



Black Country Children's Mental Health report 2022

Introduction

Black Country Healthwatch which consists of Healthwatch Wolverhampton, Healthwatch Dudley, Healthwatch Walsall and Healthwatch Sandwell are your local voice for the public in the delivery of health and social care services. They collect feedback from the public about their experiences of using health and social care services and use that feedback to work with service providers and commissioners to develop service improvements.

Throughout the pandemic, Mental Health in young people has exacerbated due to minimal socialising with the lock down, not attending education and having to support relatives. It was agreed that Black Country Healthwatch would carry out a collaborative project. Planning meetings took place to ascertain the common themes. One of the areas that all four Healthwatch were hearing was around the transition from children's mental health into adult mental health and this report will give you the findings of young people and their parents / carers.

The project was originally due to be completed by July 2021, however due to the ever changing with the lockdowns and extension of Healthwatch contract(s), the project continued through to end of March 2022.

Methodology

We used a mixture of ways to collect feedback from young people and their parents / carers across the Black Country around their mental health and experiences of transitioning. Firstly, we used a survey in order to reach a wide cohort of the public. The survey was an online survey shared via our social media channels, but we also made hard copies available at engagement events that were carried out across the Black Country.

We carried out six focus groups and 17 interviews, to gain a deeper understanding of how people's mental health has been affected due to the pandemic and what support was available.

Who took part?

We received 59 survey responses, 27 participants took part in focus groups, and we conducted semi-structured interviews. Participants in the focus group were able to complete the survey as well if they chose to. Survey respondents were asked a series of demographic questions but were free to choose not to answer those questions.

Those attending the focus group were not asked about their protected characteristics in order to help preserve their anonymity.

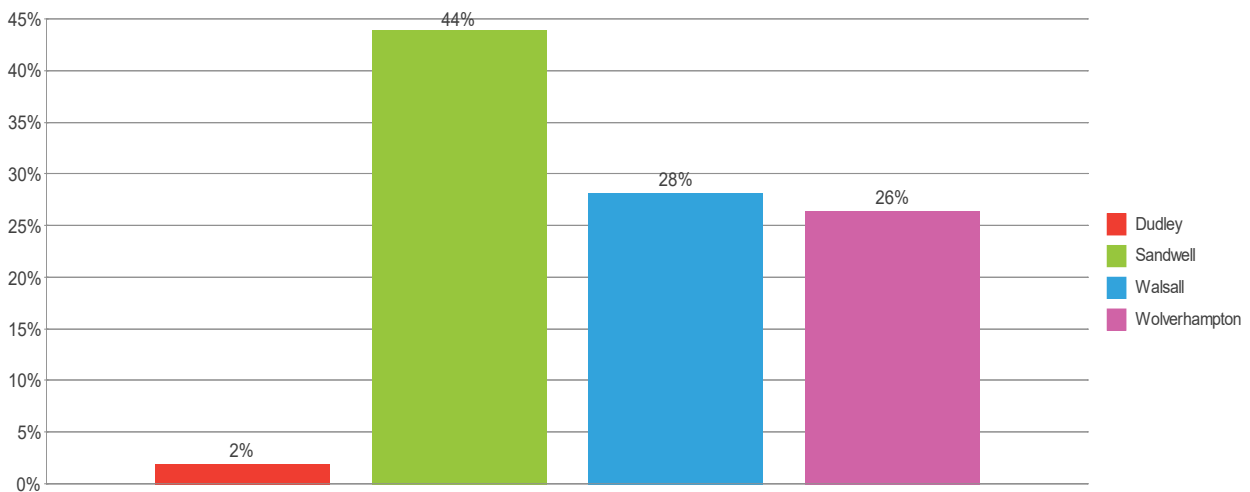
The project was targeted at young people and their carers across the Black Country who identified themselves as having poor mental health and those transitioning from children to adult services.

The numbers taking part in either the survey or the focus groups was relatively small and as such is not a representative sample of young people living with mental health conditions across the Black Country. What the findings offer is a snapshot of the experiences of the people who took part and an opportunity to learn from their feedback. Some of these experiences have been included within this report as case studies and can be found as part of Appendix 1.

Survey Findings

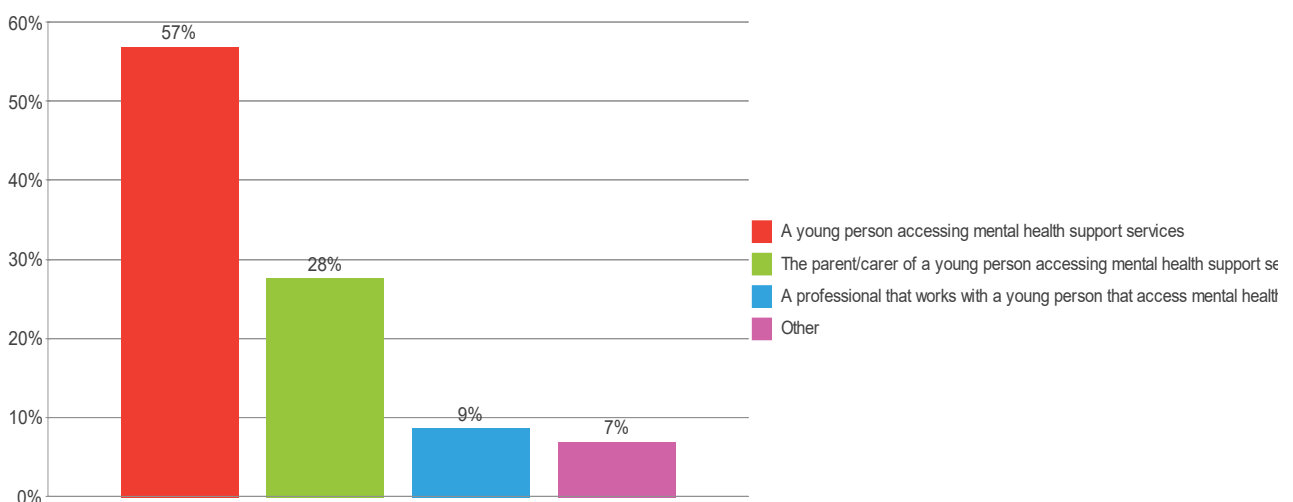
Most of the respondents reside in Sandwell (44%) with fewest in Dudley (2%)

What area of the Black Country do you live in?



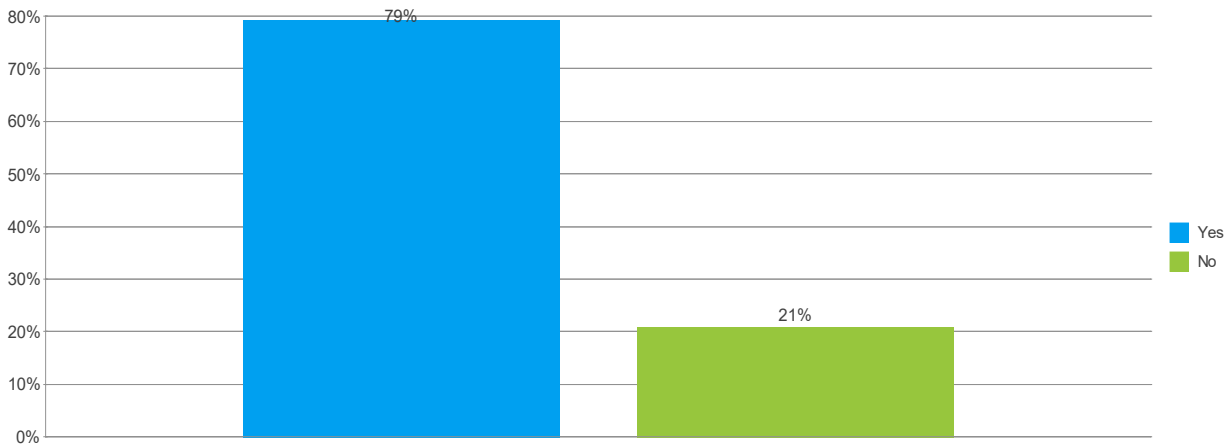
The majority of respondents are a young person accessing mental health support services (59%). For those that chose other, these were from an LGBTQ+ social group that are based in Wolverhampton but cover the Black Country surrounding area and family members whose siblings had special needs.

Are you:



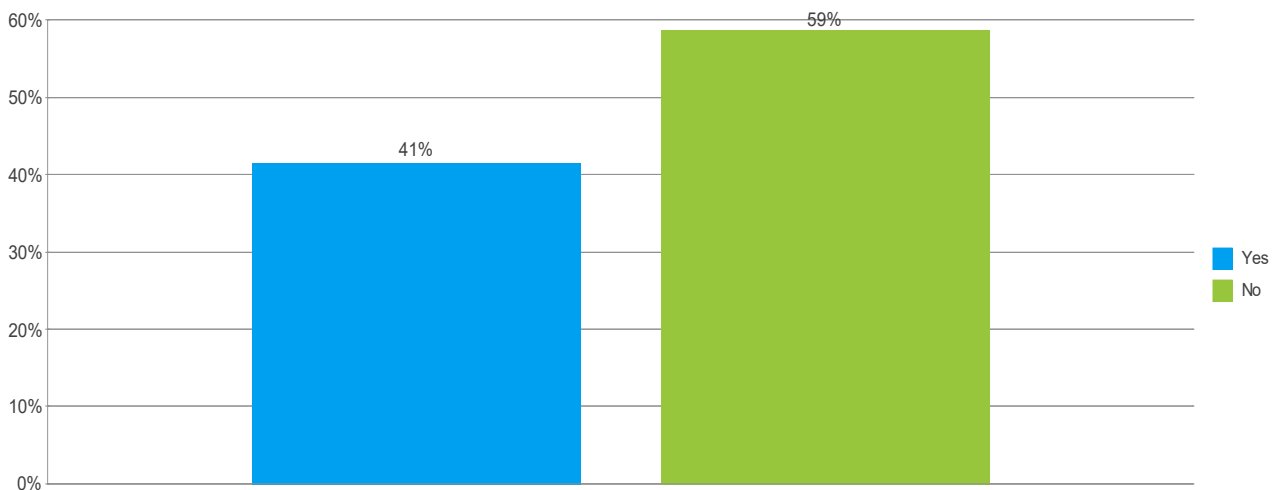
The large majority of respondents are aware of CAMHS (78%) but less than half are currently accessing CAMHS (47%). A proportion of the respondents were either users / or previous users of the service. A small proportion of the respondents were professionals who worked closely with the service.

Are you aware of what CAMHS is?



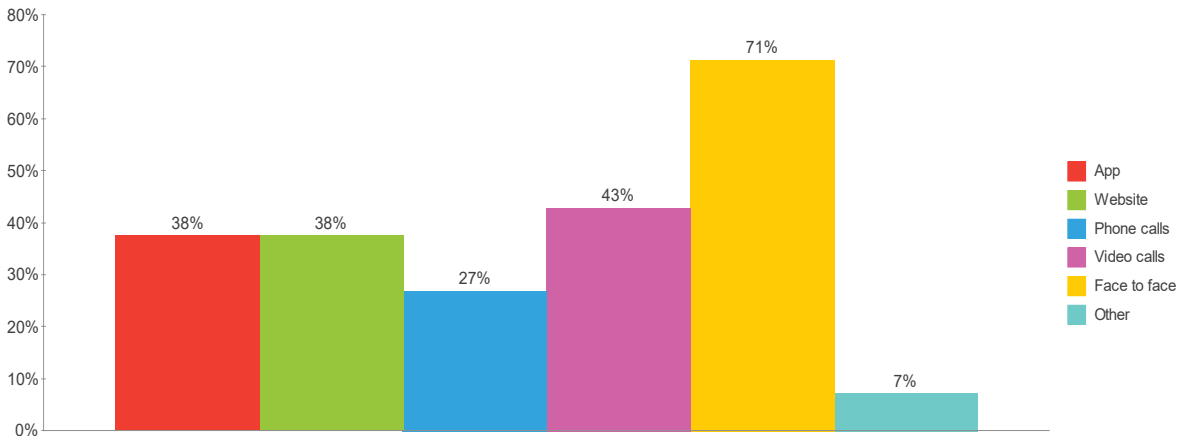
Most respondent did not know how to / or did not access CAMHS services (59%) with 41% of respondents expressing that they access or knew how to access the service.

Do you/they access CAMHS?



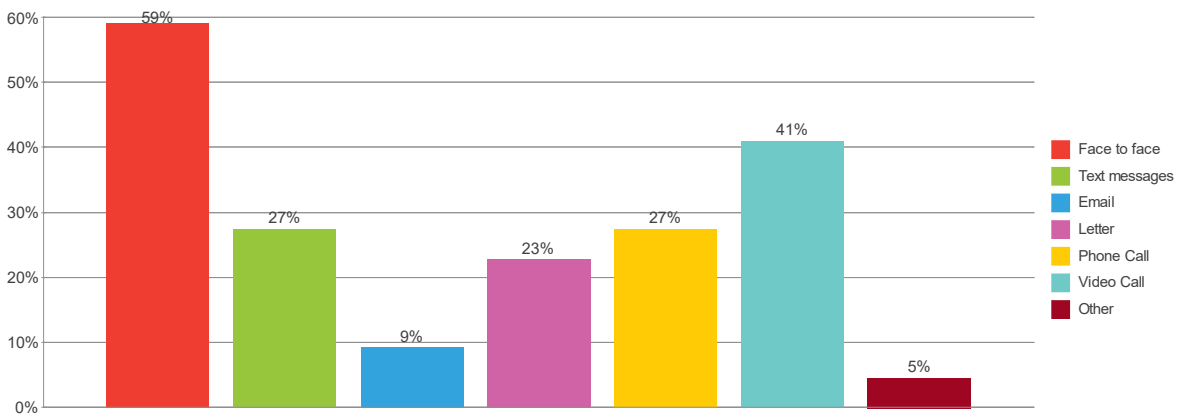
Most respondents would prefer to access their mental health support services face-to-face (31%) followed by video calls (18%), Apps (17%), website (17%), and phone calls (13%). This was largely similar for accessing CAMHS appointments. For those who chose other texting was an option they would prefer, with others expressing that they would prefer “anything that is quicker than the current wait”.

How would you prefer to access mental health support services? (Please select all that apply).



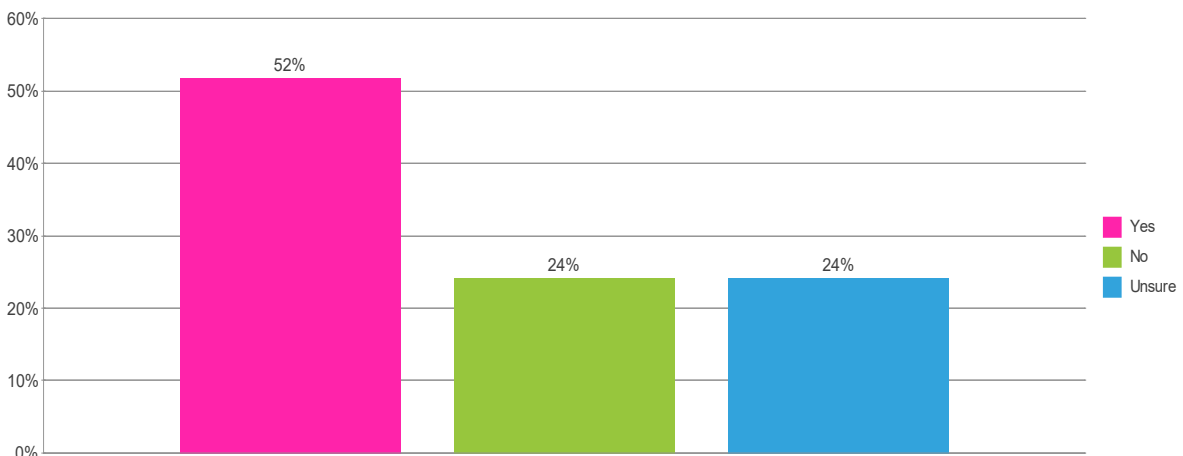
The majority of the respondents prefer face to face (59%), followed by video call (41%), with the lowest preferring email (9%)

How would you prefer to access CAMHS appointments?



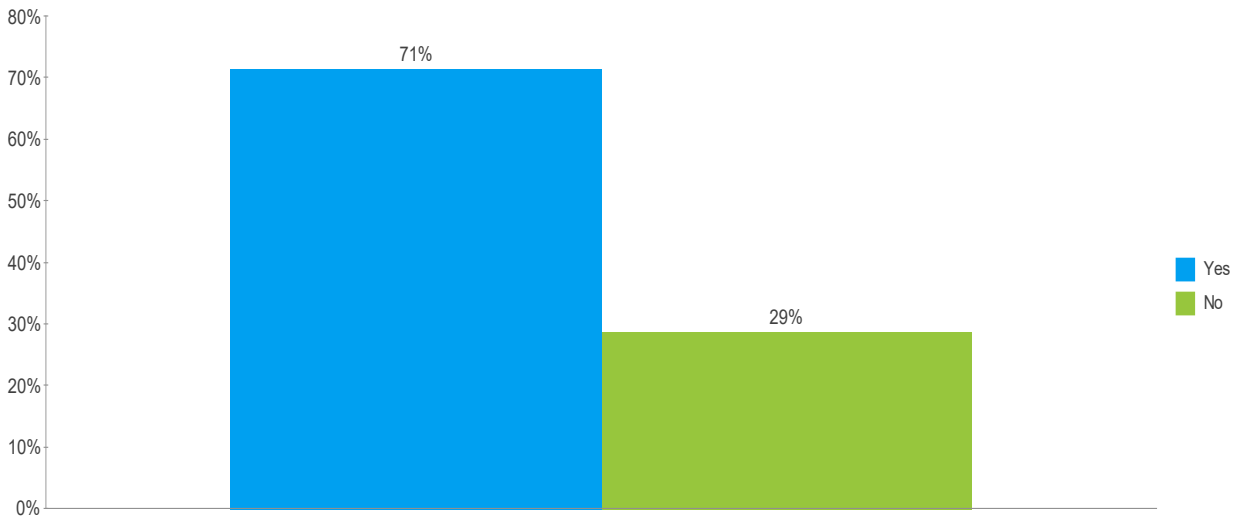
Most respondent know how to get referred into CAMHS services (52%)

Do or did you know how to get referred into CAMHS services?



Most respondents would like to be able to refer themselves into CAMHS without seeing a health professional first (71%). Some of areas that were given for this response was “It takes a long time to referred by GP”, “the process is too long”.

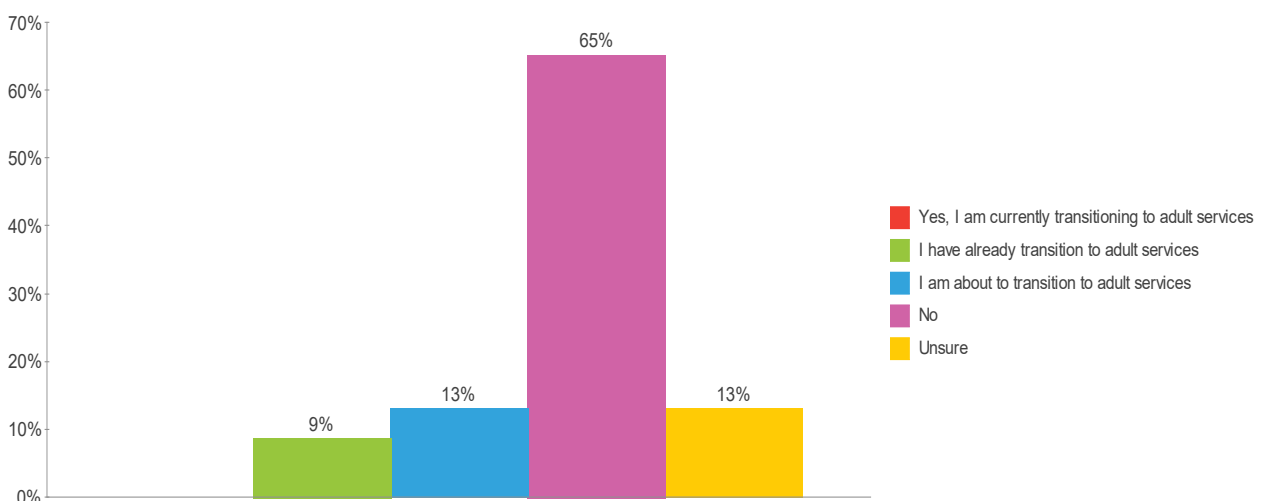
Would you like to be able to refer yourself/themselves into CAMHS rather than having to see a health professional first?



Participants were asked how long they had to wait for an appointment, this varied with 21% being seen within 4 weeks, 21% being seen under 3 months, 15% being seen between 3 and 6 months, 22% waiting to be seen between 6 and 12 months and 21% having to wait over 12 months.

Most respondents not currently transitioning from child to adult mental health services (61%) with no respondents were currently transitioning (0%), (9%) had already transitioned, (13%) were currently in the process of transitioning and (13%) unsure. Some participants expressed that “it had been a long road to get where have and a lot of assessments and meeting”, with some expressing that “it was non-existent, dropped at 18 and long waits”

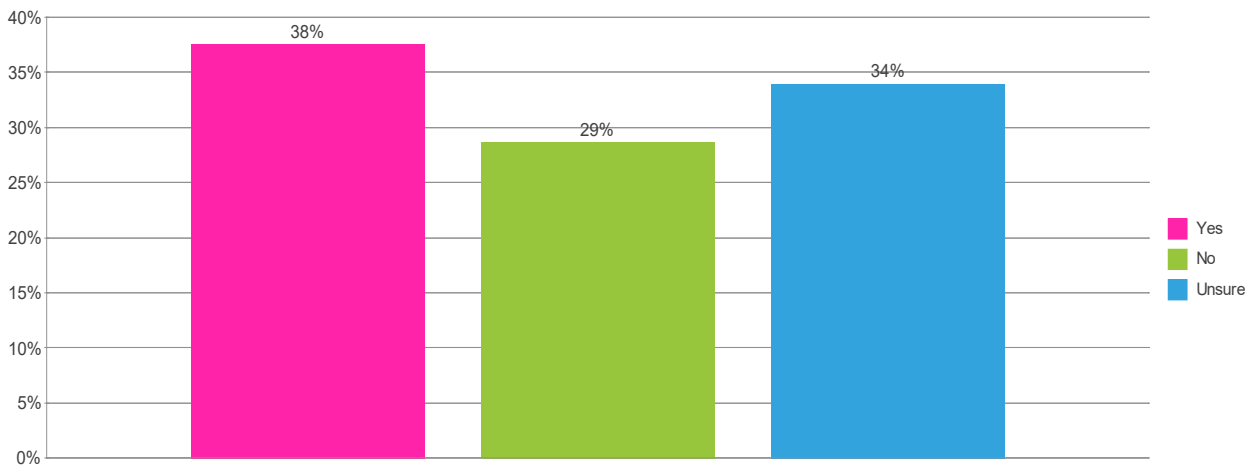
Are you/they currently transitioning from child to adult mental health services?



Some of the barriers or challenges that young people have encountered during their transition journey was communication between CAMHs and AMHs and “things are not taken seriously as a child suddenly in terms of adult services, they are not important”. Participants were asked the age they thought the age of transition should begin and end, the majority this should start at 18. With a small majority stating it should be 20 to 24 years.

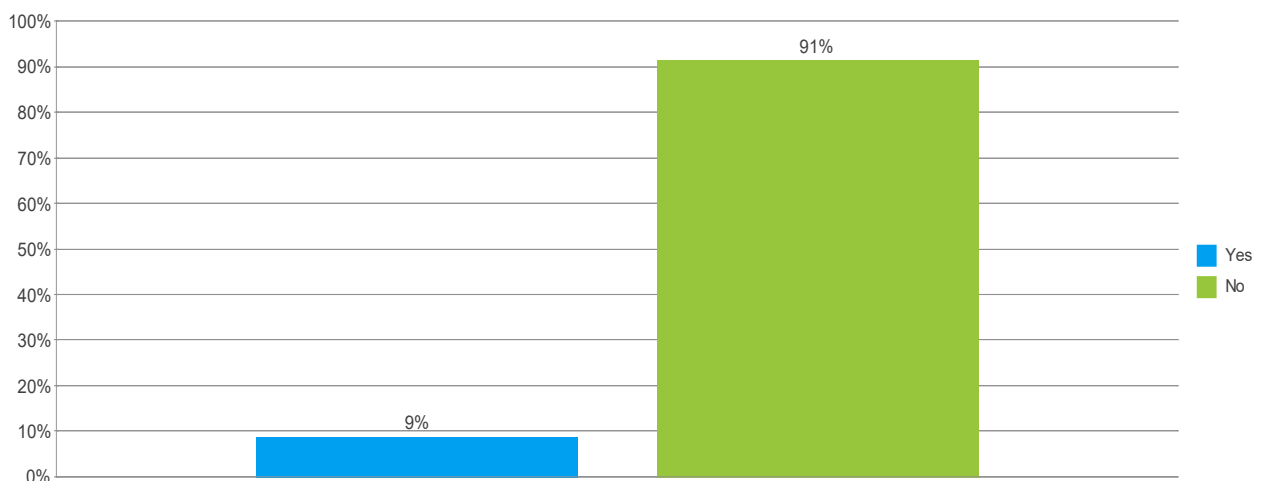
Only 39% of respondents would know where to go in a crisis with 62% not knowing or unsure where to go in a crisis.

In a crisis would you know where to go?



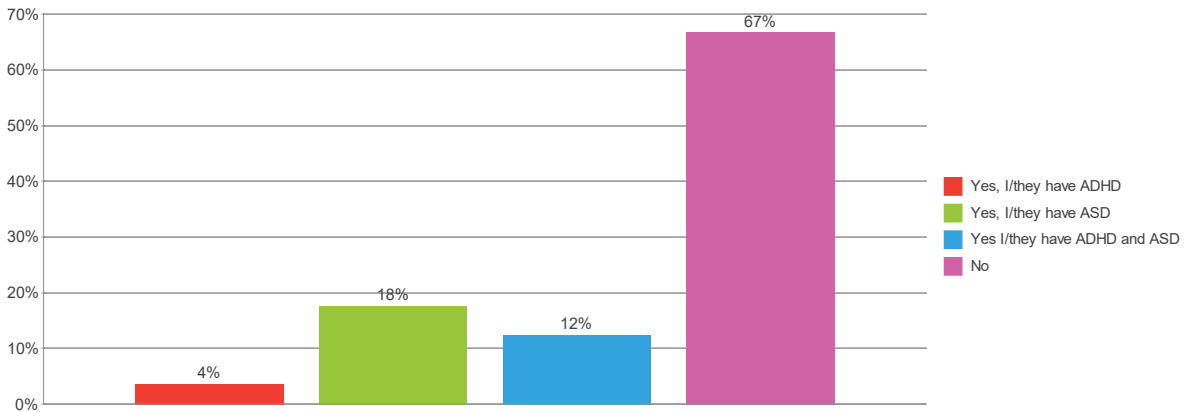
Only 9% of respondents have had access to the crisis team. The experiences were mixed of those who had access the team, with a small number having excellent experience and the majority not having a good experience at all especially “being discharged from hospital and not receiving a telephone call and being kept for 12 hours as no mental health nurse was on site”.

Have you had to access the crisis teams?



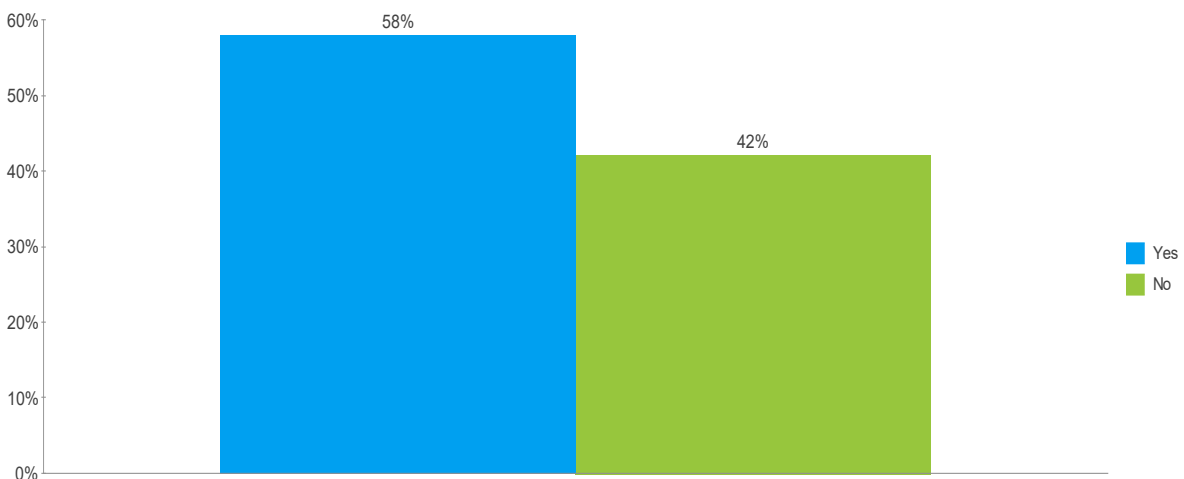
Most respondents reported they do not have ADHD or ASD (69%) with only 17% with ASD, 11% with ADHD and ASD and 2% with ADHD.

Do you/they have ADHD or ASD?



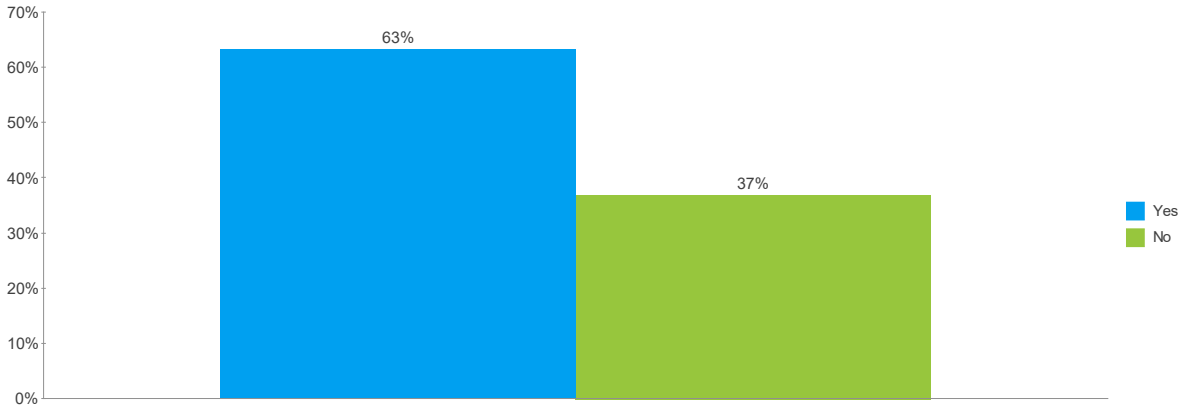
Equal numbers of yes and no for concerns about the assessments for ADHD or ASD (47%). 53% had concerns about support after being diagnosed for ADHD or ASD.

Do you have any concerns about the assessments for ADHD or ASD?



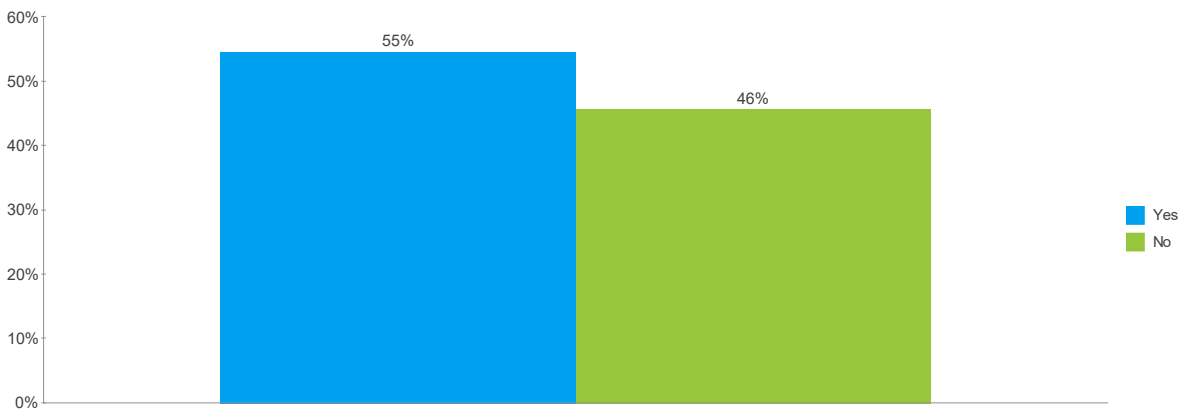
63% expressed concerns around their support after being discharged, these related to the CAMHs service in Sandwell “making the child feel uncomfortable, expressing that the room felt like a prison and the waiting room was too noisy”. “There is no autism support in Dudley”. There was limited support post diagnosis, or no support offered at all.

Do you have any concerns about support after you have been diagnosed with either of these?



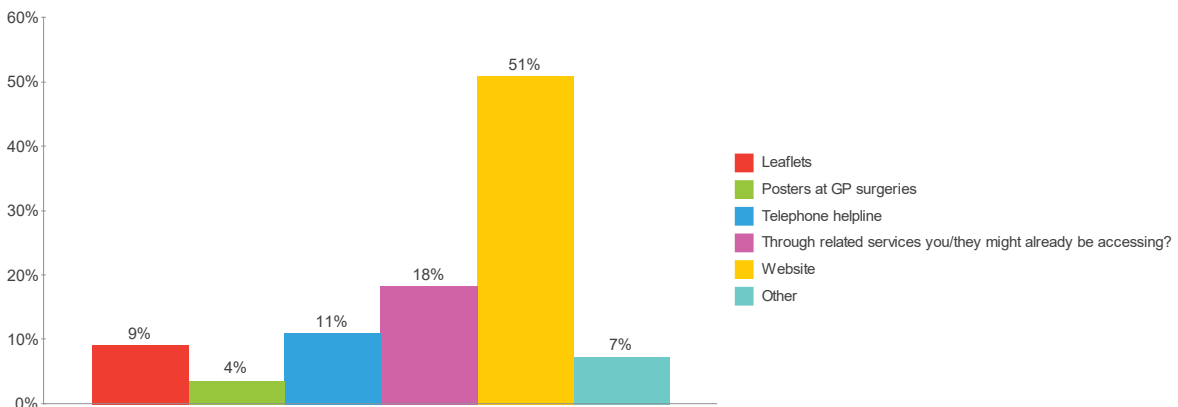
The majority of respondents felt like they are provided with enough information to support themselves (56%) and would prefer this presented to them through a website (50%).

Do you feel you are provided with enough information to support yourself/them?

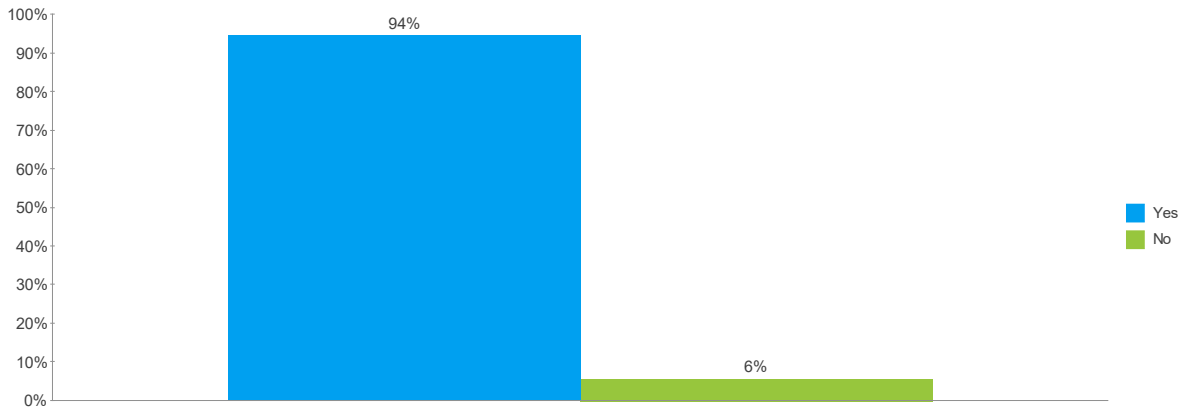


A large majority of respondents would prefer to have one contact number or website where they can go for more information (87%)

How would you like the information presented to you? (Please select all that apply)



Would you prefer to have one contact number or one website where you can go for more information?



When asked if they had a magic wand, what would you like to see with services, access and transition from CAMHS? Words ‘support’, ‘help’, and ‘communication’ cropped up a lot.

Focus Group and interview responses

Focus groups and interviews were carried out with several groups including Voice 4 Parents (Wolverhampton), Young Carers (Sandwell), athletics group (Walsall) a total of 27 participants were asked 5 questions; they had a choice to respond. Dudley carried out individual interviews and engaged with a voluntary sector-based counselling service for young people (The What? Centre).

The groups were asked “about their transition journey from Child Services to Adult Services” One respondent explained that they had turned 18 in April 2021 and a request had been made from CAMHS to AMHs and would be allocated a care co-ordinator, this did not happen, whilst another expressed that a initial meeting had been set up in November 2021 with the child and parent, however the meeting could not take place due to the child being in a placement and the family had been assured by CAMHS this would not happen. This meeting has not been re-arranged as they have been trying to do it term time.

Another respondent shared that they had been involved in the whole transition process and it went at their pace, whilst another one expressed that the “sessions make me take responsibility”.

One responded expressed that they had been in CAMHS and transitioned to adult services over 20 years ago and they are seeing no difference now.

Several of the respondents shared that they were either in the process of transitioning or had transitioned, for those that had transitioned no issues were identified, for those transitioning participants expressed that the process had started 6 months prior, however there a few that were in CAMHS but not accepted in AMHs as felt they did not meet the criteria and were referred back to their GP.

The groups were asked about “how involved and supported they were during the transition”. Several expressed that they were involved in the transition with some starting at the age of 16, with a number sharing that they had been supported and communicated with throughout. However, one participant expressed that they had not transitioned, and it was explained to them

why. However, another group responded, “What transition”, “services are not linked”, there is a lack of knowledge in adult services around the diagnoses in CAMHs.

The groups were asked around “did the services communicated with them around their care”. There were mixed responses with some having positive experiences with the way they were communicated with, however one participant expressed that they “were a little disappointed as they had to tell their story all over again”. Another expressed that the “only challenge was you had to grow and adjust to being an adult overnight”, another shared that AMHs has strict criteria and some of the illnesses that they are diagnosed as a child is not recognised when they are adults. One professional expressed that referring to services across the Black Country was different and sometimes difficult especially if the young person lives outside of the area that they are currently using for example if a young person is going to a school in Sandwell but lives in Dudley, the professional is unable to refer the young person into CAMHs as they only accept referrals from GP’s / Social workers in Dudley.

The groups were asked around “experience any barriers or challenges when transitioning”. The majority of the respondents had not experienced any barriers or challenges; however, a few had shared that there were concerns over the strict criteria to access AMHs, another shared that there had been a short delay in the transition and another sharing that they did not fully transition. However, one respondent had experienced and still experiences barriers and challenges with the support that is needed for their child. There is no joined up support when individuals don’t meet the criteria and “have to go into crisis before they get the support that they need”.

The groups were asked “what would they change”. A few shared that they had nothing they would like to change as their transition was smooth and they had not identified any issues. However, several expressed that they would like continuity of the staff that they see. Another respondent expressed that they would like to see a care co-ordinator that has a role within both Health and Social care, another respondent expressed that that a transition post needs to be across both children and adult services, more monitoring needs to take place when children are placed outside of the Black Country. Another respondent expressed that they would like to see the same styles of operating as they are different at the moment. Another respondent expressed that they would like to be prepared for becoming more independent, another expressed that they would have liked the transition to be longer as they “nearly disengaged” with the process.

Another respondent expressed that they would like to see more training in adult services to understand conditions that are diagnosed when they are in children’s services and the rationale behind it. Another expressed that they would like to see the health passport being moved across into adult services. Another expressed that planning needs to start earlier and individuals need to feel secure. Several expressed that they would like the information around mental health services all in one place and in a format that is easy to understand. There were suggestions amount having “counsellors drop in sessions at school because little things become big things”, also “more places to go for emotional needs, more youth groups, so don’t feel alone”.

Our recommendations

The Black Country Healthwatch partnership welcomes that the region is embarking on a journey of considerable and exciting change for local mental health services. We recognise that plans are already underway to join up service provision across the region, enabling communities previously served by different Trusts, to receive equitable mental health access.

The following recommendations have been drawn from recent experiences captured through this study and we hope that as services develop, the views we have collected will help to influence how services look and feel for children and young adults moving forward.

- ✓ Consider more continuity with the staff that children / young people see.
- ✓ Consider providing a care-coordinator that covers both health and social care.
- ✓ Monitor the support that children / young people receive when they are placed outside of the Black Country.
- ✓ Improve communication and awareness around CAMHS and how it can be accessed
- ✓ When children / young people are discharged from hospital ensure that follow up calls take place
- ✓ Consider the age of the transition from children to adult services as this varies across the Black Country, needs to be more consistent.
- ✓ Consider more training in adult services around the conditions that children are diagnosed with.
- ✓ Consider how health passports used in children's services could follow through into adult services.
- ✓ Work with partners including education, charities and community organisations and voluntary sector to better understand how physical and mental health services can complement each other to result in more joined up service provision.
- ✓ Build opportunities into new systems to continually listen to children, young people, and families, to learn from their experiences and to co-produce services in ways that are meaningful for them including age-appropriate activities.

Appendix 1 - Case Studies

Experience from a parent

A parent expressed that their child has Autism, OCD and Depression and has been placed on the crisis team at risk register during lockdown due to the family preventing them from taking their own life, they are now not allowed to be left at home.

The parent expressed that when seeking support, it was a “constant fight”, “everything is short term not getting to the route cause”, “someone who has autism takes up to 6 weeks to get used to individuals”.

“Crisis team support is dependent on who answers the phone”, “support for carers isn’t really there, its benefits etc but not practical support to give parents a break or even support for our own mental health”.

“If I had a magic wand I would like “long term consistent support” and “recognition that someone with autism can also have mental health needs and mental health support meets the autistic needs”.

Individual experience of CAMHs

Individual who is 19 has had episodes of “psychotic, depression and self-harm” and their experience of CAMHs was expressed as “bad”. The individual expressed that they were closed to CAMHs specialist services before they were ready which means their mental health continues to date. The individual expressed that they were left feeling that they could not go back to the services after being discharged at the age of 14.

Whilst receiving support from CAMHs they expressed that they were willing to get better and get help, but this never happened, they put a plaster on it. The individual expressed that “people told me.....medical people that I am a moody teenager and was asked if I doing this (self-harming) for attention”.

The individual expressed that having poor mental health support in the past they have no confidence using the services now.

“If I had a magic wand I would want to be listened, respected and being helped”.

Sarah’s experience of mental health services as a care leaver

My neighbour called the police saying that I was attacking my boyfriend when in reality, I wasn’t being aggressive to anyone but myself. The police asked if I needed any help with my mental health but there wasn’t ever any follow up. This was in 2020, I was 17 and had been trying for two years at that point to get a diagnosis by repeated calls to my GP that didn’t lead to anything.

I ended up calling the crisis team and was referred into adult services. I wasn't a child as had grown up in foster homes and had been living independently since I was 16. I didn't want to be patronised and hoped that adult services would give me the support I needed.

If someone is calling for help there is a reason, and it needs to be taken seriously, especially if services haven't heard from that person before. I had researched my symptoms and knew I needed help with my mental health, I told them that I was thinking of taking my own life, but they just told me to self-refer and prescribed me with promazine.

I didn't feel as though the crisis team were taking me seriously, but I did as I was told and went to therapy. I think it is only good when you are in the room and it didn't help me long term, I felt I needed more targeted treatment from a psychiatrist instead of drugs and what felt like silly advice, the whole experience was exhausting.

They told me to get a job because meeting other people would help me as would the routine. I got a job but I kept having panic attacks. My co-workers looked at me weirdly because I was the mentally ill one, I was told to take a month off to sort myself out and then they fired me.

If services had listened to me and worked with me to give me the support I really needed, things could be different for me. I also think that organised activities for young people are important.

I had lived in care since 8 or 9 so was offered activities as a foster kid, my advice to anyone planning this kind of stuff would be to use open terms such as 'youth club' rather than a mental health meet up and make sure that what happens there actually appeals to young people. They should be able to share their ideas and help plan what happens, so it feels welcoming and genuine. I went to a group that slowly worked up to higher value activities and it made me keep going, we chilled in the park, went to a trampoline centre and for attending everything we were taken to a theme park. I remember making lots of friends that summer and really looking forward to going every week.

I have turned down every mental health drop in because all they do is sit in a circle and talk, that really doesn't appeal to me. It doesn't have to be expensive; I went to a youth club in a local library that wasn't a big deal, just a few bean bags on the floor and a play station (the play station was very important). We played games, the one with lots of chairs where you walk around and they take one away and bulldog, though I think that one got banned!

Instead of saying you are here for your mental health, really concentrate on the activities and conversations can be built around that, you can learn so much from a ten-minute chat in between or while stuff is happening.

Presentations can be built in around sexual health or online safety to help people with their mental health. Some people will speak to anyone online and it can be so dangerous. I know people my age who have been groomed online; they have done everything at such a young age they haven't got anything left to give. The impact on them emotionally is overwhelming.

Ultimately, professionals need to treat young people as people and not as a chore, really listen and have genuine conversations, make me feel like a human, not a patient. Professionals have signed up to do a job and I know they get paid but it's also a public service, helping people should be at the centre of that.

Dominic's story of learning disability and low-level mental health support

My son doesn't fit into any boxes because he has never received a formal diagnosis for his learning disability even though he always had special educational needs. He was referred into a local day centre because he struggles with his mental health, and it was better than nothing but the environment wasn't right for him as a young man as it was mainly attended by much older people.

My son can get up and wash and dress himself though he would really struggle to be completely independent. He doesn't belong to any social groups at all and this further impacts on his mental wellbeing. It would be great if he had a mentor or a friend that he feels comfortable with, just someone who isn't his mom. He needs company, to find people with similar interests, friendship from peers, all of the things that I cannot give him.

I'm not criticising people who lead services, just commenting on the lack of support that there seems to be for people in my son's position. Help might be there for young people at school, college, younger people who receive benefits but then it stops when you reach a certain age.

We are in a fortunate position that we could pay for activities if we can find something that he can access but we don't know where to start looking - and what about other young people?

We have found some charitable projects, but it really feels as though there is a lack of statutory support, especially for lower-level mental ill health. If you were to ask him, my son would perhaps not be as concerned as I am, but I believe that if he doesn't become better connected and more resilient now, he will be less and less able to do so as he gets older.

As a mom I am doing everything that I can, but I worry so much about what the future will hold for my son and I'm not going to be here forever. We need support now before his mental health declines further.

Taylor's journey through children's services

My ex-husband was emotionally abusive and very controlling, he left home when my child was in primary school. My child accessed activities as part of a Sandwell Women's Aid summer programme during this time to help deal with emotions that they found useful. They initially had regular contact with their dad but after two years he told them that he intended to leave the country. This was a massive shock to my 12-year-old.

Two weeks later, in August 2020 my child lost sight in one eye and was taken to Sandwell hospital after being assessed by the ambulance service, it was even more concerning as my ex's family has a history of mini stroke (TI) so we were asked to go to Midland Eye hospital for more tests that night.

A few weeks later my child was taken to Sandwell A&E after experiencing audio and visual hallucinations which resulted in them being admitted to a paediatric ward in Sandwell Hospital where they had an MRI scan to see if anything in the brain might explain the symptoms (they had been on the waiting list for this following the sight loss).

Whilst in hospital, which was a week stay, Sandwell CAMHS were called in to do a mental health assessment. They did not think the visual and audio hallucinations were due to psychosis but felt some support was needed, my child was referred to ICAMHS in Dudley due to our postcode which

resulted in a face-to-face assessment and being signed up for 12 weeks of counselling sessions from a Dudley based charity The What? Centre.

These sessions were delivered online due to Covid and at the same time my child developed tics so we informed the counsellor. The counselling gave my child a safe space to disclose how they felt that they fitted into the LGBT community but wasn't sure where. Initially, they questioned their sexuality and went on to identify as non-binary.

I wasn't aware that they had been feeling like this and the end of the 12 weeks I was informed that they would benefit further from counselling, but we would have to pay for it, I don't know what information went back to CAMHS.

The What? Centre also invited my child to join a free LGBTQ+ peer support group which they continue to attend. They have found it extremely valuable with coming to terms with who they are, and I've always felt comfortable with feeding back any issues I might have as a mom. Engaging with the What? Centre has given my child the confidence to talk to school about their identity and to participate in a student voice group around equality. I don't think they would have done this otherwise.

At the time of receiving counselling the eye hospital diagnosed functional loss of the right eye, meaning there was nothing wrong with the eye and brain and that it was psychological. This led to discharge from the eye hospital without any further referral to other services, including sight loss services or mental health services, even though I was told CAMHS would be involved.

For a year and a half since discharge we have been requesting rereferral to any mental health services through the paediatrician and our GP. Eventually our GP took notice and made a referral back to CAMHS as a choice appointment assessment, this was after several days off school over several months, because my child's mental health and mine had both been deteriorating.

Choice Appointment assessment took longer than expected and had to be carried out over two appointments due to the complexity of my child's needs. During this assessment we were told that the development of tics had been happening to lots of children because of the emotional impact of Covid lockdowns.

We were also told that there isn't a specific service within CAHMS to deal with gender issues locally. We were referred to a service in London and informed there would be a two year wait, as it is the only service available to us in the country. This was disappointing but we have had some very recent positive news that our referral has been accepted.

Although my child has been assessed as having complex needs, we were still told that there isn't any tier three support available around their mental health currently, as self-harm and suicide risk cases are taking a greater priority. Even though my child had stated they were still experiencing negative thoughts and audio hallucinations.

We feel let down by statutory services both around the visual impairment and the mental health issues, due to safeguarding a youth worker was allocated to our case for a short time though some issues were addressed, referrals to mental health services that were promised still did not occur.

The only support we have had has been from services that we have researched and chased ourselves. No information surrounding the sight loss diagnosis was given by the eye hospital, we finally got help through small sight loss charities, but due to sight loss being a psychological issue we have not received any help from NHS or council services.

Our local independent optician raised their concern on how our case has been left and wrote to our GP requesting my child be referred into eye services. This was also followed through with a paediatrician. After months of badgering, we have received a new appointment for the Eye Clinic in Sandwell but I'm not sure what action made this happen.

Since the beginning of the year my child has received one to one support from a young people's service Here 4 Youth, in dealing with mental health and wellbeing. School staff have also been helpful and have tried their best to support both sight loss issue and gender identity, but we feel really let down in the main by statutory bodies, especially eye services and I would have hoped for better NHS and mental health support.

I know that mental health services are under tremendous pressure as a result of Covid, but I am also aware that mental health support for young people has always been stretched and that charities seem to be picking up a lot of the pressures whilst struggling to get the funding they need.

Beacon Vision, Guide Dogs and Look UK have all been amazing in terms of finding our way around the diagnosis and adaptations to my child's sight loss. Look UK have provided a safe space under their mentoring scheme for my child to deal with the emotions of their sight loss and a space for me as a parent to ask questions on how to support my visually impaired child. The What? Centre have also been fantastic in providing a safe place for my child to deal with gender identity and emotions.

I have had to learn so much and tackle a lot whilst being a full-time single mom and working full time, whilst all the time my child is becoming increasingly stressed leading to sensory overloads and tics that are draining and frustrating. As a mom, I obviously want to give my child the best support that I can but am extremely frustrated by the lack of input and support. Just because my child's sight loss is psychological does not mean they don't need support in coming to terms with that diagnosis. I really feel that more joined up work is needed with physical NHS care and Mental Health services.

[All names have been changed]

A mental health support service for young people

Young people come to us with extremely complex issues, often around anxiety, self-harm and suicidal thoughts. Our support is targeted to their needs, and we work around offering 12 counselling sessions, some will need more and some less.

We see many young people in crisis who have been referred to us by A&E and I-CAMHS, sometimes it's hard to see how some of our referrals don't meet the criteria for CAMHS but thresholds are so high, that many young people are left really struggling. I don't know what can be done about this locally, as it is very much a national issue that needs to be addressed.

Our qualified experienced staff and therapists support young people and their families with a wide variety of complex issues, including education, relationships, housing, homelessness, health, and LGBTQ+ issues.

Young people are referred by GPs and CAHMS for counselling and our sessions are free to young people, but they aren't cheap to deliver. We have overheads, increasing building costs, have regular meetings with system leads and pay for a very secure system to store our data. This all drives up the cost of our sessions, which we must find funding for.

Coming out of Covid is creating an even greater demand for services. For some young people the pandemic has given a safe reflective space away from the pressures of school, so going back has caused extreme anxiety. For others, being at home has resulted in bullying from families and siblings, they have missed their friends and fallen behind with their schoolwork.

It's a real time for change for local mental health services with all the Black Country system developments that are happening. We have been fortunate in that we have been able to access non-recurrent funding, to enable our service to continue and have good relationships with our CCG and strong community partnerships but we still have waiting lists.

The voluntary sector provides tremendous support to the system, picking up young people when they fall into crisis and helping them to become more resilient. I'm not criticising decision making as I really do understand the pressures, I just hope that as new systems grow and develop, that the necessary funding will be available and that voluntary sector partners will be recognised and well-funded, as the already immense needs of young people are continuing to grow at pace.

The What? Centre provides 9- to 25-year-olds with holistic mental health and well-being services including individual counselling, groupwork and advice from our bases in Stourbridge and Dudley and also through remote options including Zoom and by text. In 2022, we have delivered an average of 600 counselling sessions per month and are currently providing treatment to over 400 young people.

healthwatch