatch County Durham



This report has been produced by Healthwatch County Durham (HWCD). We are an independent organisation whose aim is to help people get the best out of their local health and social care services, whether it's improving them today or helping to shape them for tomorrow. Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience.

As a statutory watchdog, our role is to ensure that local decision makers put the experiences of people at the heart of their care so that those who buy (commissioners) and provide our services (NHS Trusts, GPs, the voluntary sector and independent providers) can benefit from what people tell us.

The Healthwatch network consists of 152 Healthwatch organisations across each of the local authority areas in England. It also has a national body called Healthwatch England based in London.

For more information about us please see click on this link: Healthwatch County Durham



Summary

In 2020/21 Healthwatch County Durham invited the public to vote on their priorities for health and care services, to inform their work plan for the next 12 months. One of the priorities that emerged was Children and Young Persons Mental Health.

So, over the course of 2021 we engaged with over 900 children with a wide range of activities and focus groups. Our report on the findings was published in March 2022. This piece of work concentrated on primary school age children. The report was well received by service providers and commissioners. Health

We wanted to know what we should do next and, after talking to both Public Health and service commissioners, we decided to undertake a further piece of work that looked at the mental health experiences of young people between the ages of 13 and 25 years.

We were interested in looking at alternative, creative ways of engaging with young people in this age group. We wanted it to be powerful, 'bringing them into the room'. We wanted them to be able to express their views and experiences directly in their own words about services they'd interacted with in County Durham.

Quotes from the young people we interviewed:

"When poorly, it was easier to focus on other people's problems rather than facing mine, so hope this helps encourage people to talk about their struggles"





"Understanding that what was happening to me happens to other people, but it was the way I dealt with it that was unhealthy"



"Counsellors were very different to each other, first often phoned in sick and only talked 'at' me, gave me medication. The second listened to me as a person rather than as an illness"

"Understanding triggers-will get angry and frustrated for no obvious reason which can then lead to a panic attack. Loud noises and bright lights can trigger an attack also"





"Informal support-when you are aware someone is just doing their job-it is different"



So why use video diaries?

Video diaries can be made in a wide variety of settings, this could be in people's own homes or other places where they feel comfortable and safe. It's a powerful way of people being able to tell us what's important to them in their own words. They are a good way to reach people whose voices may otherwise go unheard.

We also realised that after the project was finished, we would have a valuable resource that we could share on our website and other relevant social media platforms.

Our three videos have been successful in getting some important messages across to the commissioners and service providers, and their responses have been very positive. Some of the key responses can be found later in this document (Page 17)

We have also shared our findings with both local and national Healthwatch.

To see the final videos please see the links below:

Adam playlist - (111) Video Diaries - Adam - YouTube

Andrea playlist - (111) Video Diaries - Andrea - YouTube

Mia playlist - (111) Video Diaries - Mia - YouTube



Introduction

The project involved five engagement volunteers, one volunteer board member, a community film maker and the Volunteer Supporter (HWCD)

It was important that from the planning stage onwards there would be input from the key partners included, responding to issues raised in the videos themselves. This would give confidence to participants and volunteers that the experiences shared would be used to influence and inform partners and providers about the way services are delivered. Once the videos were completed, we felt it was important that we got prompt responses to the issues raised, including anything that might take longer to resolve.

The HWCD board were happy to support the project, which included additional funding requirements to meet the project costs. The next steps were:

- Identifying participants
- Agreeing the way they were happy to be involved.
- Finding a film maker that was sensitive to the theme and to the young people we would be working with

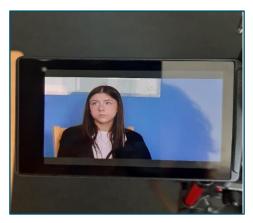
After identifying three participants that matched the criteria, we worked with a community film maker to capture four videos with each participant over a period of time that fitted in to their circumstances. The participants had pre-set questions and prompts in order to best share their experiences (video links are included at 'so why use video diaries'-page 5).

Some of the questions we asked the young people to talk about and answer were:

- Describe issues leading to concerns
- Why did you agree to take part in this project?
- What matters most or is most important to you?
- Did services make connections between physical and Mental Health?



Method



Capturing user feedback by making 'Video Diaries', particularly with younger participants, was a new way of working for us that we thought might have more appeal.

The volunteer group met several times to consider the initial ideas and who to involve. They also made sure that the project paperwork was in place and understood before talking to any young people. Areas such as GDPR considerations, safeguarding awareness, suitability of timings and venues, relevant consent

amongst other things, had to be in place.

The next issue was to identify the three young people who met the criteria; age range (13-25 years), living in County Durham and had experience of support from services either now or in the past for Mental Health issues. We were aware of the sensitivities of how young people might be hesitant in getting involved, given the subject matter and the medium used. Service providers put the word out to their user-groups, and this resulted in two of the three participants being signed-up. We ran an advert across our social media platforms for the project, inviting young people to contact HWCD if they were interested. We also asked the young people about a title for the project and 'So, here's the thing' was agreed as the most popular.

In order to record and understand the young people's experiences we organised 4 separate sessions (as well as having a pre-meeting, which sometimes involved family members as requested/required) with each participant.

Two of the three participants were happy to be videoed sharing their experiences, but one participant did not want to appear on video. This meant that we needed to find an actress who fitted the description (14-year-old female) who could present the scripted video.

We were led by the preferences and needs of young people when organising the video sessions. This included getting the timing of the sessions right and finding somewhere private and quiet where the person was comfortable. Sometimes sessions on the day would be shortened or re-arranged if need be.

When complete (but before editing), we were careful in making sure that participants and/or carers agreed and were happy with the content of each of their own videos and consented to their showing and circulation.



Findings

1. **Types of support** - were identified as a significant issue for all three young people. As well as understanding the need for formal intervention, they talked about the value of 'friendly, informal support', 'neutral, honest and open' interaction and the opportunity to have support that was non-pressured.

"Sat in a room which was quite formal with a worker, no friendship or relationship, felt like talking to someone who is being paid to listen"

2. Quality of support - whilst the young people recognised that services generally are stretched in this area, they felt that access to a counsellor required one hour (where most had been limited to 30 minutes). Another aspect raised was 'who the young person would like to involve and how' (agree the direction of communication, who would be best positioned to do this and to make sure all parties understood this). The young people, at one point or another during their care, felt that the focus was on treating the resulting associated behaviour, rather than the cause. They felt this was part of why they had been misdiagnosed at times which could have been avoided with further exploration and discussion. Being listened to and encouraged to talk were raised as important aspects of positive support. All mentioned that if staff came across as interested, it helped override the fact that you knew you were talking to someone who was being paid to listen. The type and character of person offering support, therefore makes a huge difference to how support is perceived and received.

"School counsellor takes in and listens to me, as a person through having a long-standing relationship"

3. Communication - All three young people said that to have information better explained to them would have helped. Where services could link up, for example to transfer information, this had helped lots by giving confidence that the person had been listened to and understood. Not to have to share with a new person all over again (especially regarding sensitive information i.e. - where self-harm had happened). People understanding connections between physical and mental health was so important in order to avoid misdiagnosis

"It's not the sort of thing you want to have to keep telling a stranger!"



4. Difficulties - Understanding early 'triggers' was identified by the young people themselves as being useful in order to avoid distress and further poor health. 'Over thinking' clearly leads to anxiety, which can further develop into negative areas such as mood swings and isolation. Wider issues such as bullying can result in poor Mental Health and other things such as medication and simply a change to a person's living situation can lead to difficulties. Appreciating that physical symptoms can be a result of some underlying worry or concern, which if treated may resolve itself. Where exposed to unknown people and settings, this can be difficult so requires support and understanding to do this. People judging does not help, this leads to stigma and unfair perceptions. Guilt of snapping at loved ones is awful but also unavoidable it seems, at the time. Seeing past and beyond diagnosis was raised as important.

"Tactics-learning to leave a situation, time to relax and think before getting to a breaking point"

5. Most important - Family and friends, what came through strongly was that 'family and friends' were one of the most important things to participants. The young people also mentioned how developing tactics to manage a situation had helped them (services had helped with this). We heard more than once that some of the hardest things were having to talk to strangers formally in services (especially when their details had not been communicated prior to meeting). All three told us that meeting their goals were important. All three young people mentioned that what would have, and would make things easier, would be if services and people generally looked beyond a symptom to understand the cause

What does this mean for the people who took part and what could be done to overcome this?

There were consistent, repeated messages that came from the young people:

- There is a need for mixed support in terms of both formal and informal interaction. Also, the quality of the care has an impact; if it feels pressured there will be a different response.
- Young people feel strongly that they should be both listened to and encouraged to talk. Better explanation of information is needed, which would result in better understanding and avoid further anxiety.
- Seeing that triggers can have an impact is very relevant too.
- The friendliness and interest of staff makes a big difference in avoiding the feeling that people are being paid to listen/care/support.



- There should be more focus looking at tactics to avoid further ill health, this would be helpful.
- Services need to consider and understand individual goals, as these are very important to young people.
- Consider an emphasis on treating the cause rather than symptoms-although probably more time consuming this is important. So being aware that physical symptoms often are a result of other underlying issues.
- Instilling awareness that bullying, unfair judgment and over thinking can lead to poor Mental Health.
- Guilt is a negative thing for young people to deal with, and it often occurs in relation to other family members and friends.



• Talking to strangers is difficult and uncomfortable, so where the sharing of information can happen between staff members and service providers, this will really help.

Main issues/experiences raised:

Described issues leading to concern/s:

- Meeting new people and new situations (especially when having to talk), which progressed into an anxiety disorder
- Diagnosed with Autism and anxiety disorder, depression. Anxiety has roots in bullying (victim of bullying for 14 years)
- Overthinking things was not healthy

What matters most or is most important:

- Family and friends (especially as could not make friends until recently, found it impossible)
- Family and friends always supported and listened to me. Never judged me
- Now have some good friends (very important)
- Completing college/further education
- Meeting my goals/aspirations

Why were you interested in taking part:

- Breaking down the stigma of Mental Health
- Links well with my college course
- When poorly, it was easier to focus on other people's problems rather than facing mine, so hope this helps encourage people to talk about their struggles



- Because it's important for people to know that just because you have a Mental Health diagnosis, you are still a person, have emotions, and a personality. Some people don't see past the diagnosis
- Important for people to know that bullying can lead to, and have a Mental Health impact on a young person

What might have helped/made things easier?

- If asked who I would like to have involved in my care (also would help in avoiding assumptions being made)
- Consider that individuals manage amounts of pressure differently
- If services looked beyond a symptom to understand the cause
- Having one hour counselling session rather than just half an hour
- More workers available
- Information relevantly shared prior to support
- Being able to communicate directly with my mam myself rather than the services ringing mam (vice versa)
- Understanding triggers-will get angry and frustrated for no obvious reason can then lead to a panic attack. Loud noises and bright lights can trigger an attack.

How and when did you know you were feeling/getting better and improving?

- Sleeping improved
- Mood was better
- Gradual change to better self-control
- When I stopped isolating myself
- Times when it was not as bad -I'd be distracted with other activities (Football/video games for e.g.)
- Medication helps but sometimes takes/alters my emotions (so that's a cost)
- Don't really know because I'm not better

How are you now?

- Unusual sleeping pattern
- Now left school -much happier now
- If unduly pressured still will sometimes overreact or shut down
- Much improved, can still get anxious but have a different mind-set where I don't catastrophize situations

What was the hardest thing about that time?

- Seeing family going through this and not understanding it
- Unfairly snapping at family and the guilt afterwards
- Having to talk to strangers in services (especially when story had not been communicated prior to meeting)
- Other people's unfair perceptions- 'so you can do this- but you can't do that!'
- Moving from one person to another (services)
- Over thinking issues



- At my worst constantly asking had I said anything over and over again-so annoying my parents, but I couldn't stop
- Not being able to be happy without being sad. Mood swings create an apprehension of not having one without the other

Did services make connections between physical and Mental Health?

- Anxiety around going to school made me physically sick, but services didn't see this as a side effect and wrongly diagnosed an eating disorder
- Yes, services saw that tummy aches and headaches were associated symptoms
- I started putting off going to sleep until later and later as going to bed meant being alone with my thoughts-overthinking things
- CAMHS recognised and helped with self-harming but not the sleep, as it was not that bad then. It got much worse when I moved into my own place it got bad
- 'Durham Help' were great and able to put two and two together. They supported and listened to me and tried to get me back into my hobbies
- 'Durham Enable' recognised my need and supported me in looking at getting some work

What did help?

- Having parent involved (especially so I was able to ask to do something/go somewhere instead of sitting in my bedroom)
- Music
- Tactics-learning to leave a situation, time to relax and think before getting to a breaking point
- Understanding that what was happening happens to other people, but it was the way I dealt with it that was unhealthy
- School having open ended support (trusted relationship there)
- Access to the same person
- Understanding when I was over thinking something (CAMHS helped with this)
- Project-where I have an informal group of friends. Just a place to hang out, if you're having bad day, you can approach staff who you know will listen. Open up more to friends here
- Informal support-when you are aware someone is doing their job-it is different
- Cater for individual need-just because something works for one person it won't necessarily for all
- Having someone neutral to talk to, not family or friends but also not a stranger
- Honesty and openness help you relax and allows you to be able to trust
- Interacting with services as I want to get better, if I don't follow advice how will I do that?
- 'Durham Help' not pressurising me or asking me to do anything I didn't want to do. They were interested in my hobbies, working out what I'd enjoy taking my mind off what I was going though

Do you have someone to talk to now?



- Parents-never judge me, let me talk
- My old school counsellor-she is my 'safe' person

When did you feel proud of yourself/aspirations for the future?

- In work-nice email from a parent saying I'd made SEN child feel comfortable
- Better with going into uncomfortable environments and getting used to talking with people more
- Go to University away from home to study law
- Taking part in this project
- Passing my driving test, improving at the gym
- Passing my college course and want to join the RAF
- I wish to build robots, own a business, talk about autism and anti-bullying. Move my anti bullying campaign ('Together against bullying') forward
- To be mentally well again



Recommendations and/or next steps



Services should look at the most appropriate type of support, both formal and informal to suit individual young people. Providing good quality care with appropriate offer of time to both be listened to and encouraged to talk. Ensure staff members can provide information with good explanations of what is being proposed and that it is fully understood.

Services and staff need to be aware that 'Triggers' occur and look at offering tactics to enable young people to manage their own poor Mental Health

and/or unhealthy responses (including the area of dealing with guilt). Services should consider focusing on treating the cause as well as the symptoms.

A wide scale drive to instil awareness around what can lead to poor mental health generally, would be welcomed (specifically around bullying, over thinking and unfair judgement).

Services need to ensure that staff members need to be approachable, have empathy, be friendly and interested in order to bring confidence and trust to a young person. Sharing information to relevant people should be an automatic response and should be a priority.

When considering care, services should appreciate that young people have individual goals that are important for the future that can be affected.

We will use what we have found out to inform commissioners and service providers which will allow them to reflect on the way in which the support is delivered allowing them to learn from good practice and make improvements



Key stakeholders Responses to videos

"I think they're incredibly informative and show a realistic portrayal of these young people's individual experiences. I'm not entirely sure they represent all young people in County Durham, but they are certainly true to themselves. These young people were incredibly brave and it's a shame there weren't more young people involved, but I'm afraid the stigma around mental health makes it incredibly difficult to get young people to publicly engage. I was very impressed with what was produced"-Catharine Harwood (Participation & Engagement Officer, Durham Youth Council, Durham County Council)

"Love the videos, as I said at the presentation hearing from the young people themselves is very powerful and I'm sure many other young people will be able to relate and hopefully will give professionals and services working with young people a greater degree of insight into their experiences of mental Health. Transcripts are a helpful addition especially in relation to accessibility. I will share with CYPS Commissioning colleagues. I will also share with The Bridge Young Carers Service as I think something like this for young carers would be fab too - they could use these as inspiration for raising awareness of the challenges young people face. I also think they will find them useful as many of the young carers they work with need support with their MH. Thanks to you and the team for all your efforts in producing these" -Rachael Mawston, Commissioning Policy and Planning Officer, Durham County Council

"Thank for allowing us to view these deeply personal video diaries as part of this project. The young people (Adam, Andrea and Mia) have shown great courage in sharing their experience of CAMHS services in County Durham. As commissioners of mental health services, we will challenge our providers of CAMHS services to address the important issues raised, including:

Continuity of clinician wherever possible, to build trust

Developing care plans jointly with the individual, explaining clearly the process and next steps

Discussing with the individual service user who they would like to be involved in their care

Which services they would like information to be shared with (to prevent having to repeat difficult conversations)

Recognising the difference between the symptoms and causes of anxiety

Consideration to the physical environment of service delivery (informal settings where possible)

With permission, we would like these videos to be shared with the County Durham Mental Health Partnership and the Northeast and North Cumbria Integrated Care Board Quality and Safety Group for their awareness/action" -Rob Milner Quality and Development Manager, Northeast & North Cumbria Integrated Care Board



"I would like to share the link to these videos with ICB involvement leads, and also the ICB Quality & safety Committee, so they all have a chance to view them for themselves"-Daniel Blagdon (NHS NORTH EAST AND NORTH CUMBRIA ICB)

"These are powerful and insightful recounts of lived experience that are valuable for all professionals working with young people to have access to and use (e.g., in staff inductions/training for example)

Some of the negative experiences described in them, we as a service are acutely aware of (ease of access to support, services not being joined up, repeating their story, 'not listening')

We are engaged in various pieces of work internally at TEWV-CAMHS and with the local authorities & other partners across Durham and Tees to streamline and improve access to support, improve the 'quality' of advice given to young people and carers, and remove the burden of families and young people to navigate what can be a complicated system

I envisage further opportunities to hear and use young peoples (with lived experience) voices in this work and will certainly be looking to link in with yourselves to do this, if you are agreeable" James Graham (General Manager - Durham and Tees Valley Community CAMHS, Tees, Esk and Wear Valleys NHS FT)





Acknowledgments

Thank you to the four amazing young people who made our videos come to life. (Three who gave us their experiences and one who was an actress and portrayed one of the stories)

Also, to -

Harriet Wright (Healthwatch Leeds) -advice and support

Kris Taylor-Community Film Maker

Waddington Street Project-use of venue

Investing in Children (Chris Affleck and Nicola Hall)

Durham Youth Council (Catherine Harwood)

HWCD Volunteers input throughout project (Anne Thompson, Tony Bentley, Mervyn Hockin, Mia Grimes, and Helen Smith)

HWCD Board support (especially to Zena Forster who acted as an initial mentor) and to the staff team for support throughout the project

Appendix









QUESTIONS 1-4.docx information sheet HWCD Video Video Diaries HWCD for participarGDPR-Data Diaries Il Project services inter

References



Young Person's Mental Health Report 2022(2).pdf