



ACoRNs Newsletter



A warm welcome to the summer edition of the ACoRNS newsletter: In this issue:

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- Student projects throw light on aspects of autistic experience: P2-3
- Interns update + introducing next year's students: P4-5
- Reading Group and Research Updates: P6-7

AUTISTIC VOICES: ACROSS THE SPECTRUM

In May we hosted our latest online event: Autistic Voices – Across the Spectrum. We hear so much about autistic voice but what different ways can people across the whole spectrum make their voices heard? We brought together 6 panel members who provided insights into their varied approaches to autistic voice. We then opened the floor to small group discussion and a larger Q+A session.

We kicked off the session with Dr Luran Doak from Nottingham Trent University. She highlighted the chronic under-representation in research of autistic people with learning disabilities and explained how actions, not just words, are also communications, showing examples from her video analysis work. Following this we had a great presentation from Beth Sutton of the University of Sussex, who focused on her 2021 research paper, "[I like you being here](#)", discussing her method of illustrative interviewing. We concluded the first half of the event with an insightful presentation from Professor Sarah Parsons of ACoRNS Southampton, showing the [role video stories](#) can play in showing life from the perspective of autistic people.

Her presentation really highlighted that 'seeing is believing'.

Marysia Szlenker from the University of Sussex led off the second half of the event with a powerful performance of her moving poem depicting the struggles of being autistic with PDA at university. She shone a light on her experiences of the current system and reforms needed, and several people asked to share the video for wider impact. Next up, Sadie Gillett from the Brighton and Hove Inclusion Support Service (BHISS) spoke about current provision to collect pupil voice in mainstream schools and suggested different ways schools can collect autistic voice in more autism-friendly ways. Simon Smith, an autistic teaching assistant from Downview Life Skills College, concluded the presentations relating his experiences as an autistic staff member, and how this really helps him connect with autistic students. The audience asked lots of great questions and had lively breakout discussions – so much so that as organisers, we are analysing and summarising the ideas. To read a more in-depth report of the event visit our [blog](#).

RECENT SUSSEX STUDENT RESEARCH ON AUTISTIC VOICE: TWO FINAL-YEAR PROJECTS SUPERVISED BY NICOLA YUILL SPEAK TO HOW AUTISM IS UNDERSTOOD AND REPRESENTED

CHANGING ATTITUDES AND KNOWLEDGE ABOUT AUTISM USING DIGITAL STORIES

Lucy Williams aimed to see whether video stories made by autistic stakeholders can help people understand more about lived experience in autism and learning disabilities. Lucy constructed an online survey to assess both knowledge and attitudes. This involved much reflection on what 'facts' to include – there are different views and ever-changing understanding about autism and the spectrum. Respondents, who were all students, had to judge whether various 'facts' were true or false and to give their attitudes to autism, and finally were asked to write down words that came to mind when thinking about autism. They then watched an 8-minute video compilation of 3 digital stories taken from the Our Stories project, and finally answered the same set of questions about autism, and provided some more words. There was a small but significant increase in positive attitudes when comparing the pre-and-post video responses, and interestingly, a small but significant drop in knowledge from pre to post-test.

Perhaps this drop in knowledge suggests the stories made people question their initial assumptions about autism. What's more, the words people used showed a marked change pre and post-watching the videos.



After watching, students showed a significant increase in use of positive words, and words that appeared much more often included *playful, affectionate, and happy*. Respondents commented afterwards: *"it was nice to see the children portrayed in a positive light....be a part of loving and caring", "It was lovely to see the perspectives in different contexts... how his autism did not limit his ability to compete in a sport he loves..."*. It is great to see the positive impact digital stories could have.

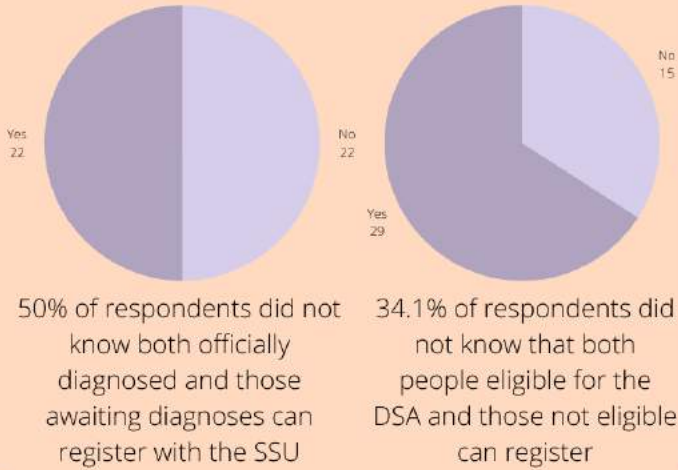
Lucy cited the idea that just teaching about autism doesn't shift attitudes, but maybe showing does - "seeing is believing". This project also lays down a great foundation for further work to find out if such methods can be used more widely to increase understanding and empathy.

THE SUSSEX UNI STUDENT SUPPORT UNIT

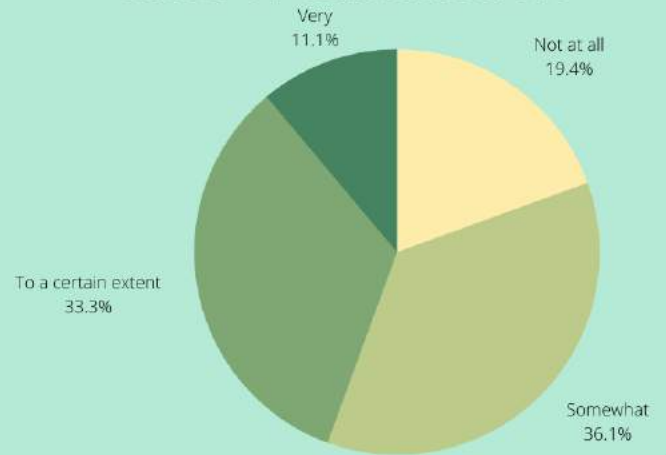
Ethan Lam, the ACoRNS intern last year, completed his final-year Psychology dissertation with a survey of autistic students accessing support at the University of Sussex. Forty-four students responded: Ethan's poster on the findings is on the next page. This research complements the initiatives being taken by the University of Sussex student connectors' work on creating an Autism-Friendlier University, supervised by Nicola Yuill and Sophie Anns: more about their work [here](#).

AUTISTIC STUDENTS' EXPERIENCES ACCESSING SUPPORT AT THE SSU

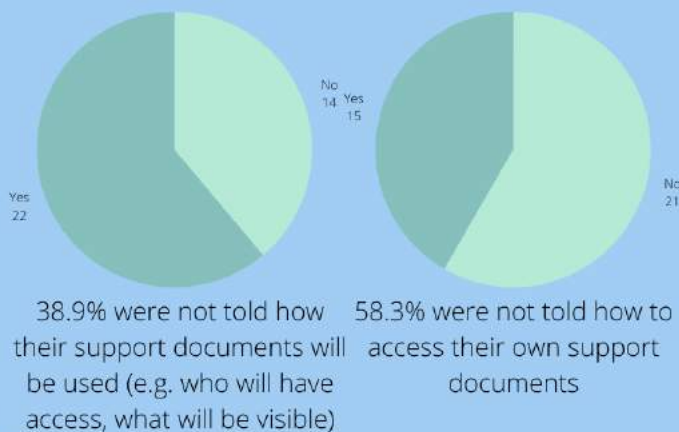
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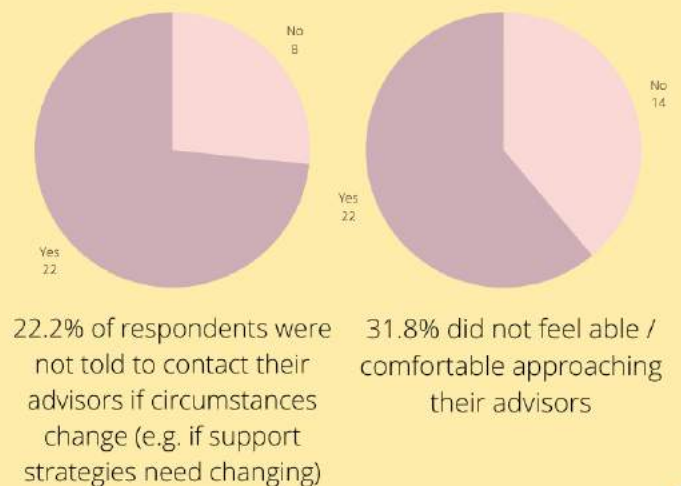
SSU REGISTRATION EXPERIENCE - LEVEL OF SATISFACTION



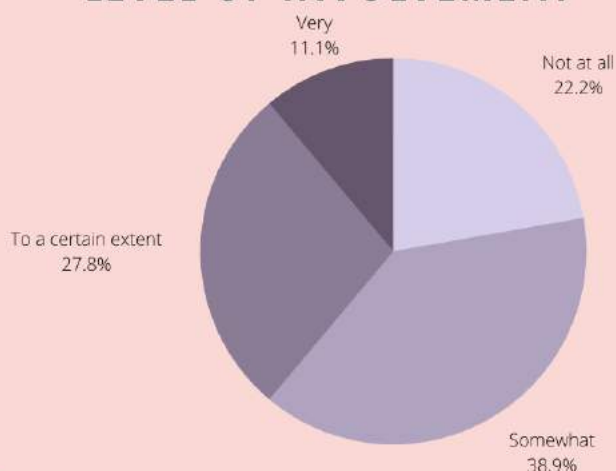
KNOWLEDGE ABOUT SUPPORT DOCUMENTS



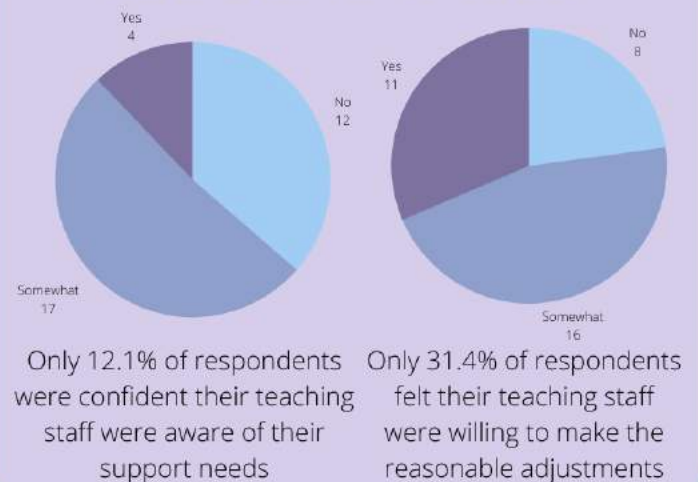
SUPPORT AFTER REGISTRATION



SSU REGISTRATION EXPERIENCE - LEVEL OF INVOLVEMENT



LEARNING EXPERIENCE



PLACEMENT STUDENT'S REFLECTIONS



ALICE WHITE



Jemima Matthews

Jemima and Alice write: "Our time working with ACoRNS is nearly coming to an end and we have really enjoyed our year. We've loved the varied experiences we have been able to get involved with. We have been helping within the research network in a whole range of ways – the newsletter, social media (maintaining [twitter](#) and setting up the new [Instagram](#) account), hosting events, updating the website, and creating animations. We have aimed to engage stakeholders as much as we can. One of the main ways we have done this is through running the monthly Autism Reading Group: doing this via Zoom has enabled more people to participate, with a wide range of people from teachers, educational psychologists, autistic people, and parents as well as parent group representatives –and members are both neurotypical and neurodiverse. From carrying out this placement we both now feel so much more prepared for the final year of our psychology undergraduate degree and have Nicola and Jacqui, ACoRNS co-directors, to thank for this. Below is a poster we created for an end of placement year event, that describes the main thoughts we have collated from hosting the reading group".

As Alice and Jemima say goodbye to the internship with a farewell picnic in June, we say hello to our two new interns, Anjali and Owen:

Owen Hole

"I am currently an undergraduate psychology student with a strong interest in social and behavioural psychology. I'm very excited to have the opportunity to work on the various ACoRNs projects throughout my placements.

I am looking forward to being able to get involved with the reading group and assisting in facilitating a space for conversation with and learning from the experiences of autistic individuals and their families. I am particularly interested in getting involved with the running of the social media as well.

I am excited to learn more about the research at ACoRNs and plan to get myself involved and help out wherever possible."

Anjali Das

"I am a recent graduate of Psychology and Cognitive Science from the University of Sussex.

My previous work experience and passion for working with autistic children has contributed significantly to my interest in this placement.

I am excited to be involved in the various projects being conducted by ACoRNs Sussex and look forward to running the reading group. I hope to extend my knowledge on neurological and developmental disorders and evolve transferable skills that would aid me in pursuing a career in Clinical Psychology. "

Running an Autism Reading Group: What Have We Learnt About Gaps in Provision?



Alice White and Jemima Matthews
ACoRNSussex, ChatLab, University of Sussex



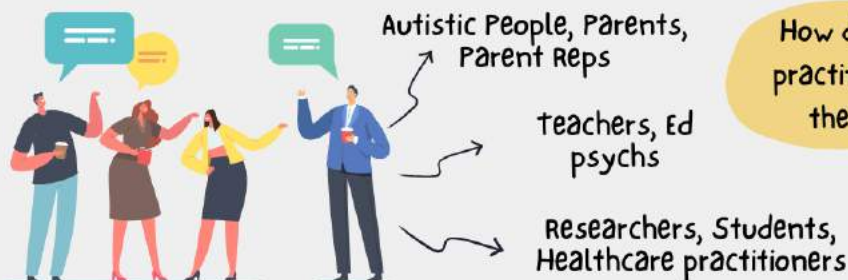
- We've been doing our placement with Autism Community Research Network Sussex (ACoRNS) which seeks to improve the lives of autistic children and young people
- It strives to do this by engaging the local community and especially autistic stakeholders



How have we engaged stakeholders?

- Running a monthly Autism Reading Group via Zoom with a new topic each month
- Writing a blog to maintain engagement outside meetings and improve the inclusivity of the event
- Setting up an Instagram page to widen our reach.
- Interviewing local stakeholders such as local parent carer group mASCot

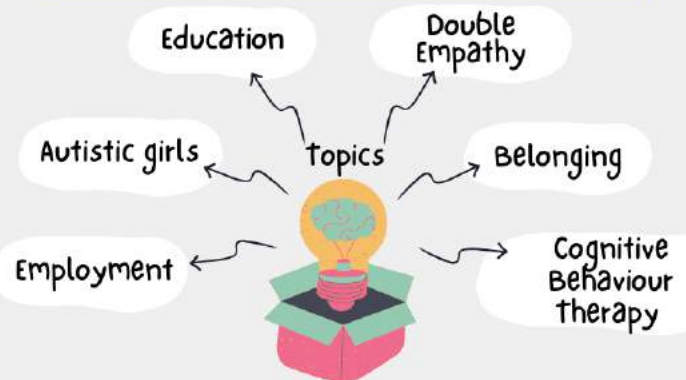
Who attends the reading group?



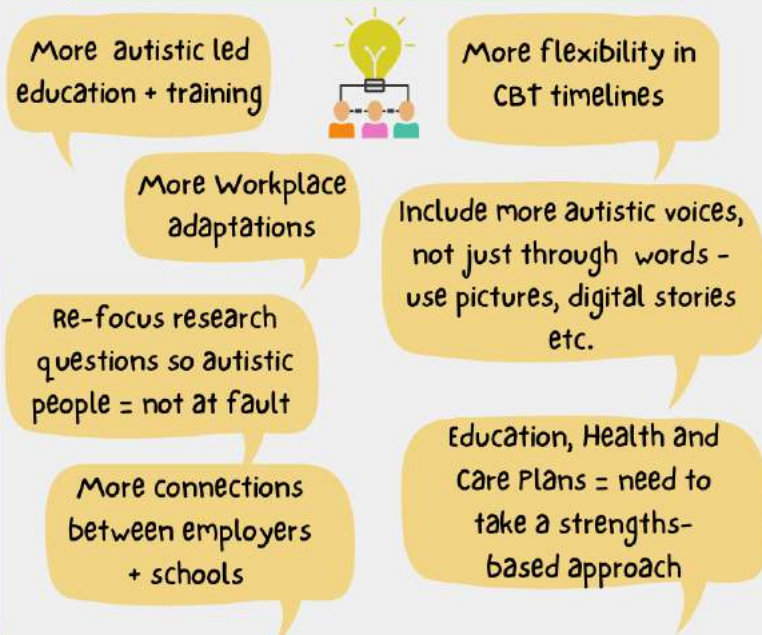
Find out more: <https://www.acorns-sussex.org.uk>

Acknowledgements: With thanks to all our stakeholders who attended our events this year, and acorns co-directors Nicola Yuill and Jacqui Shepherd.

What have we discussed?



What needs to change?



What questions have been raised?

- How does masking affect practitioner evaluations of the success of CBT?
- How can we reap the benefits of autistic-autistic peer support?
- How can creating a sense of belonging help reduce the high suicide rates in the autistic population?



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Autism Reading Group

The group has gone from strength to strength, creatively curated by interns Jemima and Alice. Check out the blog www.acorns-sussex.org.uk/blog to see what we've discussed recently, from gender identity to autistic sense of belonging. The reading group will continue after the summer break, run by new interns Owen and Anjali.

The reading group is open to anyone interested in having an informal discussion about current topics and research about autism. To join, email - acorns@sussex.ac.uk.



Are you enjoying in-person meetings again? Read on....

Last year, a team from ChatLab, funded by a special Covid-19 initiative from National Institute of Health Research (NIHR-ARCKSS), published some popular research-informed [guidelines](#) on how to support good online therapeutic meetings. The ACoRNS interns also made this [cool animation](#)

But now people are meeting in person again, many have added online meetings as part of a combined therapeutic package. So, what have we learned about using online methods in combination, or instead of in-person meetings? The ACoRNS interns are set to find out, with a new survey: if you provide any form of pastoral or therapeutic support, [click here](#) to take the survey!

Healthy Ageing project

Following the Just Right and Time for Autism Our Stories projects we are now launching a new digital stories project - Healthy Ageing. Led by Professor Nicola Yuill and Dr Samantha Holt, this project aims to produce a digital story with an autistic adult attending a day care centre. This project is a methods-based project and aims to investigate how to transfer the methods from the 'Our Stories' project to a different context.



Get in touch

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DO YOU PROVIDE SERVICES* THAT INVOLVE:

- NURTURE OR WELLBEING SUPPORT
- PASTORAL SUPPORT
- MENTAL HEALTH SUPPORT

Want to help us provide new guidance
about online and in person services?

Complete our online survey

All participants will be
entered into a prize-
draw for the chance to
win a £25 voucher

*any service outside the NHS

