



IN OUR OWN  
WORDS

Surrey Youth  
**VO!CE**

# In Our Own Words Findings Report



**SURREY**  
COUNTY COUNCIL

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# Introduction

## Introducing some of our youth researchers!

Marianne, Amber, Reneè, Evie, Ash, Jordan ,Ems and Seren (in their comic form!)



### What is In Our Own Words?

In Our Own Words is a project for neurodivergent young people as lived experience experts. Over the past year, eleven young people have completed a social research training programme, equipping them with the skills to explore and understand the mental health and wellbeing experiences of neurodivergent young people and their families in Surrey, as well as the services available to them. This youth-led initiative empowers young people to direct their own research, choosing the specific areas of mental health and wellbeing they are passionate about and wish to investigate.

From March – October 2024, youth researchers had two months of training sessions in social research and four months of project sessions where they carried out their research, analysed data and displayed their findings and recommendations. The youth researchers collectively gathered 160 new pieces

of feedback from neurodivergent young people, parents and carers, educators and Surrey Police staff, therefore helping us to better understand the current needs of the community in Surrey.

Below is an overview of some of the key themes that came out of the youth research projects:

1. Experience of waiting
2. School based support for neurodivergent students
3. Teacher training and understanding of neurodivergence
4. Education and work based non attendance
5. Understanding of neurodiversity in the wider community

In this report the findings are broken down in to the above mentioned themes.

## Experience of waiting

A common experience we hear at Surrey Youth Voice is that neurodiverse young people spend long periods of time on waitlists whether it be for a diagnosis or for mental health support. Throughout the questionnaires both young people and teachers had the opportunity to share their views on the experience of waiting.

Two research projects aimed to understand how young people feel about waiting. One of these projects specifically focused on LGBTQ+ young people's experiences of being on a waitlist. Ten young people, aged 14 to 20, participated in the survey. All of them were part of the LGBTQ+ community, including transgender, non-binary, gay, and bisexual individuals.

The other project asked both young people and school staff about the support provided to young people while they are waiting, as well as the impact of being on a waitlist. Five young people, aged 13 to 16, participated in this project. Sixteen school staff members



answered the survey, with eleven of them working in primary schools.

## Impact of waiting

Across the UK, waiting times for neurodevelopmental (ND) diagnoses can be long for many children and young people. According to a study by the Children's Commissioner for England, 41% of children experienced a wait of over two years for a diagnosis, while 17% waited more than four years. Young people said that not knowing how long they would have to wait led to feelings of uncertainty. They also reported that their mental health worsened while they were on the waitlist. This shows the importance of young people being offered support while waiting as well as, where possible, letting them know how long the wait will be.

- “Waiting left uncertainty especially without a known end time period but joining the wait list was specific to the fact that I knew these emotions were going to get worse, waiting just made it so I had no immediate support.”

Teachers also shared the same views around the impact being on a waitlist can have on a young person.

- “Have been waiting over a year for a formal diagnosis despite professionals and school agreeing the child is neurodivergent. No updates regarding waiting times just left in the dark. Very upsetting and unsettling for child.” (teacher)
- “Getting a diagnosis or even getting an initial appointment is taking too long.” (teacher)
- “The long length of time a young person has to wait for a diagnosis puts considerable strain on them and their family.” (teacher)

## LGBTQ+ experiences of waiting

One of the youth researchers wanted to focus specifically on understanding how being part of the LGBTQ+ community may impact experiences of waiting for support. When asked what impact, if any, LGBTQ+ identity had on a willingness to get help, responses were mixed. Two young people said that



they did not have any concerns about asking for help, two said that they hadn't thought about it, whilst three said that they were concerned about asking for help from diagnostic services.

All participants said support groups where they could meet other young people like them, either before or after diagnosis, would help them to understand themselves, their diagnosis and their unique experiences of being a part of the LGBTQ+ community.

- “A few of my mental health issues and emotions do directly relate to my transgender identity.”
- “For there to be less of an assumption that the mental health issues are directly to blame due to being LGBTQ+.”
- “I needed a reason that I felt so out of place even before I came out. But I was made worse after and having a diagnosis would have given me comfort that I wasn't weird, just autistic.”
- “I've had problems with being autistic and LGBT but I've never really thought about them effecting me to ask for help.”
- “And went through the entirety of second school not knowing why I was struggling so much while being miss gendered and unsupported by school. The good support I did receive was from an Eikon worker and a Barnardos worker - both could have completely changed my school experience but due to there positions any requests or suggestion to help me were over ruled by the school. I was failed by both my school and CAMHS and I'm the one who has to pay for it.”

## Improving support while waiting

Many of the young people and teachers' fed back about the support that neurodiverse young people receive while they are on a wait list. This included support from schools and other services. 58% of young people shared that they felt unsupported while on waitlists for either a diagnosis or mental health support.



With 53% of young people from the In Our Own Words surveys feeling unsupported while waiting, it is important to look at how the experience of waiting can be improved. Young people suggested that one way to help is by providing regular updates on the wait time. This would address the uncertainty about how long they have to wait and could make the experience less stressful. In addition young people also wanted support in school and wanted to make sure they received enough information about the diagnosis process.

- “Give an eta on waiting time, give every 2-3 month update for the first year than extend it to every 5 months there on, if it goes past two years, offer a call up, to let the person know they aren’t forgotten in the sea of people who are also on the waitlist.”
- “Help in school would have helped greatly during the two times I’ve been on the CAMHS waiting list and other waiting lists.”
- “Having schools, family members and myself be more informed about the diagnosis so it wouldn't have been such a stressful process.”
- “Support groups and therapy offered after or before diagnosis.”
- “Having more people push for the help that was needed, e.g. schools setting up individual support systems, people knowing more etc.”



*Graffiti art by youth researcher*

# School-based support for neurodiverse young people

The youth researchers identified that school can often be a difficult place for neurodiverse young people. Finding out more about neurodiverse young people's experience of school was a key priority for some of the youth researchers. Across three projects that focused on this theme, 36 young people aged between 8 and 20 shared their experience of support in school.

## Impact of diagnosis on support at school

For many young people, getting a diagnosis can be a key part in their journey and can affect many parts of their lives. One of the key themes that came through in the research was around the impact that having a diagnosis had on the support young people received at school. Many young people said that the help they received at school improved after they were diagnosed. Some also mentioned that a diagnosis helped their teachers understand them and their needs better.

- "I definitely got the help I needed after my diagnosis. School was a lot easier for me as I feel like the teachers understood me and could help me."
- "They just didn't do anything to support till diagnoses was completed."
- "[In reference to getting support at school] Not until diagnosis - I was just getting into trouble."
- "It took a long time to get a diagnosis and before I had one and an EHCP my school did not support me."
- "I said no [to feeling supported or understood] because in my school when I was waiting for the diagnosis, they didn't do anything to help."



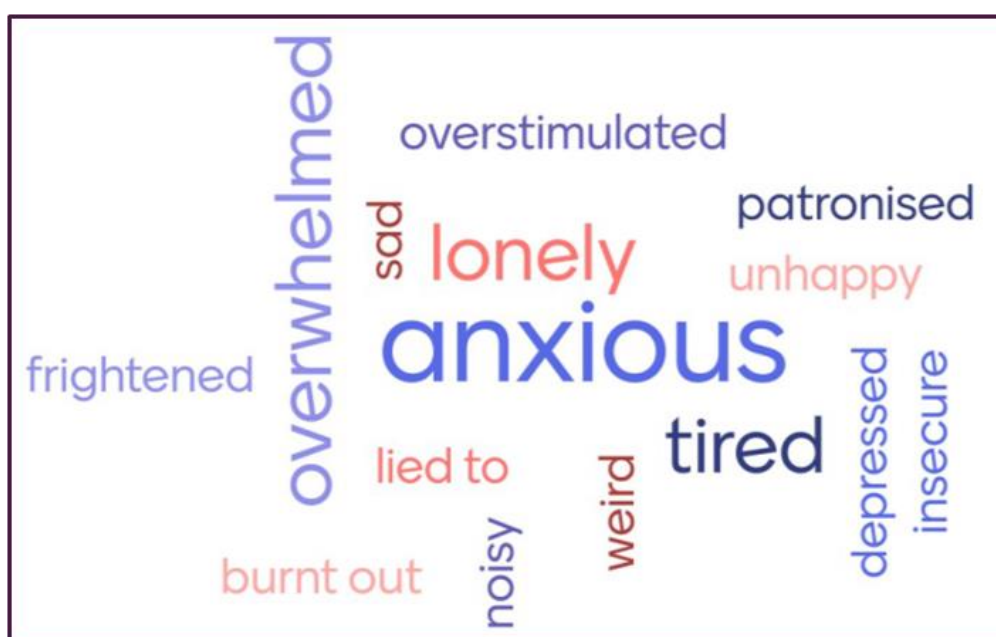
## Overall experience of support at school

Neurodiverse young people have shared both positive and challenging experiences. Most of the positive experiences were reported during their time in primary school, while the majority of negative experiences occurred in secondary school. This shift raises several important questions.

The youth researchers asked: Do these challenges show that secondary schools need better support systems to help all students succeed? Another idea is that understanding their own experiences with neurodiversity, finding the right adjustments, and speaking up for themselves is key for neurodivergent young people to get through school. Also, the school environment and classmates might not be as accepting or knowledgeable about how to support neurodivergent students. It's probably a mix of these reasons that make it hard for neurodivergent young people in secondary school.

The youth researcher who led this project emphasized that neurodivergent young people need to be taken seriously when they express their needs. If not, they may become more withdrawn and lose confidence in those who could potentially support them

Below is a word cloud showing the words that young people used to describe their experience at secondary school:



In one research project 6/7 young people shared they felt like school had a negative impact on their emotional wellbeing and mental health

- “Teachers not recognising I have autism and dyslexia. Not enough time to think and process info. Not enough small group support. Detentions are a nightmare, I’m often given them for my neurodivergence. My mum has to ask for everything, the SENCO doesn’t volunteer support e.g. laptop, reading pen, exit card. I’m very anxious, when school work or friendships are hard then I really struggle going into school. Getting to school by bus was really hard - too noisy, too smelly, too busy, too many people, older children are scary.”

## Helpful support young people are getting

Young people shared examples of support that they found helpful in school.



## Flexible Learning Environments

- “I can leave the classroom when I feel stressed or anxious and work in a smaller room. I leave lessons early to not be in busy halls.”
- “Get to leave the class when needed.”

## Personalized Support

- “Mental health support worker providing family support as many of the difficulties we were having were at home as he was masking at school.”
- “ELSA programme and Learning Space. A trained staff member would take me out of lessons privately for an hour for fun activities such as crafts and painting and for chatting.”

## Safe and Calm Spaces

- “Calm safe space, trusted regular go-to person, to know changes in advance, allowed to doodle in class.”

## Clear Communication and Guidance

- “They give me straightforward instructions on what the task needs me to do, have weekly check-ins with me, always making sure I know what I’m doing.”

## What would have helped

During the surveys young people had the chance to share what support they believed would have been helpful when they were at school.

Many examples young people gave related to building trusting relationships and communication with members of staff and having increased support in classrooms for learning.

### Building relationships with trusted adults at school:

- “I think maybe a sit down chat with someone just as a check in sort of.”
- Support staff. Someone that understands my diagnosis and is willing to help me with the challenges I face.”
- “Teachers and staff members trained to understand autism and anxiety. Educating other children to avoid bullying others with special needs.”

### Increased classroom support:

- “More one to one support in lessons and clear written instructions and quiet zones to sit and work.”
- “The teachers could give me more warning in what is happening in the next lessons and more visual information. They could have

more assistants in the classrooms. More mental health services at school.”

- “To have a teaching assistant in the lessons I need support in. Allowed to have more fidget toys. Allowed to have a reduced timetable.”
- “1-1 support is helpful as I get distracted very easily. Their patience as, although I have glasses, the words still run across the page/board so I need more time to copy the board or page. Don’t pick on me when looking for an answer.”

## Masking at School

One of the research projects focused on the experience of autistic girls in school with an interest in their experiences of masking at school.

- “Go out on a walk outside and take a break from the masking and let out any feelings you’ve bottled up. I would suggest having these breaks out throughout the school day.”
- “I don’t act like myself with others and faking my genuine emotions. And I don’t tell anyone about it either”.



## Sensory needs

Another theme young people shared was around sensory experiences of school. It was highlighted that school can be an overwhelming place sensory wise.

- “I felt that in secondary school there should have been more accommodations for sensory needs and there should have been sensory rooms for those with autism to help calm down. As many with or without diagnosis are sent through mainstream schools that cannot accommodate.”

- “More quiet places where you can be alone. Or more fidgets.”

## Flexible timetables/ attendance

Another common experience was shared around difficulties with attendance or struggling to cope in lessons. One of the adjustments that young people shared would have helped was flexibility around attendance, for example allowing flexible timetables and/or allowing young people to complete some lessons from home if they aren't able to make it in to school.

- “Could provide an option to do the lesson at home and not make a big deal and huff about missing school.”
- “They could be more understanding about attendance.”

## Neurodiversity and mental health

When creating their questionnaire, one of the youth researchers thought it was important to hear from neurodiverse young people about their experience of accessing emotional wellbeing and mental health services. The results from their project showed that 7 out of 9 young people said that they feel that the way people have treated them because of their neurodiversity has impacted their mental health. In addition, 6 out of 9 young people shared that they feel that their experience of mental health services has led to a lack of trust in professionals.

As part of the questionnaire young people were also asked to describe their experience of mental health services in three words, below is a word cloud showing the words they used:





## Teacher training and understanding of neurodiversity

Linking in closely with school-based support for neurodiverse young people is another key theme of teacher training and understanding of neurodiversity.

Some of our youth researchers were interested in learning about the training that is offered to teachers around neurodiversity as well as what teachers would like to know more about neurodiversity. For this project 8 teachers answered the survey, with 5 teachers working in secondary schools and 3 in primary schools.

Much of the data that fits in this theme also comes from one of the projects which looked at the experience of waiting and support at school from the perspective of both teachers and students.

### Connection between support and teachers' understanding

One of the questions asked teachers to rate their knowledge of autism from 1 to 10; 1 being little knowledge, 5 being average and 10 being really good. All

teachers rated their knowledge as around average, no-one rated their knowledge above a 6.

The data highlights that it's important for teachers to understand neurodiversity. Many young people say they feel like they don't get the right support because teachers don't fully understand neurodiversity or student's individual needs.

When asked if they felt like teachers understood their needs 70% of young people felt that they didn't.

- “They say I’m away with the fairies when I’m actually trying to get through my day. They don’t help when I ask for help. And they say I’m disrupting class. My anxiety is very bad when at school.”
- “We waited 2 years on the CAMHS waiting list before paying privately for assessment. We had to fight for the initial referral as school did not recognise the needs as my child is very intelligent and doing well academically.”
- “T was supported fully at nursery however not in school. He was placed in the wrong setting and has only just been offered an alternative after 18 months.”
- “It often depended on the teacher I was with as some of the more open-minded teachers helped (ish) whereas as a majority of them didn't do anything.”
- “And I also had a meeting with the headteacher where before my mum said, ‘she is getting diagnosed with autism so she might struggle with eye contact’ as soon as I joined the headteacher shouted, saying ‘look at me’, I got too overwhelmed and left.”
- “My teachers don’t recognise when I am feeling anxious or overwhelmed and have little understanding of my needs.”
- “Teachers not really understand what is. Teachers never help. Teachers never listen to people and just say it’s fake.”

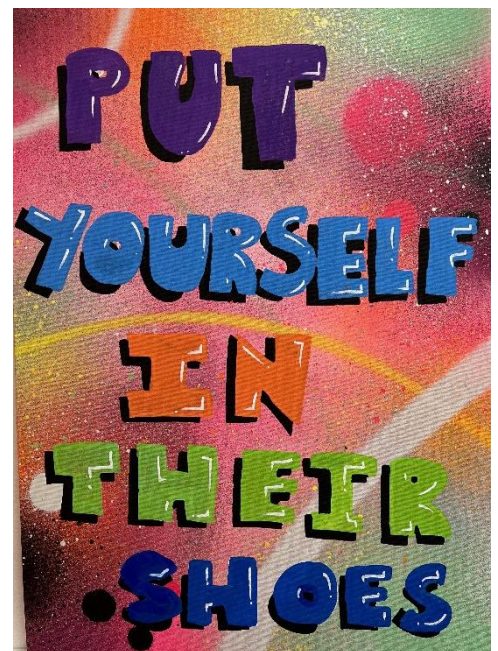


## Misinterpretation of behaviour

Many neurodiverse young people also shared experiences where they felt misunderstood by their teachers. This lack of understanding then led to their behaviours being misinterpreted as “naughty” or disruptive. As a result, the young people shared that they are often told off or punished. This creates a break down in the relationship between neurodiverse students and their teachers, leading to a lack of mutual trust.

From the experience young people have shared it is clear that building trusting relationships with teachers where students feel understood and supported is key for a positive experience of school.

- “I was always in trouble for things I couldn’t help. Not making eye contact, forgetting equipment, not listening or completing enough work in class. I found it hard to wear a blazer, but I was forced to and marched daily to my locker to get it.”
- “Nobody understood or supported me. I was taken into a private room where no one could hear me and got shouted at by staff members, who told me to “toughen” up. Teachers didn’t care about me.”
- “In mainstream school I was not understood or supported. I was sent out of class a lot instead of being given the support I needed.”
- “My teachers would send me out of the classroom and never listened to me. They told me off and gave me detention all the time.”
- “Teachers told me off all the time for being different. Even my support teacher was rude to me.”



*Graffiti art by youth researcher*

## Teachers' perspectives on training

Teachers were asked if there was anything, regarding neurodiversity and mental health, that wasn't included in their training that they would find helpful to learn about or have more information on. Teachers said that they would like formal training on different conditions such as Oppositional Defiant Disorder and Tourette's as training is often centred towards autism and ADHD. However, it was noted that mainstream schools need tailored training that works in the context of a mainstream setting, where resources, facilities and staffing may be different to specialist schools.

- "Strategies to support students with ODD (Oppositional Defiant Disorder)."
- "The ways neurodivergence can give people extra skills / interests and how to help them develop those."
- "I've had training specifically on ADHD and ASD, as well as general neurodivergence. However, I likely would have benefited from formal training on OCD, Tourette's, and Oppositional Defiant Disorder as I taught students with these conditions from very early in my career and had to learn from experience how to support these students and sought out training/research myself but know not all teachers do."
- "I have worked in and for specialist settings and I find a lot of training is from specialist settings addressed to mainstream schools. And they are SO different, what they suggested should happen, I know the ideal, I also know it has to be adapted to be achievable in a mainstream setting."
- "There is a gap, and it would be good for neurodivergent training to come from mainstream schools sharing good practice rather than always from specialist settings that are incomparable."

## Education and work-based avoidance:

Another key experience that the youth researchers identified was education and work based non attendance. This could be for many different reasons, for example mental health struggles or finding education or work settings difficult or inaccessible as a neurodivergent young person. In the context of schools, this is also called Emotionally Based School Non Attendance or EBSNA. Two of the research projects focused on neurodiverse young people's experience of being out of education or work.

One project looked at the experience of EBSNA and the impact it can have on young people's friendships and social relationships. 8 young people aged 14 to 17 took part in the questionnaire.

The second project focused on the impact of mental health on education and work based avoidance. The youth researcher asked both neurodiverse young people and parents and carers about experiences of struggling to attend education or work due to mental health needs. 8 parents and carers took part in the questionnaire, all with neurodiverse children, and 4 young people aged 14 to 22 participated.

- "I was off over Covid from a state school then my parents remortgaged to send me to a small, nurturing private school. The new school offered small classes for the subjects I struggled in ie math's and English - 5 in each class. It was a school with 2 forms in the senior school which was easier to manage for me."
- "Actually communicating with us. Has been off since February but had very few points of contact from school. Nobody bothered that child is not in, they're y11 so leaving anyway. Barely respond to emails, child doesn't feel welcome there any more, or like they even matter. Wasn't even invited to school leavers' assembly, desperately sad." – (Parent carer)





## Things that led to young people avoiding school, college or work

There are many things that could lead to a young person being unable to go to school, college or employment.

- “I have struggled with severe anxiety for as long as I can remember, particularly generalised anxiety and social anxiety”.
- “Coupled with autistic burn out as a consequence of a systemic lack of support in regards to my additional needs. Because of this school became too much of a demand on my physical and mental health and nervous system.”
- “There is too much pressure and my mental health couldn't cope, I couldn't hope with the environment and I was just burnt-out and feeling low. When I was at school the teachers really didn't understand mental health and didn't want to talk about it .”
- “They refused to make reasonable adjustments as they didn't have the resources to support me so I had to stop attending as I couldn't cope with it and they couldn't keep me safe.”
- “Unable to eat, drink or use the toilet while in mainstream school due to unmet sensory needs. Shouted at by teachers resulting in mistrust. Running away at school as they were not given the opportunity to re-regulate when dysregulated. Unable to engage in learning due to the way it was presented not being suitable for their autism.” – (parent carer of primary school student)
- “It's clear that the effort to mask at school, combined with sensory differences, is making our daughter too exhausted and unable to manage in the school environment.” – (Parent/carers of primary school student)

- “Poor support at specialist school, EHCP not followed properly, Trauma from experience at school, chronic fatigue and autistic burnout.”

## Effect of being off school on schoolwork and friendships

A key interest of one of the youth researchers was the effect being off school had on young people’s friendships. They found that 4 out of 5 young people said that at times they found it hard to keep in contact with their friends while they were not attending school. All young people said they felt lonely or isolated at points when they weren’t attending school. In addition 3 out of 5 young people said that they did not complete any school work during their time out of school:

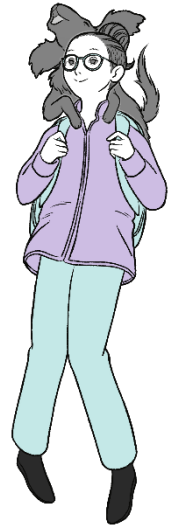
- “It's strained and it upsets me cause I have barely any [in reference to friendships].”
- “I felt isolated and my self esteem went down so I was depressed.”
- “I lost touch with almost all of my friends as they all stopped contacting me. I really only have 1 good friend now whereas before I was in a group of 6 people. I go months without seeing or hearing from any of my old friends because they are too busy with their lives.”
- “My 2 very close friends just get me and if I don’t message or see them they contact me and come and see me even if I didn’t want them to. I’m glad that they did as I just didn’t want to see anyone. The bigger circle of friends just think I’m lucky as I didn’t go to school and kept asking questions which I didn’t want to answer.”

## Barriers for young people returning to school

Youth researchers wanted to explore what may make it more challenging for a young person returning to an in-person educational setting. Despite motivation and hope for re-engagement, survey respondents experienced extreme anxiety

and fear about returning to school. This anxiety is increased by concerns about what other pupils and teachers might think, leading to a perceived stigma around emotionally based school non-attendance (EBSNA).

The researchers suggest that schools should adopt a comprehensive approach to reduce this stigma. By promoting education and awareness, schools can create a supportive environment that encourages re-engagement and addresses the emotional barriers associated with EBSNA.



- “Once you stop attending it’s 1000x harder to go back because of the anxiety around what people are going to say when they see you again. I have always wished that I was able to attend school and if I could I genuinely would but it’s just not possible. I want to continue on to college education but I cannot find anywhere who can accommodate my needs and the system just makes it impossible for children like me.”
- “I find it so hard to get in the classroom to get my learning and I spend time in the support room but then I don’t really get any learning to do. I still want to learn and do well in my GCSEs, I just don’t know how I can get back into the classroom as it gives me severe anxiety and panic attacks and I can’t hear anything.”
- “I felt less than. Perhaps it needs to be made normal.”

## Work-based Avoidance

One of the youth researchers highlighted that it is often not just school or education settings that neurodiverse young people struggle to attend - it can also be the workplace. In their project many of the young who participated had experience of struggling to attend work. There was mixed experience of being neurodiverse and working. Some young people spoke about the importance of understanding both mental health struggles and neurodiversity in the workplace as well as the importance of reasonable adjustments in the workplace.

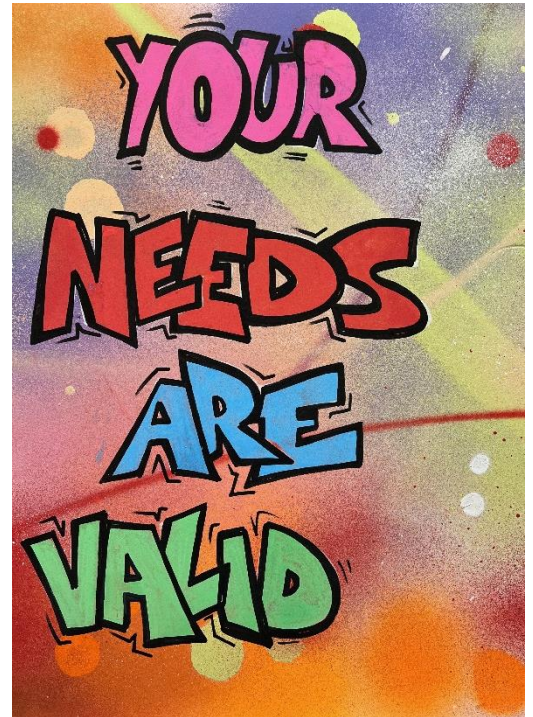
- “When I started working mental health and neurodiversity was really talked about, they spoke about looking after your wellbeing but didn't do nothing to talk about mental health problems, like people with more complex struggles, not just like wellbeing. I have diagnosed mental health conditions and I don't feel comfortable then like talking about it to my manager or stuff as I don't know what their reaction would be. So I struggle to say when I am actually struggling so I end up either missing work or just being too overwhelmed to actually do anything when I'm meant to be working.”
- “I get a lot of pre-work anxiety from previous negative interactions with colleagues/supervisors/managers etc that result in me making a lot of 'what-ifs', but this was mainly back when I was working about one shift a week when I was still in sixth form (so I had quite a lot of stress on my plate anyway). Nowadays, this doesn't occur as often at the minute since I've finished sixth form.”
- “Strangely going to college however I never really felt much anxiety going to lessons, although sometimes I would be burnt out and therefore have mental health days, this was less often during Y13 though as I was raised around the idea I shouldn't really skip lessons for important info for my A-Levels. Even with that, when I was off for whatever reason, I would make sure I can self-research the content myself (luckily is a strength with my autism).”

## Support that would help with school/ work attendance

There is a consistent theme around the importance of communication between school, young people and parent carers:

- “Actually communicating with us. Has been off since February but had very few points of contact from school. Nobody bothered that child is not in, they're y11 so leaving anyway. Barely respond to emails, child doesn't feel welcome there anymore, or like they even matter. Wasn't even invited to school leavers' assembly, desperately sad.” – (Parent carer)

- “I’d like a better, more collaborative relationship with school. Currently, they are doing lots for my daughter but it feels really intimidating - meetings where 5 staff show up when we were expecting 2, minutes being taken etc. It doesn’t feel equal. I feel powerless. They focus on attendance more than her well being. I don’t feel listened to.” – (parent carer)
- “Communication from school, like a partnership. Like I’ve had in all other previous schools for this child and eldest child (autistic, just finished a levels in mainstream). Barely manage 2 way communication.”



*Graffiti art by youth researcher*

## Positive examples of support offered in work and school

- “Kinetic sand break, movement break, fidgets to play with. Wears loop ear plugs all day at school. Comes home every lunch. Has 1 to 1 ELSA sessions with Home School Link Worker. Is in a Wednesday brioche club for children who need additional support. Can go in early and use her calm box, can go to head teacher’s office first rather than classroom.” – (Parent carer)
- “My boss is extremely well informed on how best to support my mental health as well as my additional needs because of the sector I work in. For example- my boss allows me to have a flexible work timetable and plenty of opportunities to rest should I need to. He also recognised and accommodates my preference for advanced notice on upcoming opportunities/ work cancellations due to being autistic and anxious around change”



## Recreational activities and mental health

One of the studies wanted to find out the impact of recreational activities, such as clubs or sporting activities, on supporting young people's mental health whilst out of work or school. Most respondents answered that they 'sometimes' engage in recreational activities, although all but one agreed that they support mental wellbeing in a positive way. A few young people and parents said that whilst they know the positive benefits of recreational activities and exercise, accessing support or finances to engage in these activities is challenging and creates a barrier to attending.

- "Can't access them really"
- "We have signed up to a gym and will use Personal Assistant (PA) hours to support this. It's great because it's a new environment to feel settled in. It is a private gym i.e. less people, less noisy changing rooms, cleaner facilities (OCD). This type of accommodation always comes with extra cost which the family or benefits have to meet."
- "When they can manage it, it's really positive. It's very very lonely being out of school. People forget you, child very sensitive to rejection (RSD) and it's hard to keep in touch with people you no longer see regularly at school."
- "feels "normal" and exercise is good for mental health. Reduces time in bedroom."
- "Guides are much more inclusive than mainstream school and are happy to learn about autism and ADHD and make reasonable adjustments."
- "I don't have friends locally so going to do recreational activities such as dance classes/sessions help me substantially with keeping me active but also helps me to build a community of friends in general."

- “I find that going to the gym or exercising in any capacity drastically improves my mental wellbeing however I don't have the support to access this regularly enough.”

## Understanding of neurodiversity in the wider community

One of the youth research projects focused on Surrey Police and their interactions with neurodiverse young people. 9 professionals from Surrey Police answered a survey which included questions about the Pegasus Scheme as well as knowledge and understanding of neurodiversity.

### Pegasus Scheme

One of the youth researchers was interested in Surrey Police's experience and views of the Pegasus Scheme. The Pegasus Scheme is for anyone who might find it difficult to communicate with the police. The scheme allows Surrey Police to keep pre-registered information about an individual, they can then access the information when the person calls them.

When planning the research project, the youth researchers spoke about how beneficial the Pegasus Scheme could be when used correctly, they identified it as an important area to ask police about and gather a better understanding of their experience of using it.

### Increasing awareness of the Pegasus Scheme

There is a reoccurring theme in the data about the awareness and understanding of the Pegasus Scheme among both those that work at Surrey Police and young people in Surrey.

Many professionals at Surrey Police stated that they believe there needs to be better and wider knowledge and understanding of what the Pegasus Scheme is and how it can be used.

- “I don't think it is publicised enough for young people who are neurodiverse that they can utilise it when talking to us.”
- “I know about the Pegasus Scheme because it's a part of my job to know. I am not sure, however, how widely known it is to all my colleagues in different roles within Surrey Police?”
- “While I am in a role that doesn't involve me engaging with young people, I do think that maybe a reinvigoration of the scheme could be beneficial to highlight what it can do, aims and objectives.”
- “I think it is more about in house training around what the scheme is, how it can be used by us to help others. I think knowledge around the scheme is very minimal.”
- “1. Promote the scheme and what it is about more widely - both within Surrey Police and to the general public 2. Give some examples of how it can be used and how it can help people to communicate their wishes and needs 3. Include information about the Pegasus Scheme to everyone who joins Surrey Police in whatever role they are employed to do. Not just officers or PCSOs but everyone.”
- “Reinvigoration, promotion, anonymised case study, success story examples.”



## Surrey Police's ideas for improving the Pegasus Scheme

Staff at Surrey Police also shared their ideas of how the Pegasus Scheme could be improved other than increasing awareness.

Many of the improvements focussed on the practical use of the scheme, for example making it more accessible and easier for young people to use. A flowchart was suggested to help support young people to communicate more easily what is happening. Another idea was to simplify the access process so young people don't have to remember a PIN; instead they could just use their

name and phone number. These changes aim to make the scheme more user friendly and accessible.

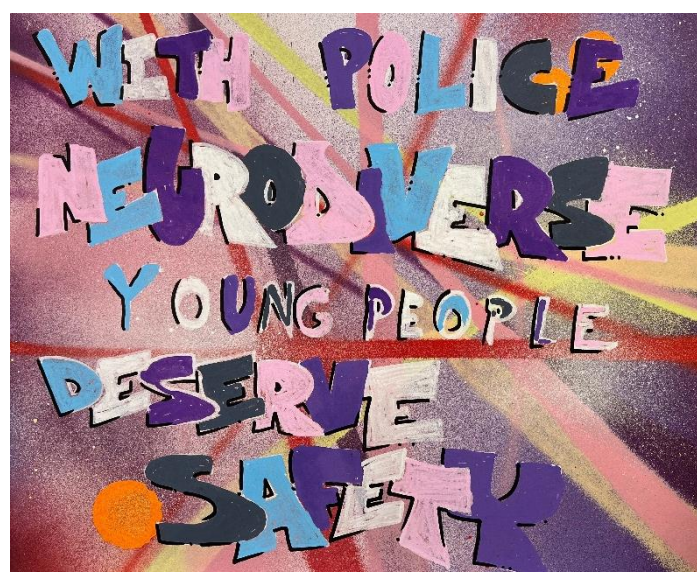
- “Pegasus is of limited use to us in the CTC, because all it can really do is pre-load their details. They've still got to explain what it is they're reporting which is where they tend to struggle. I don't really have any suggestions for how to improve this - perhaps a "flowchart" of options could be incorporated into D101, so they can select what they need to report without needing to verbalise it?”
- “I think it would be better if you didn't need to remember your pin and that the Pegasus information could auto populate just by giving your name or number.”
- “I haven't used it as I am not a front-line officer but I would suggest a method that allows verbal and non-verbal communication possible is paramount for neurodiverse YP being confident to speak to police in an emergency.”
- “I do not have occasion for young people to contact me in an emergency, but anything that can improve this interaction is very important. If someone needs help, what we need to know is where are you and what is happening. Sometimes in a stressful situation this information gets lost, and technology can assist with this, but is not infallible. Simple things like, being aware of your surroundings, noting landmarks around you when all is well, so if something does happen and you need to dial 999, you have in your mind something that can help emergency services get to your location.”

## Surrey Police and neurodiversity

### Experience of interaction with the police

Professionals at Surrey Police were asked to share how neurodiverse young people have reacted to them.

- “I have encountered a wide range of reactions. Most very calm when speaking with me, some have felt that I do not understand their reactions which I have to admit on occasions has been correct however I have been able to engage in open and honest conversations around this to help with my understanding which has been very well received.”
- “Normally calm as they are aware of my meeting and have support in place.”
- “Generally, I have found that people do respond well to me as I always try to convey a calm, interested and supportive manner in all my communications. I have a lifetime of personal experience of living with and working with people with a variety of neurodiversities. I am also a qualified teacher and have practical experience of providing different learning styles into my methods of communication.”
- “They have been defensive and anxious but when approached in a calm, friendly but firm manner I have had good levels of communication.”
- “Due to personal experience and situations where I have worked with neurodiverse young people at work and had positive experiences with them. I feel confident to be able to assist in calming them down and communicating effectively.”



*Graffiti art by youth researcher*



## Ways that interactions are made positive

- “I do not wear uniform, so I have found this helps a lot. I feel that I am skilled in communicating with the neurodiverse community. I like to make it my mission to have positive interactions and build good relationships and rapports with people.”
- “My role is not that of a police officer but I meet and work with people both inside and outside the organisation, some of whom will be neurodiverse. I always try to gauge my questions, explanations or answers to questions in different ways to try to ensure clear understanding. I always try to check that the people with whom I am engaging do understand what I am trying to convey. I use different styles of communication - written, visual and sometimes physical (by actually demonstrating what I mean).”
- “I always try to gauge how a conversation is progressing, mainly by listening to what is being said to me and how.”

## Knowledge and training on neurodiversity

Staff at Surrey Police report that they interact with neurodiverse young people regularly. This shows how important it is for them to have a good up to date knowledge of neurodiversity to help ensure the interactions are positive.

- “Police officers need more training and practical advice on understanding neurodiversity and how best to communicate with people who are neurodiverse. I still hear police officers referring to autism and ADHD as mental health issues. I don't think police officers are confident on how to safely restrain and arrest someone who is neurodiverse if necessary.”
- “When I joined the police, these conditions were not recognised or acknowledged well. Young people who presented as difficult or non-compliant were seen as naughty, trouble or criminally minded. While

I have tried to evolve to move with the times, we can always do more to improve our understanding, so bespoke training is always welcome.”

- “Not having enough work related knowledge around it. Can only relate to skills I have gained from personal life.”
- “I feel that there is so much to learn about neurodiversity that, without proper training that relates to our role, it can be very difficult to interact with 100% confidence. It can be hard to identify this during a brief telephone call.”
- “I don't respond to calls, all my interactions are pre planned. As I said above I have some empathy but would always value further training to assist me in my interactions.”

### What Surrey Police would like to know more about neurodiversity

- “More about how to adapt communication to suit an individual dependent on their needs. I would hate to inadvertently offend someone or worsen a situation due to a lack of understanding. I also think it is important to be able to understand 'triggers' to aid with dealing with certain situations.”
- “It would be beneficial to hear from young people themselves, about how they feel and possible approaches that they may be more likely to respond well to.”
- “This area is changing so quickly, I just need to be kept up to date with the latest thinking on how best to work with neurodivergent people.”
- “I think it is so important to listen to neurodiverse people to understand how best to support them.”

# Recommendations

These are the recommendations that each of the youth researchers came up with. They are written, as far as possible, in the youth researchers' own words.

## Evie's recommendations – The Impact of Diagnosis on Support at School

- Increase teacher awareness and understanding of diverse processing needs to make sure all students receive appropriate support and that teachers understand each neurodivergent young person as an individual.

## Marianne's Recommendations – Autistic Girls' Experiences of School in Surrey

- In the In Our Own Words project around "Autistic girl's experiences of school in Surrey", 70% of young people in the survey reported that they mask their autism. Education around masking should be prioritised for teachers but also peers and other students. This is to encourage more open conversations around masking where greater understanding can be created towards the experiences of autistic people, particularly girls, and how to support them.
- Every young person should have access to sensory support items, such as fidgets, in classrooms to help them focus and manage sensory challenges. Despite reports from young people that fidgets have been banned in some schools, these tools should be made available by all teachers, ensuring that the decision to offer them is not left to individual schools.
- Noisy classrooms and behaviour can be disruptive to neurodivergent young people, as well as other students. Classroom environments need to accommodate to everyone's learning needs and peers have the responsibility to support appropriate classroom behaviour.

## Amber's Recommendations – The Impact of Diagnosis Waiting Time, Understanding Student and Teacher Perspectives

- Schools should be informed when a student is on the waitlist for a clinical or mental health diagnosis. Additionally, teachers and school leadership teams should receive training on "How to Support Students Whilst They Are Waiting" to ensure that sensitive, helpful support, understanding, and empathy are provided by school staff, improving the waiting experience for students within the school environment.
- Reasonable adjustments should be prioritised and available to students waiting, as well as those with an Education, Health and Care Plan (EHCP), such as learning breaks and time-out cards to provide immediate relief to students so they can cope in schools.
- For students who are waiting, there should be support groups in schools to create a community for sharing experiences, resources and building social connections. These groups can directly feedback to school senior leadership teams or student councils so the voice of neurodiverse students can be represented, and their ideas used to make the school a more neurodivergent friendly environment.
- Systems or ways for providing regular updates on the diagnostic process need to be prioritised to keep families informed and reduce anxiety for young people on the waitlist.

## Jordan's Recommendations – Teacher Training on Neurodiversity

- Update teacher training on neurodiversity annually, designed by neurodivergent young people. This ensures that training is relevant and reflects the latest understanding and strategies. To make sure this is helpful for schools and teachers, training should consider the needs and resources of individual schools. For example, training from specialist schools should not be applied to mainstream schools. Instead, best practice techniques and methods should be shared between schools with similar environments.

- Increase teacher awareness and understanding of diverse processing needs, and how profiles may change with co-morbid conditions, to ensure all students receive appropriate support and are seen in an individual and holistic way.

### Ash's recommendations – Wait times, Neurodivergence and the LGBTQ+ Community

- There should be more support groups available to people on the waiting list.

Some sort of co-production / brainstorming group should be made, because we can't fix the problem of the long wait list times, but we can give young people on those waiting lists a space to share their issues and propose their ideas on how their experience could be less stressful. This is especially important for young people from the LGBTQ+ community as they will have their own unique experiences and challenges.

- The NHS or MindWorks should give updates to the lengths of waiting lists by either text or email.

### Renee's Recommendations – The Impact of Mental Health on Education and Work-Based Avoidance

- Non-attendance: Practical actions
  - To Increase overall attendance by offering more adaptable scheduling options.
  - Develop and promote flexible timetables to accommodate different students' needs.
- Non-attendance: Psycho-social actions
  - Foster a culture of empathy and psychological safety concerning emotionally based school non-attendance challenges to make sure students feel safe and supported when discussing attendance concerns.

- Education and training for teachers to reduce the use of scare tactics regarding attendance to create a more supportive and understanding environment for students.
- Reasonable adjustments are non-negotiable and should be actively implemented by all staff within a school. Reasonable adjustments should be applied universally, not just for those with formal diagnoses to promote inclusivity and support for all students.
- Recreational activities both inside and outside of school should be promoted and encouraged more widely to help students to explore different options and engage. Social prescribing support could be brought into schools to help students directly. Ensure recreational activities foster a beginner and neurodivergent friendly environment as disabled and neurodivergent students are more likely to feel excluded in these spaces despite the positive impact on wellbeing.
- More training and resources are needed to educate teachers, students and families on educational processes such as Education, Health and Care Plans (EHCP's) and other relevant procedures. There should be a particular focus on developing targeted information, resources, and training for underrepresented groups or groups that may experience barriers, such as boys and people of colour, working with young people and professionals from these communities. Advocacy campaigns or education towards children and young people, parents, carers and families may be needed to empower them to speak up when resources and information is needed. Research suggested that parents and carers may not feel comfortable or confident to raise their voices as they felt 'overpowered' by teachers. This is to make sure all students, including those from minority groups, receive good support and resources.

### Ems' Recommendations – Time off School and the Impact on Social Relationships

- A whole-school approach is needed for awareness and support around Emotionally Based School Non-Attendance (EBSNA), including young



people and teachers. It is not just the responsibility of the young person who is off school - friends and peers of the young person experiencing EBSNA also need support with understanding what their friend is going through and how to help them.

- Call to Action: Schools to educate young people on EBSNA and how to support their friends and peers to address the identified misunderstanding and insensitivity towards students going through EBSNA.
- Young people need more personalised support when returning to school. Re-entering school is hard. "Once you stop attending it's 1000x harder to go back because of the anxiety around what people are going to say when they see you again".
  - Call to Action: Schools to support young people experiencing EBSNA with the tools and social script for how to manage conversations/interactions with friends & peers when returning to school. It addresses the identified feelings of anxiety around what to say to friends/peers when returning to school.

### Youth researcher recommendations – Police Perspectives: Interactions with Neurodiverse Young People

- To improve interactions between Surrey Police and neurodivergent young people, the Pegasus Scheme should be more widely promoted and simplified. This scheme, which helps individuals communicate with the police by pre-registering their information, needs better awareness among both police officers and the general public. Information about the scheme should be delivered to young people in schools. Simplifying the scheme, such as allowing information to auto-populate by giving a name or number instead of remembering a PIN, can make it more accessible and user-friendly.
- Regular and comprehensive training for police officers on neurodiversity is essential. This training should be delivered or supported by

neurodivergent young people to ensure it is relevant and effective. Officers need practical advice on understanding neurodiversity and how best to communicate with neurodivergent individuals. This will help build trust and improve interaction.

## Moving Forward

This work is just beginning. The Surrey Youth Voice team is dedicated to advancing the findings and recommendations of our youth researchers to support positive changes in support and services for young people in Surrey.

Across Surrey, strides are being made in transforming services and support for neurodivergent young people. For instance, the Local Area SEND Partnership Improvement Plan, launched in 2024, is dedicated to helping Surrey children and young people aged 0 to 25 with additional needs and/or disabilities lead the best possible life. Although we've made positive progress, it's essential to continue advocating for youth voices to ensure that any improvements truly benefit children and young people. This youth research offers an invaluable opportunity to listen to new, updated feedback, analysed through a lived experience perspective. It helps us understand what support currently feels like for young people and identifies priority areas for intervention and initiatives to address immediate needs.

To make a real impact, we need to collaborate through partnership working and bring in key stakeholders. This includes professionals both inside and outside local authorities, educators, and, most importantly, young people and their families. By working together, we can ensure that the voices of young

people are at the forefront of decision-making and that their needs are met effectively.

So how will we do this? We aim to achieve this strategically by collaborating with Surrey County Council, existing governance structures, and partner organisations. Together, we will explore the implications of the youth-led research and identify opportunities for this work to influence the development of projects, policies, planning, and service improvements. Additionally, we are committed to sharing these insights on the frontline by engaging with mental health practitioners, teachers, and schools, as this was a priority for our youth researchers. We are eager to connect with projects that can benefit from these findings. Recognising the value of this work and peer-led research as a participatory approach, we are committed to supporting more young people in engaging with research opportunities. We will continue to actively listen to youth peer researchers as experts by lived experience.

The In Our Own Words team and youth researchers hope that you find this information valuable in enhancing your understanding of the needs of neurodivergent young people in Surrey and how their mental health can be supported. If you use the youth researcher findings for any work or projects, let us know! Please use our [Impact Tracking form](#) or contact the team at [user.voice@surreycc.gov.uk](mailto:user.voice@surreycc.gov.uk). This allows us to monitor the impact of our work and, most importantly, provide feedback to our youth researchers on how and where their excellent research has helped to make positive change. It is crucial for young people to recognise the influence of their hard work and understand the value of their participation.



*Graffiti art by youth researcher*

Thank you to all the In Our Own Words youth researchers for leading these important projects. Your hard work, dedication and passion will lead to positive change and better outcomes for young people and their families in Surrey.