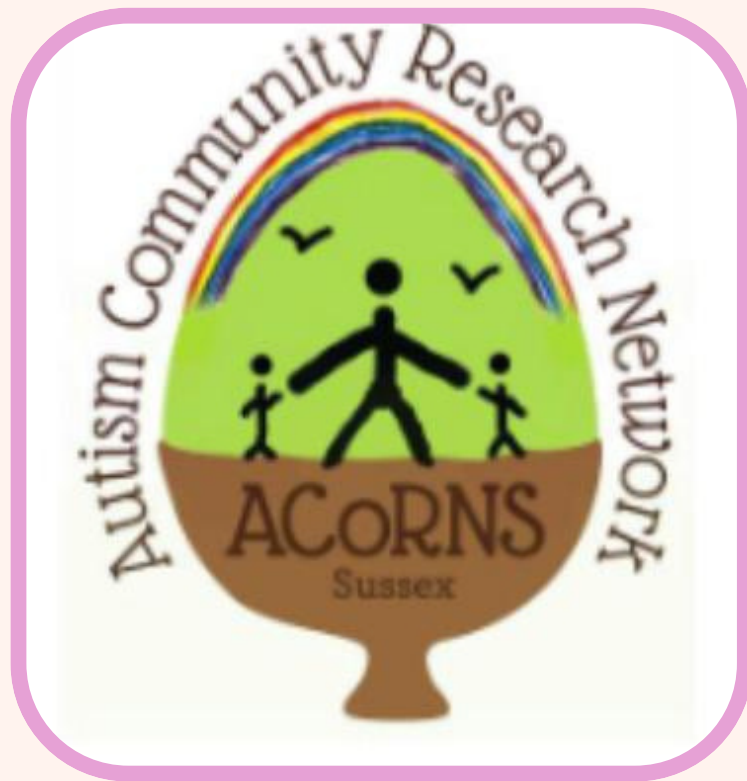


2023-2024

ANNUAL REPORT



PREPARED BY

AUTISM COMMUNITY RESEARCH NETWORK SUSSEX

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WELCOME MESSAGE FROM DIRECTORS

This is the first time we've done an annual report, rather than our termly newsletters, and it's given us a great chance to reflect on ACoRNS -- where it came from, what it is now and where we might go next. We had our first steering group meeting in February 2020, hoping to launch on World Autism Awareness Day on 2nd April 2020. As you'll recall, this was upstaged by the Covid-19 lockdown, and we have been conducting our termly steering groups online since then. This makes our annual picnic in Stanmer park more special this year, where we'll say thank you in person to our wonderful placement students Jessica Millar and Ellie Drake, who have produced this annual report as one of their final contributions to the year. We also thank our wonderful steering group, who inspire and motivate us, and our community of members.

ACoRNS is the younger sibling of ACoRNS Southampton [[Link to webpage](#)] and we keep in close touch with them, We also work with the Pan-Sussex Autism in Schools Network coordinated in West Sussex, and aim to support their ambitious Autism Ambassadors conference at the AmEx stadium in October.

This year, we welcome our collaboration with Dr Sophie Anns in Psychology at Sussex, with her outstanding programme of autism research. We've also been inspired by projects involving members of our steering group: just to mention a few, the EQUALS project with David Orr and Tish Marrable, looking at improving social care in autistic service users, Jacqui Shepherds' work with the Oliver McGowan 'Train the Trainers' initiative and a highlight for us, our visit to the [SAND project](#) in Worthing, guided by Rachel Macdonald-Taylor, their education lead. The project offers inclusive work training, supporting transition into paid employment based on interests and talents: they also do a great coffee and superb home-made cakes in their cafe.

We extend a warm welcome to our new placement students: we will have 2 ACoRNS students and 2 students working with Dr Sophie Anns on her autism research projects. Sophie also joins us with her ambitious Autism in Universities project. We welcome some new members to the steering group and say thank you to some retiring ones [[link to webpage](#)]. Jacqui will move from Co-Director to member of the steering group, while Christina Hancock steps in as Deputy Director to ensure we are jointly steered between Psychology and Education. Christina is Director of the Centre for Teaching and Learning Research at University of Sussex. One of our new highlights with the additions to our steering group will be working more closely with health practitioners in the medical school, as Lisa Quadt joins us, and developing new projects in social care, with Polly Bishop from Independent Lives. Here's looking forward to new ventures in 2024-5!

*by Professor Nicola Yuill &
Dr Jacqui Shepherd*

MEET THE TEAM

Professor Nicola Yuill

School of Psychology, University of Sussex



I am Professor of Developmental Psychology in the School of Psychology at the University of Sussex and run the Children and Technology Lab ([@chatlabuk](#)).

My current projects include working with @Acornsoton on Our Stories, co-creating immersive video stories with autistic children, young people and their families to support transitions in emotion (with Just Right, Brighton & Hove) and in healthcare (with BSMS Time for Autism). I relish finding collaborative low-cost ways to support participatory research and evaluation with local partners. I especially enjoy fine analysis of video of interactions in natural settings and thinking how we can co-design spaces that work well for everyone across the spectrum of neurodiversity.

Dr Jacqui Shepherd

Disability Inclusion Consultant



I am an honorary Senior Lecturer in inclusive education at Sussex and also work as a freelance disability inclusion and SEND consultant. I worked for SightSavers, an international NGO, as the Global Technical Lead for inclusive learning and teaching from 2021-2023. Previously I was a lecturer in education at the University of Sussex convening modules such as 'Disabled Childhoods' and 'Understanding Autism and Education'. I also coordinated the SEND provision for trainee teachers. Before working at Sussex I was a teacher and assistant principal working in local schools and colleges. My PhD investigated the transition experiences of young autistic people who left special school to go to mainstream further education.

PLACEMENT STUDENTS 2023-24

Ellie Drake

A BSc Psychology student with a criminology pathway.
Has interests in autism, education, mental health, developmental psychology and criminology/forensics.



Jessica Millar

A BSc Psychology student with a British Sign Language pathway.
Has interests in mental health, language development, masking and neurodivergence.

PLACEMENT PROJECTS

Carden Project

We were approached by Differing Minds and Carden Nursery and Primary School to help with their evaluation of their re-designed classroom. The school is the site for a competition to re-design a classroom into a sensory room. Ultimately the school decided to combine two designs into the finalised brief of the room. The installation is scheduled to occur over the summer holidays, which the school are excited about.

For our evaluation we are looking into views and behaviours before and after the installation to assess the potential benefits of the re-designed space. To do this we are performing interviews with staff and designers as well as utilising student voice to gather thoughts, feelings and experiences with the re-designed classroom.

Downs View Project

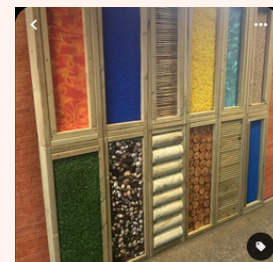
We were asked by Downs View school to provide them with some help in how they might use the embankments and wooden panelling and fencing in their recently refurbished playground.

After much research, we compiled a portfolio of ideas such as sensory tiles or a water wall, and presented them to the school, who were thrilled to have so many options to consider. Following this, we have connected the school with the SAND project in Worthing. The first step is to use the local community skills to co-create sensory tiles to be set up throughout the playground.

Neuro-affirmative Creative Therapies Project

This year, we were approached by Brighton and Hove Schools Mental Health Service, seeking an evaluation on a new early intervention. The focus was on younger children who have not yet been referred to CAMHS (Child and Adolescent Mental Health Services), but who are struggling at school, and require additional support. The therapy itself focuses on small groups, who are encouraged to get to know one another, to affirm a sense of acceptance of themselves as neurodivergent, and to find ways to assist emotional regulation.

Over the summer, we will be collecting data from the Primary Mental Health Workers who run the sessions, as well as from the children via their parents. It is a highly promising therapy, and we are working with the team to pin down the important ingredients.





PLACEMENT PROJECTS



ACoRNS Survey

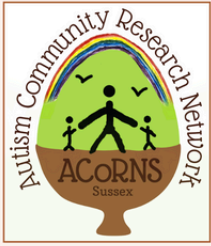
This academic year we launched a survey to our mailing list to fuel our ongoing research agenda, help make the website more accessible and get our reading group to be better suited to our communities' interests. We gained insight into what our community felt were their main concerns about autistic lives, local services, and provisions. Respondents expressed major concern with mental health services and looked for effective therapies for autistic people that are not pathologised. Other concerns were: lack of understanding and accessible support across services, school provisions, autism awareness and stigma, diagnostic services and wait times. Our community also fed into the redesign of the website which will happen in the coming year. We also had great suggestions for reading group topics, including gender difference in presentation of autism, physical health links, late diagnosis and burnout.



Sensory experiences

During Neurodiversity celebration week in March, we turned the ACoRNS lab space into a sensory room. We aimed to provide experiences to help with sensory regulation that would be pleasing in times of sensory distress. We mainly focused on touch, sight and sound, as research suggested these were the senses most often affected. Sessions included galaxy projector lights, a playlist of calming music, a range of tactile materials as well as bubbles, fidget toys and colouring. Feedback showed that these sessions were enjoyed by both staff and students at the University of Sussex and that they would be appreciated as a continuing feature on campus.





SENSORY EXPERIENCES



Ellie Drake and Jessica Millar
Autism Community Research Network
Placement Students 2023-24

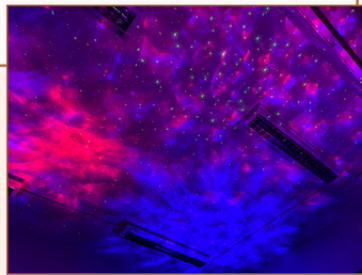
WHAT IS SENSORY SENSITIVITY?

Our senses provide information about ourselves and our environment. Attention is drawn to sensations we find particularly pleasant or unpleasant.

Autistic people can often experience sensitivity to sensory stimuli:

- Hypo-sensitive= seek out stimuli or greater frequency of stimuli to achieve desired response
- Hyper-sensitive= over-sensitive to stimuli, can be overwhelming, painful, annoying and frustrating.

Research suggests the senses most often affected are sight, sound and touch.



OUR RESEARCH

The easiest method to avoid discomfort and potential sensory overload from sensory stimuli is avoidance. For example, many autistic people use items such as ear defenders/headphones to avoid unpleasant acoustic stimuli.

Key research points:

- Sensory issues can be overwhelming and disabling
- Unwanted sensory stimulation can lead to frustration, annoyance, physical discomfort and even pain
- Being aware of the stimuli causing sensory stress and controlling them is important for reducing stress and anxiety
- Atypical responses to sensory stimuli are positively correlated with autism
- Sensitivities appear across multiple modalities (senses)



WHAT WE DID

We took over the ACoRNS lab for a week to provide experiences that would help with sensory regulation and be pleasing in times of sensory distress.

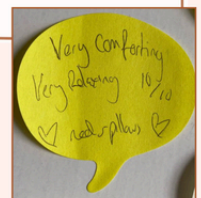
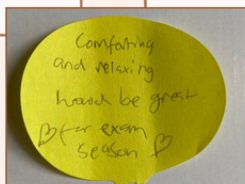
Sessions featured:

- Range of tactile materials such as kinetic sand, plasticine and fidget toys.
- Display of galaxy light projectors
- Calming music
- Peaceful activities such as colouring.

The sessions were a big hit, with visits from students and staff. Feedback said that the experience was helpful for emotional regulation and reducing stress. Many reported that the sessions produced a positive calming effect.

CONCLUSION

- Visiting students said they would like a permanent or pop-up space on campus that ran similar sessions.
- They stated this would be especially beneficial during times of stress, such as exam season.
- We were particularly curious about why the galaxy lights and calming music were so impactful.
- Little research has been done on why such experiences can have such a positive impact, and whether they can lead to longer term benefits.
- We think this is an area that absolutely warrants further research, especially regarding autism.



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Howe, F.E.J., Stagg, S.D. How Sensory Experiences Affect Adolescents with an Autistic Spectrum Condition within the Classroom. *J Autism Dev Disord* 46, 1656-1668 (2016). <https://doi.org/10.1007/s10803-015-2693-1>

Robertson, A.E. and Simmons, D.R., 2013. The relationship between sensory sensitivity and autistic traits in the general population. *Journal of Autism and Developmental disorders*, 43, pp.775-784.

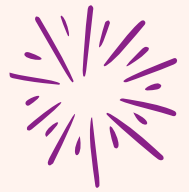
Minshew, N.J., Hobson, J.A. Sensory Sensitivities and Performance on Sensory Perceptual Tasks in High-functioning Individuals with Autism. *J Autism Dev Disord* 38, 1485-1498 (2008). <https://doi.org/10.1007/s10803-007-0528-4>

<https://embrace-autism.com/decoding-autism-in-the-dsm-5/>





PROJECT SPOTLIGHT



Autism Friendlier University Project

by Dr Sophie Anns

Research conducted by ACoRNS (Davis, Millington & Anns, in press) highlighted that autistic students' academic performance is significantly higher than their non-autistic peers yet their confidence in completing their degree is significantly lower. Attention from educators is needed to support academic learning experiences for autistic students in areas such as sensory sensitivity, social experiences in group learning, peer support and cognitive flexibility.

Following this research it was identified that the social, academic, physical and learning environments at university are not always set up sufficiently to support students in their learning and living experiences at university. And so, ACoRNS worked with five autistic students at Sussex, as part of the University of Sussex Student Connector programme, on a participatory project which aimed to address some of these issues.

Our five students identified three key areas of difficulty for autistic students around 1) dissemination of information, 2) community, 3) the sensory environment and 4) staff awareness. As a result, they created a booklet for incoming first year autistic students detailing all essential information in one place such as disability support services, quiet spaces and shopping, the Buddy Scheme and reasonable adjustments. They also suggested that neurodivergent students could select to be paired with other neurodivergent students in the Buddy Scheme and they fed into future developments that the library are planning to make it an improved inclusive learning space. Lastly, they created an infographic for staff awareness which focused on crisis management in the event of a student having a shutdown or meltdown.

ACoRNS is now driving a wider initiative at the University of Sussex to capitalise pockets of strength across the university, such as in careers, alumni relations, research and scholarship across several schools, to create a more autism friendly university. As well as this Sophie runs the Autism in Universities Research Project which is displayed in the infographics on page 8:

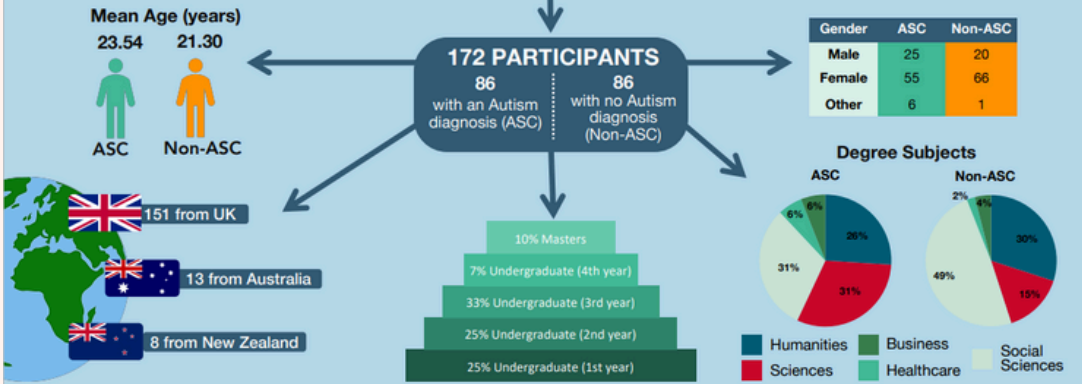


THE AUTISM IN UNIVERSITIES PROJECT

Sophie Anns, Jess Millington, Clare Davis & Pia Rodway (June, 2022)



This study compared the **academic learning experiences** of autistic university students to non-autistic peers as well as: **Cognitive flexibility** (adaptability), **Alexithymia** (difficulty identifying and describing emotions), and **Academic & Social satisfaction**. This infographic presents our findings and suggestions for supporting autistic students.



FINDINGS

The Academic Learning Experiences Questionnaire (ALE-Q), devised for this study, measured strengths and challenges surrounding:

- Sensory sensitivity
- Information processing
- Organisation/time management
- Group learning
- Social interaction
- Social anxiety

Autistic students reported significantly **more challenges** (as denoted by a lower score)

| Measure | ASC | Non-ASC |
|-------------------------------|-------|---------|
| Academic Learning Experiences | 120.9 | 155.6 |
| Cognitive Flexibility | 37.35 | 46.24 |
| Alexithymia | 63.17 | 47.71 |

Autistic students reported significantly **less cognitive flexibility**

Autistic students had significantly **more alexithymia**

THE BIG PICTURE
For autistic students, less cognitive flexibility and more alexithymia predicted more challenges with academic learning experiences.

Participants reported their **academic and social satisfaction, confidence in degree completion and mean grade.**

Academic satisfaction was equal across autistic and non-autistic students. **BUT** 84.9% of non-autistic students were 'satisfied' or 'very satisfied' socially, compared to **only 34.9%** of autistic students.

72% of non-autistic students were 'very confident' in completing their degree, compared to **only 50%** of autistic students. **DESPITE** Mean grade was higher for autistic students (73.2%) than non-autistic peers (66.8%).

Difficulties with cognitive flexibility may relate to challenges with time management, planning ahead, managing diverse study tasks and changes to routine

Alexithymia may relate to managing stress in individual and group learning scenarios. This can affect attendance, maintaining relationships and staying on top of workload

UNIVERSITY-WIDE RECOMMENDATIONS



Supporting Inclusion

Ensure staff have sufficient understanding, confidence and resources to implement support

Speak openly and positively about autism to reduce stigma (Van Hees et al., 2015)

Facilitate social connection among autistic students and with non-autistic students through buddy schemes and social groups (Manett, 2021)

Supporting Transition

Encourage early disclosure of diagnosis and support applications to improve overall university experience (Anderson, 2017)

Before term starts, provide opportunities for students to explore campus, stay in accommodation, meet peers and discuss support needs (Lei et al., 2018)

Designate quiet times during Freshers' Fair and orientation events including a map of stalls and stands

Supporting Learning

Offer reasonable adjustments to assessments, for example:

- Takeaway papers/problem sets as alternatives to traditional exams
- Support students to complete time-pressured assignments at home or in a chosen study space

Coordinate within/between schools to space out deadlines

Seek autistic students' feedback on teaching, assessments and other academic experiences

Establish staff and student roles to represent autistic students

Supporting Sensory Sensitivities

Provide sensory rooms for students to recuperate when overwhelmed e.g. fibre optic curtain lighting, bean bag chair, weighted blankets, tactile cushions, fidget toys

Make teaching spaces sensory-friendly with minimal acoustic feedback, reduced harsh lighting and less crowding (Clouse, Wood-Nartker & Rice, 2019)

Provide quiet hours and/or low-sensory zones in independent study areas including the library



OUR GROUPS



Autism Reading Group

Once a month we host a session where we pick a topic related to autism and discuss our thoughts around it. We look at its applications in society, personal relevance etc. The sessions always produce riveting discussions highlighting different perspectives. We use a variety of material including webpages, news articles, blogs etc. The Autism Reading Group is targeted towards our wider community comprising professionals, parents, autistic members of the local community and more. Recent topics have included: Autism Independence and Interdependence, The theory of Monotropism, and Autism and Hypermobility. We welcome topic suggestions at every session and the responses from our survey have helped fuel topic choices and discussion as well. We feel it is important to discuss topics that are important to our community.



Autism Article Club



During term time we host sessions targeted towards University of Sussex students and staff. These run similarly to the Autism Reading Group, but we use academic journal articles about autism research. We look at the articles and discuss different perspectives and interpretations of research. As well as this we consider the applications the research has on society and the lives of autistic individuals. We have had a lovely turnout this year at our sessions and improved our knowledge and critical evaluation of autism research.

RECENT PUBLICATIONS

★ Shepherd, J., Sutton, B., Smith, S. & Szlenkier, M. (2024) 'Sea-glass survivors': Autistic testimonies about education experiences. *British Journal of Special Education*, 00, 1-14. Available from: <https://nasenjournals.onlinelibrary.wiley.com/doi/10.1111/1467-8578.12506>

★ Glass, D., & Yuill, N. (2023). Social motor synchrony in autism spectrum conditions: A systematic review. *Autism*, 0(0). <https://doi.org/10.1177/13623613231213295>

★ Glass, D., Yuill, N. Moving Together: Social Motor Synchrony in Autistic Peer Partners Depends on Partner and Activity Type. *J Autism Dev Disord* (2023). <https://doi-org.sussex.idm.oclc.org/10.1007/s10803-023-05917-8>

★ Parsons, S., Kovshoff, H., Yuill, N., Glass, D., Holt, S., Ward, A., Barron, C., & Ward, R. (2023). 'Our Stories...': Co-Constructing Digital Storytelling Methodologies for Supporting the Transitions of Autistic Children - Study Protocol. *International Journal of Qualitative Methods*, 22. <https://doi-org.sussex.idm.oclc.org/10.1177/16094069221145286>



STUDENT RESEARCH

Every year, we have final year undergraduates in the lab working on their dissertations. This year brought a strong focus on autism, with interviews on the kinds of peer social support that autistic university students want to see, and a fascinating discussion of video game spaces in how they support autistic people to feel 'more autistic, less disabled'. Three studies looked at people's attitudes to autism, and two of these addressed how the ACoRNS 'digital stories' work might change people's perceptions of autistic children with learning disability. Results were very encouraging, with story viewers showing more positive attitudes and seeing children in the videos much more in terms of their mental attributes- with 'happy' being the most common description after viewing. We plan for some of these studies to be written up for publication, and to train health and care staff to use the methods with their clients.

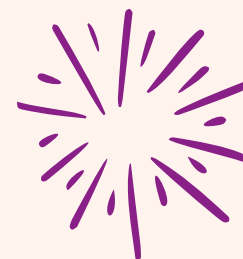
PLACEMENT STUDENT REFLECTION

This year we have worked on a variety of projects, some of which will continue into next academic year.

This year has been invaluable and we have thoroughly enjoyed the range of experiences we have been involved with. We both feel that the experience we have gained at ACoRNS has prepared us for our final year of our undergraduate degree and our future careers. We wanted to thank Nicola and Jacqui, the ACoRNS Co-Directors, for the amazing experiences and opportunities they have provided us this year.

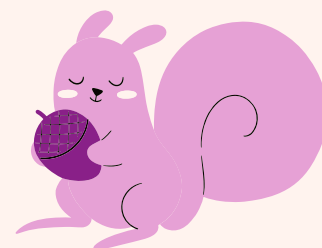


THANK YOU



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