



**IN OUR OWN
WORDS**

**IMPACT
STORY**

Doing research with young people instead of about them

A peer-led research programme for neurodivergent young people in Surrey.

Surrey Youth
VO!CE

NIHR | Applied Research Collaboration
Kent, Surrey and Sussex



ACKNOWLEDGEMENTS

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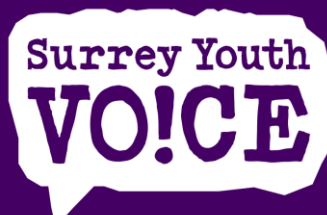
In Our Own Words is a partnership project, where organisations from across Surrey came together with the aim to explore new methods of youth participation. We would like to thank all organisations involved for their collaboration and support.

We would also like to thank the Department of Sociology at the University of Surrey, who designed and delivered the training programme to the youth researchers.

Most importantly, we would like to thank the incredible youth researchers and the In Our Own Words steering group whose passion, dedication and enthusiasm for the programme has made it a true success.

We would also like to extend our appreciation to family members and carers who have supported their young people in accessing this opportunity.

In Our Own Words would also like to acknowledge the community members who shared their stories and experiences with the youth researchers. Your feedback has been key to this project and will help to shape meaningful change to services and support for children and young people in Surrey





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The Project

What is In Our Own Words?

In Our Own Words is a pilot project for neurodivergent young people as lived experience experts. The project trains and supports young people to become researchers to understand other young people's experiences of mental health and wellbeing as well as mental health services.

It's a peer-led project where young people lead their own research and decide what areas of mental health and wellbeing they want to investigate, inspired by their own passions. This is important as it gives power and voice to the community the research is about and makes sure that the findings are accurate and helpful to them. It's all about doing research with people instead of about them.



Where did it come from?

In 2023, Surrey County Council along with partner organisations applied for a Youth Research Partnerships fund from the National Institute of Health and Care Research, Applied Research Collaboration. The funding came from an initiative to support and inspire young people to engage in, get involved with, co-produce and co-design health and care research in relation to mental health.

What were the goals?

In Our Own Words wanted to recruit a group of young people to lead research on mental health within their local community and take their findings to decision makers, so that services and support could be shaped by the voices and experiences of young people. It focused on giving neurodivergent young people a platform to share their experiences, generate new knowledge, and create solutions to challenges they face. It was important for us to engage young people that may experience barriers to getting involved in opportunities like this, as they are the voices which are important for us to hear from so we can make support and services inclusive, accessible and helpful for everyone.

In Our Own Words also wanted to support young people's teamwork and communication skills, grow their confidence and create a space for social connection and community.

Research with Neurodivergent Young People

In Our Own Words aimed to do research with young people, recognising them as experts through their lived experiences. So why did In Our Own Words recruit neurodivergent young people to lead important research? In Surrey, many young people struggle with their mental health, and a significant percentage have additional needs or neurodevelopmental conditions. Across the UK, services are struggling to provide effective, accessible, and inclusive support. Because clinical support is limited, young people often seek help in the community, like in schools and youth groups. Although Surrey County Council is doing really positive work to increase the numbers, there are limited places in specialist educational settings, and schools are overwhelmed by the growing number of students needing an Education, Health and Care Plan (EHCP). According to the latest Surrey data from 2023/24, the number of children and young people in Surrey with an active Education, Health and Care (EHC) plan has been rising year-on-year, with the last three years having seen year-on-year growth at around 10 per cent. Many young people find it hard to get the support they need, and thousands across the UK are waiting for formal diagnoses. Research from the National Institutes of Health reported Emotionally Based School Non-Attendance (EBSNA) was at 7.5% in the 2022-2023 academic year versus 5% pre-pandemic, with neurodivergent young people at a higher risk of being impacted.

This made neurodivergent young people a priority for the pilot year of this programme, as we know that they often face barriers to engagement and providing feedback. To address these challenges, young people must be involved in all parts of the process.

Surrey Youth Voice wanted to explore new participation methods, and peer-led research allowed young people to lead investigations into the challenges and make decisions. By asking important questions and gathering feedback from their peers, they could share insights based on their experiences. This means they could provide information and recommendations to decision-makers that are shaped by young people for young people.

This approach makes sure services are better designed to meet young people's needs, leading to better mental health and wellbeing outcomes.

Taking an active role in this process helped young people contribute to solutions, connect with others, learn new skills, gain work experience, and build confidence and self-esteem. The young people on the programme had the opportunity to turn their negative experiences into something positive and meaningful, with some youth researchers reporting it was a “therapeutic experience”. We want to be able to continue to offer this opportunity to a range of young people so they can unlock the same benefits of doing research in the community for their community.



What Happened?

In March 2024, 11 neurodivergent young people, aged 12-22, embarked on a transformative journey at the University of Surrey's Department of Sociology. For most, this was their first encounter with social research. Twice a month, from March to October, these youth researchers received master-classes in social research methods from professional researchers, led by Dr. Emily Setty.

Throughout the programme, the youth researchers acquired essential skills needed by professional researchers. They began by analysing existing research to identify gaps in understanding, then learned how to generate hypotheses and form research questions. They explored various research methods, such as surveys and focus groups, understanding their strengths and limitations. Ethics and participant care were key, along with techniques for gathering, analysing, and presenting data.

In Our Own Words also wanted to promote creativity and individuality as well as encourage accessible ways of communicating research and learning. Youth researchers created comic stories to represent their research journeys and participated in a graffiti workshop to highlight key messages. A public speaking workshop helped build their confidence and prepared them for presenting their findings and recommendations.

After completing their training, the youth researchers designed and led their own independent research projects, focusing on questions most important to them. Supported by the In Our Own Words team, they developed surveys to understand the experiences of neurodivergent young people in various settings, including perspectives from young people, parents, carers, educators, and police staff. Based on the collected data, the youth researchers formulated recommendations to inform service, support, and educational settings about the needs of the neurodivergent community. They shared their findings with decision makers, senior leaders, boards and organisations for mental health improvement in Surrey and at a special exhibition at the University of Surrey.

The journey doesn't end here though. The youth researchers are determined to continue sharing their learnings far and wide, aiming to influence positive change in mental health support and services for neurodivergent young people across Surrey.



Co-production

“The main aim of the In Our Own Words project was to give neurodivergent young people a real voice in shaping research that affects them. So, this project made sure their voices weren’t just heard but also led the way.

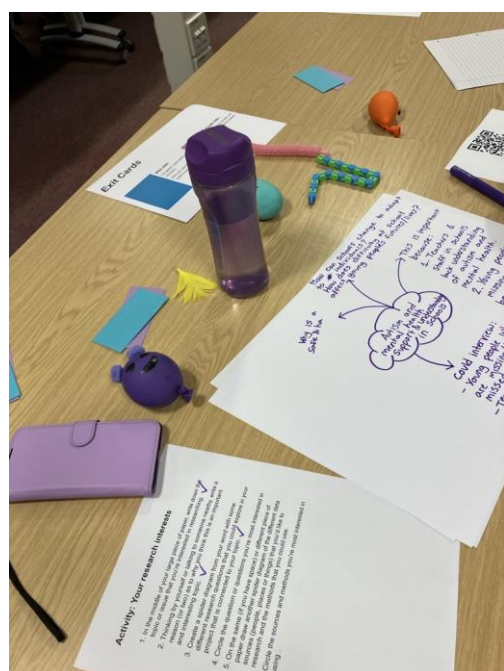
Being involved in co-production for the project was a great and meaningful experience for me. I wasn’t one of the youth researchers, but I supported the project by helping design the training sessions, assist in workshops, and make sure everything ran smoothly for the young people involved.

One of the things I helped with was developing the training materials. We wanted to make sure the sessions were interesting, understandable, and useful for the young people learning about social research for the first time. It was important to keep everything accessible and to allow space for creativity, since every young person has their own way of thinking and learning.

I also helped organise the final exhibition at the University of Surrey, where the youth researchers showed their work and shared their findings. It was amazing to give them the chance to show how far they had come and how proud they were of their achievements. Helping to set up that space and support them through the process was really rewarding.

Throughout the project, I was available for peer mentoring and joined workshops where the young people developed their research ideas. I made sure they felt supported, listened to, and encouraged. I tried to be a friendly face who listened and understood what they were trying to do.

To me, co-production means working and collaborating with people, not for them. It’s about sharing power, building trust, and making sure everyone feels like they belong and their voice matters. Being part of this project reminded me how important this mindset and approach is. It made the project stronger, and it gave the young people a space to speak and feel heard.”



Written by Lois,
a member of the
In Our Own Words
young persons' co-production group.

What Motivated the Youth Researchers to Take Part?

As a neurodivergent person who has also struggled with my mental health, I feel like my experience can and should be used to help others understand people like me.

I would like to learn how to work with other people and communicate with strangers more confidently.

I have found that so many young people struggle with mental health and the education system. I think it's important that the people who are supporting us neurodivergent young people get to understand us better.

I like the title 'In our own words' as I am trying to find my words and voice. As a family we have not felt listened to and it would feel good to make a difference.

I have an interest in researching and delving into different topics and coming up with solutions. I'm also very passionate about raising mental health and neurodiversity awareness so it would be great to work towards making a positive change for other young people in Surrey.

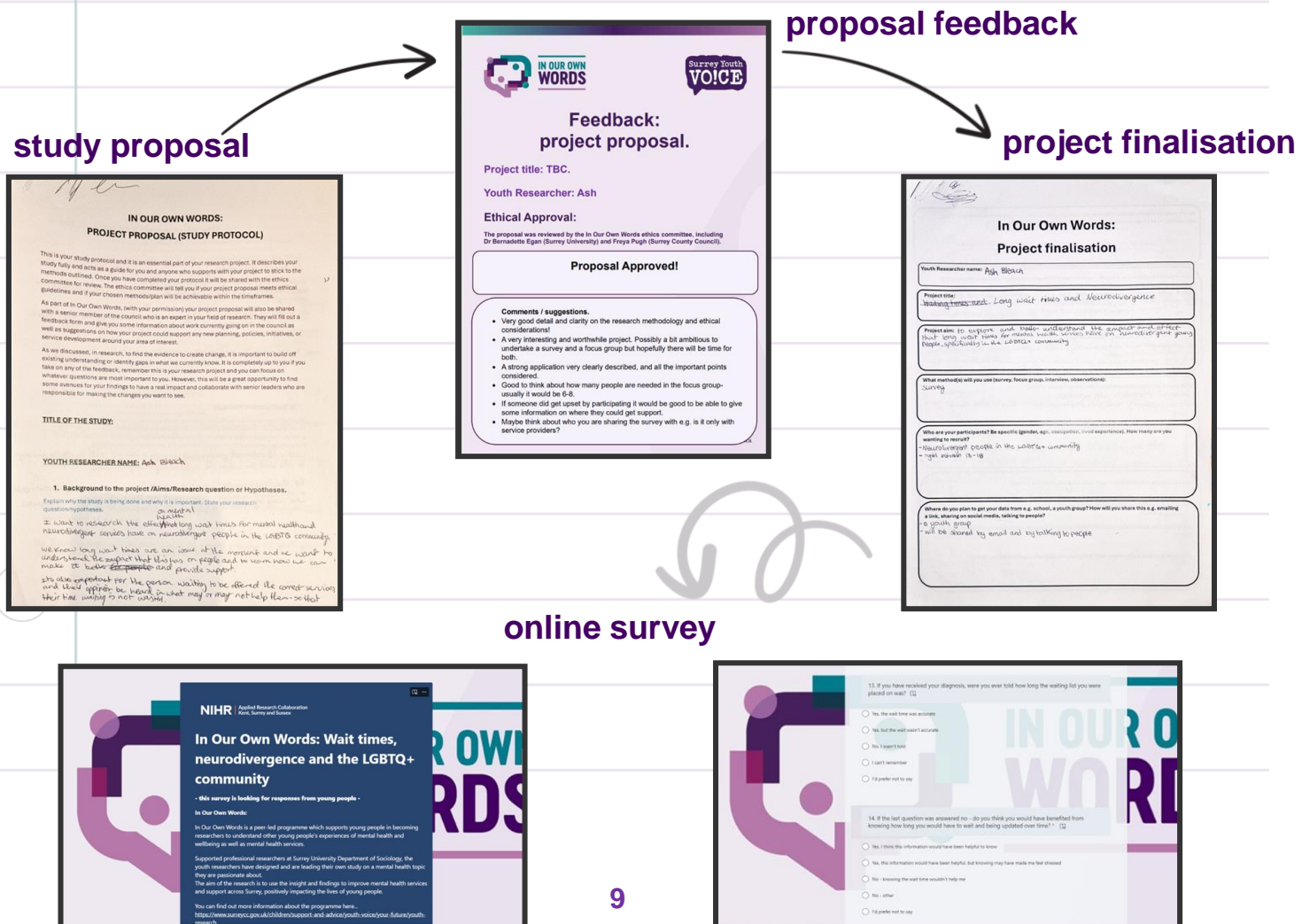
I am interested in making a difference in the world and to connect with other ND people like myself.

I want to become that voice I didn't have during my teen years and be an inspiration, a role model, an advocate on mental health.

I want to hear other young people's experiences of school and mental health because by understanding their views, I can help make things better for future neurodiverse children and teens.

The Research Process

Like professional researchers, before collecting any data, youth researchers had to complete a project proposal, outlining their research questions, target participants, and data analysis methods. These proposals were reviewed, and feedback was given from the University of Surrey ethics team as well as system leads within the council and partner organisations so youth researchers could understand what would be helpful information to gather, to support ongoing work in the mental health space. Following this, the youth researchers finalised their projects, and surveys were created and shared with the wider community. Receiving a total of 160 responses from young people, parents, carers, educators as well as police staff, the youth researchers then analysed the survey data so they could understand their findings.



Research Questions

The youth researchers were tasked with understanding experiences of mental health, support and services for neurodivergent young people in Surrey. Being neurodivergent themselves, our youth researchers are experts by lived experience. This means that they have a personal connection to the topics they are investigating. The youth researchers chose to investigate where they have struggled to access the right support or understanding in the hopes that they could gather information that may help to improve the experiences of other young people.



Youth Researchers' Questions

1. The impact of diagnosis on support at school
2. Wait times, neurodivergence and the LGBTQ+ community
3. The impacts of diagnosis waiting time, understanding student and teacher perspectives
4. Time off school and the impact on social relationships
5. The impact of mental health on education and work-based avoidance
6. Autistic girls' experiences of school in Surrey
7. Visiting the past to change the future, neurodiversity at school
8. What do you think about autism?
9. Teacher training on neurodiversity
10. Police perspectives: interactions with neurodiverse young people

Youth Research Themes

Looking at the youth researchers' projects, five clear themes emerged. These themes highlighted the community needs and priorities for neurodivergent young people in Surrey. Interestingly, these themes align with feedback from Surrey Youth Voice members over the years, showing they remain important to young people.

In Our Own Words has provided an exciting opportunity to gain new, updated insights into the current situation. Through peer-led research, our youth researchers accessed feedback from young people we haven't heard from before. This fresh perspective is crucial for understanding and addressing the evolving needs of our neurodivergent community.

RESEARCH THEMES:

1. Experiences of waiting

2. School-based support for neurodivergent young people

3. Teacher training and support for neurodivergent students

4. Education and Work-Based Avoidance

5. Understanding neurodivergence in the wider community

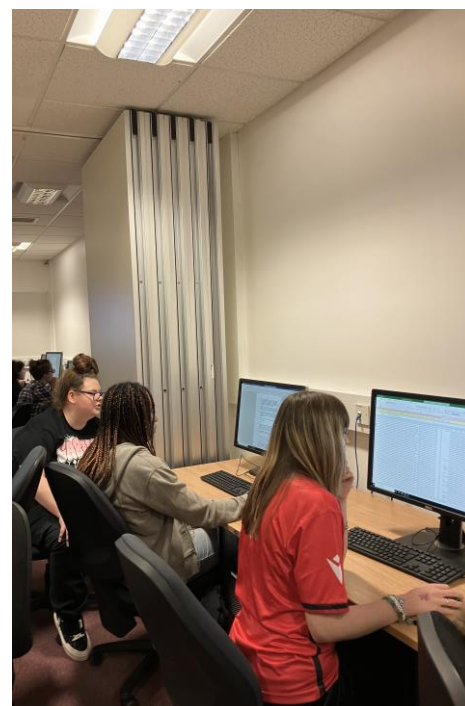


Youth Research Findings

Once the youth researchers had collected data from their community—through schools, friends, networks, youth groups, and promoting their surveys on social media—it was time to analyse their results. Using the quantitative and qualitative data analysis skills they learned from their training, they examined responses.

The youth researchers reported that seeing responses from other young people and the time they took to complete the surveys was very rewarding. It was validating to see others with similar experiences. However, it also brought up challenging feelings and emotions as they reflected on their own experiences and felt empathy for the struggles other young people have gone through.

Looking at responses through their own lived experience perspective was incredibly valuable for understanding the findings of the research. This approach ensured that the insights were deeply relevant and accurately represented the community's needs and experiences, leading to more effective and meaningful recommendations for positive change.



Experiences of waiting

The research showed that waiting for a diagnosis or mental health support has a big impact on neurodiverse young people in Surrey. Many felt uncertain and their mental health got worse while waiting. They stressed the need for support and regular updates on wait times.

Ash's project focused on LGBTQ+ young people, who all felt the strain of waiting without clear timelines. **Amber** included feedback from young people and school staff, with teachers sharing concerns about the negative effects of long waits on students and their families.

58% of young people felt unsupported while waiting. They suggested regular updates on wait times, better information about the diagnosis process and the offer of support groups to help them in the meantime. One young person said “I have been waiting over a year for a formal diagnosis... no updates regarding waiting times, just left in the dark” and another said, “help in school would have helped greatly during the two times I've been on the waiting list”.

Youth Research Findings

School-based support for neurodivergent young people

The youth researchers found that school can be challenging for neurodiverse young people. Across three projects from **Evie**, **Marianne**, and **Seren**, 36 young people shared their experiences of support in school. Many said their support improved after receiving a diagnosis, helping teachers understand their needs better. One young person said, “I 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.”

Experiences varied, with reports of primary school generally providing better support than secondary school. Most young people felt school negatively impacted their emotional wellbeing and mental health. Autistic girls reported masking at school, saying, “I don’t act like myself with others and faking my genuine emotions. And I don’t tell anyone about it either”.

Another common experience was difficulty with attendance or struggling to cope in lessons. Young people suggested that flexibility around attendance would help.

Teacher training and understanding of neurodiversity

Jordan explored the training offered to teachers and what more they wanted to learn. Many said that they would like regular updated training and information on the newest knowledge and help with supporting students with multiple conditions, for example autism and Obsessive-Compulsive Disorder (OCD).

Teachers surveyed rated their knowledge of autism as average, with no one rating above a 6 out of 10. Many young people felt that teachers did not have the right education on neurodiversity and different presentations. One young person said “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”.

Misinterpretation of behaviours as “naughty” or disruptive often led to punishment, breaking down trust between students and teachers. One young person said “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”.

Youth Research Findings

Emotionally based school and work-based non-attendance

Education and work-based non-attendance is a key issue for some neurodiverse young people. This can be due to mental health struggles or finding these settings difficult or inaccessible.

Ems' project explored how EBSNA impacts on friendships and social relationships, finding that being out of school often led to feelings of loneliness and isolation. One young person shared "**I lost touch with almost all of my friends as they all stopped contacting me**". Young people reported the difficulties they've faced with returning to school because "**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**".

Reneè explored the perspective of young people but also their parents/carers. The importance of reasonable adjustments and clear communication was highlighted for both school and work-based settings. Recreational activities appear to have a positive impact on mental health and wellbeing and keep young people connected to others during time off.

Neurodiversity in the wider community

Ellie was interested in interactions between neurodivergent young people and the police and how relationships and communication can be improved. Nine professionals from Surrey Police answered a survey about the Pegasus scheme and their knowledge of neurodiversity.

The Pegasus scheme helps individuals who find it difficult to communicate with the police by pre-registering their information. Many members of Surrey Police felt there needs to be better awareness and understanding of the Pegasus scheme. One officer said, "**I don't think it is publicised enough for young people who are neurodiverse to utilise it when talking to us**".

Surrey Police also shared their experiences with neurodiverse young people, emphasising the need for more training. One officer noted, "**Police officers need more training and practical advice on understanding neurodiversity and how best to communicate with people**". Another said that "**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.**"

Youth Research Recommendations

After reviewing their findings, the youth researchers created their own recommendations for decision makers, focusing particularly on how neurodivergent young people's mental health can be supported in schools. They hope that these recommendations will be embraced and lead to positive change.

By addressing these key areas, they aim to improve the overall wellbeing and educational experiences of neurodivergent young people. Please note, the recommendations have been shortened for the purposes of the impact story, the complete version can be found in the findings report.

Recommendations for Supporting Neurodivergent Young People on the Waitlist

- Inform schools when a student is on the waitlist for a diagnosis and train staff on supporting these students. This training should cover how to offer sensitive and empathetic support.
- Offer reasonable adjustments, like learning breaks and time-out cards, to students waiting for a diagnosis. These adjustments can help students cope while they await formal support.
- Establish support groups in schools for students on waitlists to share experiences and build connections. These groups can provide a sense of community and mutual support.
- Provide regular updates on the diagnostic process via text or email. Regular updates can help manage expectations and reduce anxiety. Keeping families informed can help manage expectations and reduce stress.
- Increase support groups for people on waiting lists. These groups can offer emotional support and practical advice.
- Create co-production groups for young people to share issues and propose solutions. This approach empowers young people to contribute to improving their own experiences.

Recommendations for Supporting Neurodivergent Young People at School

- Make sure reasonable adjustments are applied universally. This promotes inclusivity and ensures all students receive the support they need.
- Offer sensory support items, like fidgets, in classrooms to help manage sensory challenges. Ensuring these tools are available can improve focus and comfort for neurodivergent students.
- Create quieter classroom environments to accommodate all learning needs. This includes managing noise levels and promoting respectful behaviour among students.



Youth Research Recommendations

Recommendations for Teacher Training

- Annually update teacher training on neurodiversity, designed by neurodivergent young people. Ensure training is relevant, reflects the latest strategies, and considers the needs and resources of individual schools. Share best practices between similar school environments.
- Increase teacher awareness of diverse processing needs and how profiles may change with co-occurring conditions, ensuring all students receive appropriate, individualised support.

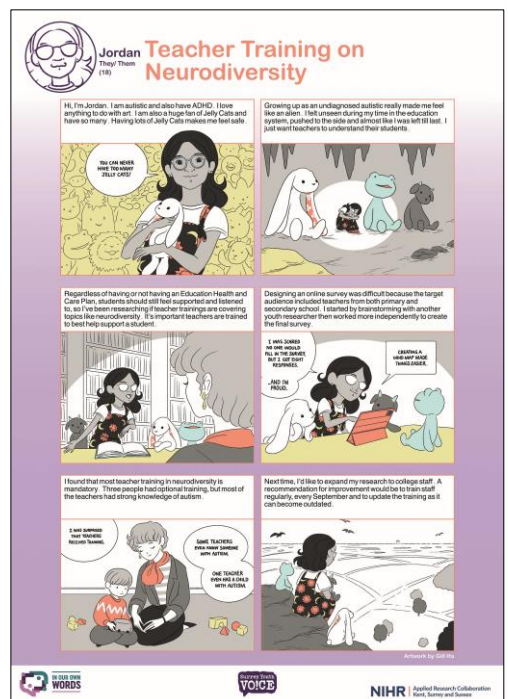
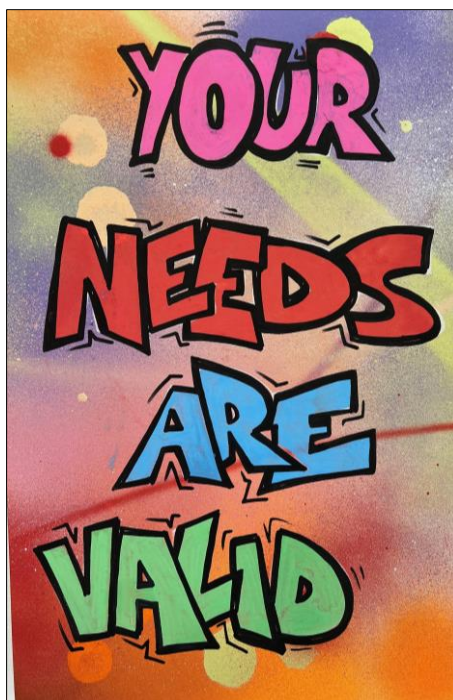
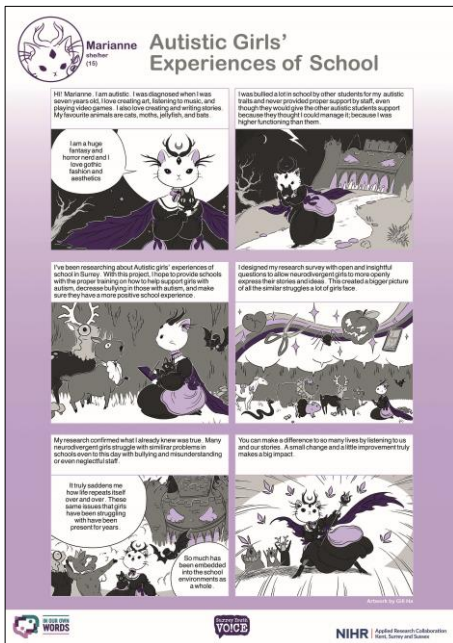
Recommendations for Supporting Neurodivergent Young People Experiencing School and Work-Based Avoidance

- 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.
- Schools to educate young people about EBSNA and how to support their friends and peers to address the identified misunderstanding and insensitivity towards students going through EBSNA.
- Offer flexible timetables to increase attendance. This can help accommodate different needs and reduce stress.
- Foster empathy and psychological safety regarding school attendance challenges. Creating a supportive environment can help students feel safe discussing their attendance issues.
- Promote recreational activities that are inclusive and neurodivergent-friendly. These activities can help students engage and improve their wellbeing.

Recommendations for Supporting Neurodivergent Young People in the Community

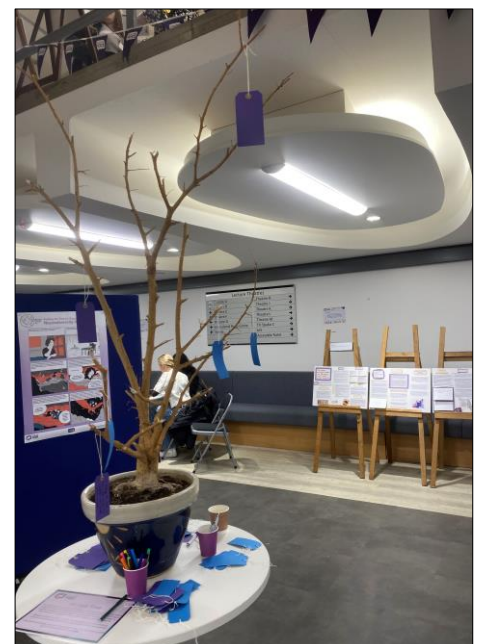
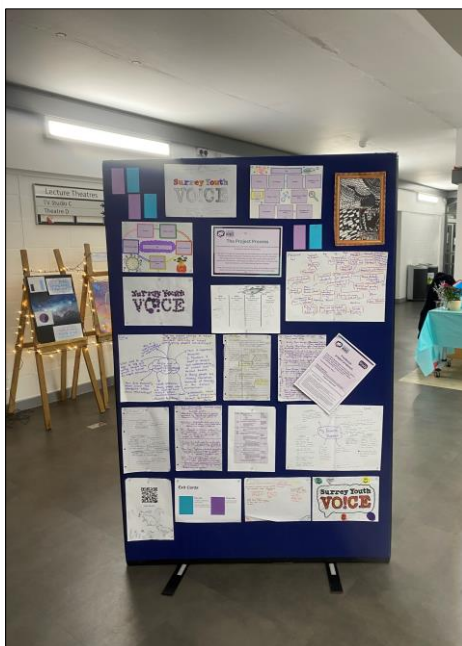
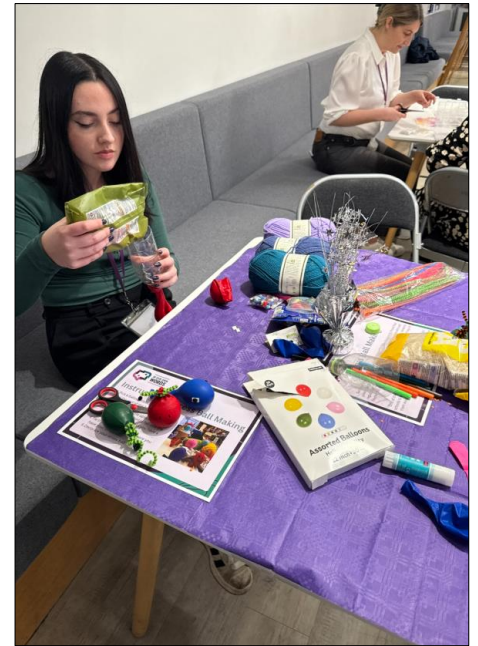
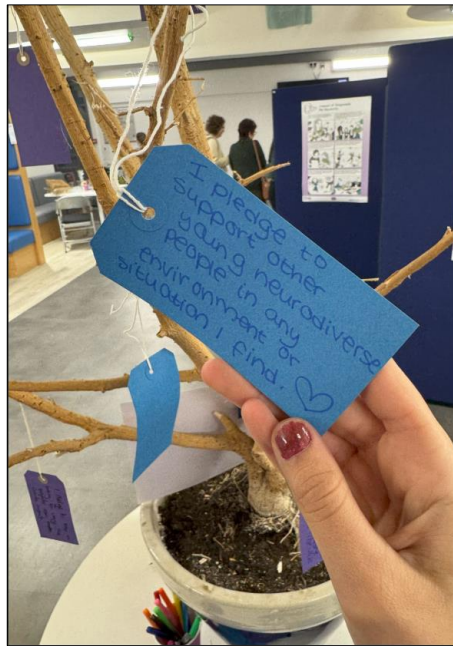
- Promote and simplify the Pegasus scheme for better communication with neurodivergent individuals. This includes increasing awareness and making the scheme easier to use.
- Increase regular training for police officers on neurodiversity, supported by neurodivergent young people. This training should provide practical advice on understanding and communicating with neurodivergent individuals, helping to build trust and improve interactions.

Getting Creative



In Our Own Words aimed to inspire youth researchers to creatively express themselves and present their research in engaging, accessible ways that showcased their unique individuality and passions.

Youth Research Exhibition



In February, In Our Own Words held an exhibition at the University of Surrey to showcase youth-led research. Youth researchers presented their projects and celebrated their achievements along with their families, friends, university researchers, and professionals in mental health, neurodivergent services, and education. The event inspired collaboration and sparked important conversations, highlighting the power of youth-led research.

Next Steps

So, now we have all this fantastic research, what do we do next? There is already great work happening in Surrey to transform services and support for neurodivergent young people. For example, the Local Area SEND Partnership Improvement Plan launched in 2024 and is committed to helping Surrey children and young people aged 0 to 25 with additional needs and/or disabilities lead the best possible life.

Progress has been made, and we are committed to making sure that youth voice is prioritized, integrated, and communicated to the appropriate audiences to drive this change. This youth research gives us valuable insights into the current experiences and feelings of children and young people, highlighting priority areas where interventions and support need more focus and implementation, so they can feel the impact in their schools and communities.

A big motivation for participating was the chance to make a real, meaningful difference. Surrey Youth Voice and the In Our Own Words partners are committed to honouring the dedication and passion of the youth researchers.

Some ways we will do this include:

- **Champion Findings and Recommendations:** Advocate for the findings and recommendations put forward by our youth researchers in various settings. The youth-led research provides valuable insights and feedback from young people across Surrey, driving meaningful change.
- **Supporting Action Card Governance:** Support Surrey Youth Voice's action card governance system, advocating for the recommendations from this programme and making sure that the voices of young people remain at the forefront of decision-making processes. We will continue to collaborate with senior leaders and decision-makers to integrate this feedback into ongoing service development, policies, and projects.
- **Resources and Learnings:** Share the resources and learnings from this project widely to inspire and inform others about the needs and priorities of neurodivergent young people in Surrey. Having seen the personal benefits to the young people involved in the programme, we hope to encourage more opportunities for community-led research, allowing more groups of young people but also adults to engage in this kind of collaboration with Surrey County Council and partners.



Our Learnings

As the youth researchers learnt, an important part of research and running a new project is reflection. Here are some of our learnings from the pilot year of In Our Own Words.



Young Carers

The project aimed to recruit both neurodivergent young people and young carers as priority cohorts. Unfortunately, we were unable to recruit any young carers to participate this year. Due to the time constraints, there was only a month to apply for the programme. Recruitment with young carers requires more time to build trust and develop relationships. In the future, we will increase our recruitment window to allow the team to get out into the community and meet young people 'where they are'.

Data Collection

Youth researchers' surveys were published at the beginning of July. Work on 'projects' only started in June and the team wanted to work at a speed that was comfortable. However, by the time all surveys were ready, there was only 2 weeks left of the school year and so surveys were sent for a limited time before the summer holidays. Moving forward, the data collection period should cover school term time so youth researchers can make the most out of having direct contact with teachers and peers.

Programme Demands

Youth researchers reported that they found the workload manageable and that there was good support and resources, as well as flexibility from the team. However, some youth researchers were in exam years at school and college so had to balance their schoolwork with their research. As we are hoping to expand the programme and our reach, we can think about different options for the 'projects'. This could include shorter term 'mini' research projects or by encouraging larger group work, so that responsibilities can be shared.

Training Session Location

Social research training sessions took place on campus at the University of Surrey. The youth researchers benefited from the in-person sessions as they offered the opportunity to experience a higher educational environment and build social connections with their peers. However, for those who lived further, travelling to campus twice a month after school or college sometimes felt challenging. Moving forward we would like to explore a hybrid teaching option, so training is more accessible.

Youth Researcher Stories



Ems (16)

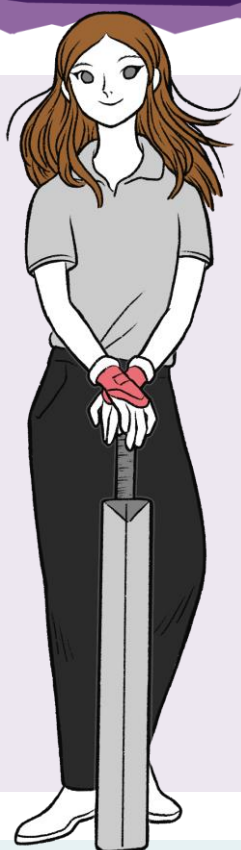
The project has been life-changing for me. I've learned so much about social research and the importance of researching with people who have lived experience. In Our Own Words has given me the incredible opportunity to take my bad experiences and turn them into something positive that helps other young people and creates change. In my project about how EBSNA impacts young people's friendships and social relationships, I found that young people's peers don't have enough support with how to interact with their friends who are off school. I hope that moving forward in the future, we will be able to spread more awareness about EBSNA and provide young people with the tools they need to return to school. When I got all the survey responses back from my participants, I found that their experiences were so similar to mine, and it made me feel like I wasn't alone. Thank you to the In Our Own Words team, for the doors you've opened for me and my fellow youth researchers.

Reneé (20)

My experience participating in the In Our Own Words project has been a great experience to learn more about social research and be empowered to help others. I was able to find out in more depth the impact of mental health on children and young people struggling with school or work avoidance. A recurring theme that I discovered was the positive impact of taking part in sports and clubs and the community of support that is often offered. However, something I found difficult was managing the workload alongside a full-time job, but I was given a lot of time to complete my project which was helpful. One of the main parts of this programme I enjoyed was the exhibition as this allowed me the opportunity to showcase my work!



Youth Researcher Stories



Amber (15)

I can only be more than grateful for the opportunity, because it helped me learn a lot about myself and other people. The In Our Own Words project was an experience I won't forget. From finally meeting people I can relate to and sharing my own experiences to making an impact. I was able to research in depth about how to conduct a survey, and about the results I got based on the impacts around diagnosis waiting times. I loved every moment of the project, and it has guided me outside of my comfort zone more often. Everyone was so perfectly supportive and helpful, such a stark contrast to my school environment. There was not a single moment where I felt in the dark or significantly worried. I was given plenty of time to complete my overall project, which made juggling my overload of schoolwork easier. I really enjoyed the exhibition, even if I was slightly anxious speaking to professionals, I finally felt able to express my thoughts and feelings on the system to adults.

Evie (16)

I really enjoyed having the opportunity to join In Our Own Words, my confidence has really grown, and I have made some new friends. I was really worried to start with as I didn't know any of the others and I had never been to a university before, but everyone was so nice, and we were all really well supported. It was great working with university lecturers learning about how to conduct a research project, process data and make a poster board to show the results. I really enjoyed the creative parts for example making the comic, graffiti boards, poster boards and eating the snacks at break time. My project was about diagnoses in schools and found that more support is needed to help teachers understand what students need before and after diagnoses. I really hope my research project can help people like me have an easier time in school and that teachers can have some training in supporting students before and after diagnoses.

