



**Ambitious
about Autism**

Research on post-diagnostic support for autistic young people

November 2023



Introduction from Ambitious about Autism

Autistic young people have told us that having a limited understanding of their own diagnosis makes their mental health worse, particularly during the transition to adulthood. Currently, post-diagnosis support is not widely available and many autistic young people from marginalised communities face additional barriers in accessing any support.

In response, Ambitious about Autism worked with autistic young people to co-design an online peer support course called **Understanding You, Discovering You** (www.ambitiousaboutautism.org.uk/post-diagnosis-peer-support). This course supports autistic young people to explore what autism is, develop a positive autistic identity, and equips young people with practical skills, with the aim to improve their mental health.

We commissioned a team of researchers, led by UCL Centre for Research in Autism in Education (CRAE), to conduct research

to help collate evidence linking autistic identity and wellbeing, investigate inequalities in accessing post-diagnostic support and lead an evaluation of the co-production and initial pilot of the online course. We wanted a strong research base to help us learn, inform the ongoing development of the online course, and provide us with a series of recommendations to make the course inclusive and accessible to more autistic young people.

With the support of UCL CRAE and their colleagues, this research is now complete and summarised in this document. We hope by sharing our learnings and the research findings we can support more autistic young people, post-diagnosis.

Full research papers are linked by QR codes in this document.

About Ambitious about Autism

Ambitious about Autism is the national charity standing with autistic children and young people. We believe every autistic child and young person has the right to be themselves and realise their ambitions. We started as one school and have become a movement for change. We champion rights, campaign for change and create opportunities.

About UCL CRAE

The UCL Centre for Research in Autism and Education (CRAE) is based within the Department of Psychology and Human Development at UCL Institute of Education. CRAE is a team of autistic and non-autistic people who conduct ground-breaking scientific research to enhance our knowledge about support, education and outcomes for autistic people, their families and those who support them.

Research overview

We wanted...

1

To conduct a review on the current state of knowledge regarding the interplay between identity and wellbeing/mental health for autistic people.

2

To investigate inequalities in access to post-diagnostic support for autistic young people.

3

To undertake an evaluation of the co-production and initial pilot of the online course.

...and for all this work to be co-produced with autistic young people.



Part one:

A review to collate what we know about the interplay between identity and wellbeing/mental health for autistic people.

Autistic-collaborators: Grace and Molly



Grace and Molly took part in a series of 'journal clubs' with researchers at UCL CRAE, where they learnt about different types of research studies and provided feedback on the work and its implications for supporting autistic young people. Our final journal club was a discussion of the review that was led by UCL CRAE, and Grace and Molly helped shape the ideas presented in the discussion of the paper.

What did we want to find out?


- What factors, if any, are associated with autistic identity?
- What is the connection between autistic identity and mental health/wellbeing?

What did we find?

We reviewed over 3000 research articles, and identified 20 that addressed our research questions. We carefully reviewed these 20 articles, to gather key information from them that could answer our questions.

-  We could not identify any individual factors (e.g., age, gender, ethnicity, age of diagnosis) that were reliably associated with autistic identity.
-  We did, however, find evidence to suggest that environmental factors (e.g., the external support and acceptance a person had) was associated with autistic identity.

What is the connection between autistic identity and mental health/wellbeing?

-  Positive autistic identity was associated with better mental health and wellbeing.

Why are these findings important?

Our results suggest that supporting autistic young people to develop a positive autistic identity is beneficial for their mental health/wellbeing.

Our results also suggest that broad support aimed at a wide range of autistic people, like the Understanding You, Discovering You programme, may be beneficial. It's important to remember that not all autistic young people may want to attend peer support groups, so Ambitious about Autism will also need to think of other ways to ensure that all autistic young people can get the support they need.

Scan to read the full paper.



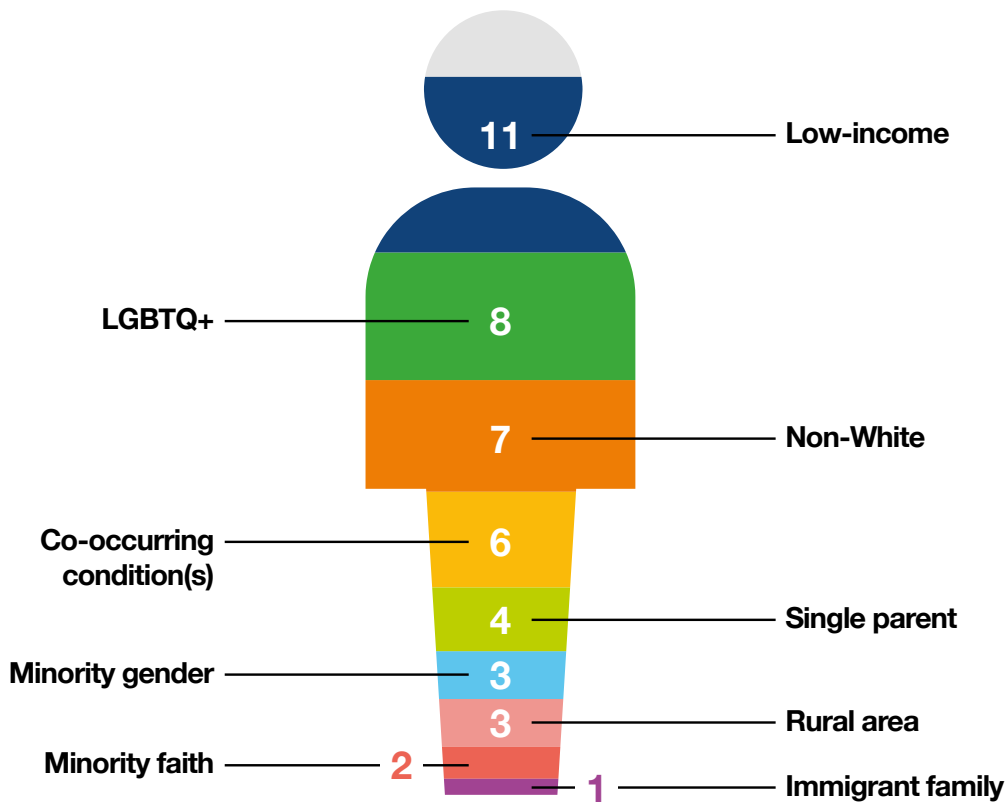
Part two: Investigating inequalities in access to post-diagnostic support for autistic young people

Autistic-collaborators: Labeedah and Susannah

We worked together with Labeedah and Susannah, who helped design the study, conduct interviews and analyse the data. Labeedah and Susannah took part in interview training and shadowed interviews, to help prepare them for conducting interviews themselves. They also received training in analysing qualitative interview data.

What we did

We interviewed 13 young people who, in addition to being autistic, also identified as having at least one other marginalised identity.



We spoke to our participants about...

- themselves and their autistic identity
- their previous experiences with accessing support
- how they thought future support could be made more accessible for all autistic young people.

Participants had the choice of how they were interviewed: eight opted for a video call, one opted for a voice call, and four opted to send their answers to us and answer follow-up questions by email.

What did we find?

Our participants told us that accessing and engaging with support was difficult for autistic young people, but that there were many ways it could be especially difficult given their multiple marginalised identities. There were three key examples that our participants gave, which illustrated this perceived inequality: (1) delayed access to a diagnosis; (2) difficulties in finding the right support, and (3) unequal access to a key ‘champion’.

Delayed access to a diagnosis

An example...

Some participants felt they were not identified as autistic as early as they could have been due to their parents’ cultural background and subsequent understanding of autism:

“My mum ... comes from the Philippines, and in the Philippines mental health is taboo, people have never heard of autism ... I think many people are diagnosed later, simply because parents didn’t know how to recognise the signs”.

Difficulties in finding the right support

An example...

Some participants from low income families struggled to cover the costs associated with travel and participation in support programmes:

“I haven’t really found [any support] too close to me. I found somewhere but it would take two and a half hours to access them, and it takes time and money, and it’s stuff, resources that I don’t have”.

Unequal access to a key champion

An example...

Not all participants had parents/carers who were able to advocate for them, despite this being a key factor underpinning the accessibility of support:

“My dad would never encourage me to [access support, due to his own poor experiences related to his cultural background] ... he’s always been suspicious of social services and stuff [because] they misunderstood his background...”.

Why are these findings important?

By highlighting the issues experienced by autistic young people with multiple marginalised identities who may experience additional challenges in accessing support, Ambitious about Autism can think about how to proactively adapt the Understanding You, Discovering You programme to be maximally inclusive and accessible.

Scan to read the full paper.



Part three: An evaluation of the co-production and initial pilot of the online course.

Autistic-collaborators: Leon and Lucy

We worked together with Leon and Lucy, who helped design the Understanding You, Discovering You course. Leon and Lucy spoke with researchers from UCL CRAE to try and identify the factors that underpinned the success of the co-production of the programme. We are delighted that Leon and Lucy will play crucial roles in the ongoing evaluation of the Understanding You, Discovering You programme too.

What we did

We systematically documented everyone's reflections about involving autistic young people in the design of Understanding You, Discovering You, to guide the creation of similar projects in the future. We also gathered initial feedback about the programme from programme attendees, to better understand their experiences and learn how to make the programme better in future.

What we found

We identified three main things that were important when involving autistic young people in the co-design of Understanding You, Discovering You: good preparation, effective and respectful communication, and making sure the collaboration is meaningful.

Programme attendees reported that they liked learning about autism, found value in the social connections they made, and gained practical skills from the programme.



These findings suggest that successfully co-designing programmes with autistic people is a good way to make sure they are useful.

Why are these findings important?

These findings provide important evidence to support Ambitious about Autism's approach to co-production, and their commitment to meaningfully involve autistic young people in the design and delivery of support and services that ultimately affect them. Other organisations may want to reflect on these learnings, to ensure that they meaningfully involve autistic young people in decision-making processes too.

Scan to read the full paper.



Key recommendations for Ambitious about Autism

- 1** Continue to lead and develop co-production with autistic young people; deepen engagement and involve young people at every step of a programme's lifespan.
- 2** Proactively adapt Understanding You, Discovering You to be maximally inclusive and accessible. For example, reducing financial burdens to access online courses by contributing to internet costs.
- 3** Not all autistic young people want to attend online peer support groups. Think of other ways and formats to ensure that all autistic young people can get the support they need (for example, self-directed support).

Key recommendations for all

- 1** Provide broad support aimed at a wide range of autistic young people to help them develop a positive autistic identity to benefit their mental health/wellbeing.
- 2** Understand the broad range of barriers that may affect autistic young people from being able to fully access and participate in support, especially for autistic young people with multiple marginalised identities.
- 3** Ensure meaningful involvement of autistic young people in decision-making processes.

Perspective from the Ambitious Youth Network

We asked our autistic collaborators why this research was important and what it meant to them...

“

I myself have experience of the severe lack of support after diagnosis and I wanted to be able to show what needs changing and make that difference...Being able to gain experience shadowing [the research interviews] while also collaborating thoughts and empathising with those experiences knowing that change needs to be made and that we are trying our hardest to bring it into the light!”

Susannah

“

With the emphasis on understanding autistic experiences, it was doubly important for an autistic researcher to provide their point of view and help with the analysis. Our study was focused specifically towards autistic people from underrepresented communities. As I myself am part of multiple underrepresented groups I thought I had the unique experience needed to be useful on this project.”

Labeebah



“

Support is the difference between life and death for many autistic people. Autistic people have as much value as anyone else and deserve to be treated equitably. It surprised me how unrepresentative and discriminatory so much of the research [examined in the autistic identity review] was, focusing heavily on late diagnosed white, autistic people, without a learning disability or complex needs.”

Grace

“

It is important to me to be involved in the research because it has given me purpose and pride to be involved in something so academic, and I am passionate about the importance of autistic individuals being included in creating research and support for other autistic people. By taking part in this research, I learned that there are people trying to help people like me, even though it doesn't always seem like it!”

Lucy

“

I feel I would have benefited from a programme like this [Understanding You, Discovering You], if it had existed when I received my diagnosis...I wanted to be able to contribute to the programme's creation by sharing my own experiences and suggesting topics... we met with researchers from UCL to share our reflections on the co-creation process so that the perspectives of all involved were fully grasped and accurately portrayed in the research paper.”

Leon



Authors' acknowledgements

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Ben Redmayne

Ambitious about Autism

Leon Allain, Susannah Carter, Molly Healy, Labeebah Islaam, Lucy Portway, and Grace Thompson

Ambitious Youth Network

Kate Cooper

Centre for Applied Autism Research,
Department of Psychology,
University of Bath

Will Mandy

Research Department of Clinical,
Educational, and Health Psychology,
University College London

Jade Davies and Laura Crane

Centre for Research in Autism and
Education (CRAE), UCL Institute of
Education



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Contact us

The Pears National Centre for Autism Education
Woodside Avenue, London N10 3JA

☎ 020 8815 5444

✉ info@ambitiousaboutautism.org.uk

🌐 ambitiousaboutautism.org.uk

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Contact us

UCL Institute of Education
University College London
55-59 Gordon Square, London WC1H 0NU

☎ 020 7331 5126

✉ IOE.crae@ucl.ac.uk

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