

# ACoRNs Newsletter



**A warm welcome to the first ACoRNs newsletter of the year.**

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## **DOES THE USE OF PPE IMPACT THE QUALITY OF THE DIAGNOSTIC PROCESS?**

Daisy Burden, a Masters' student at the University of Sussex, supervised by Nicola Yuill, studied the impact of PPE and the autism diagnostic process. First, Daisy interviewed parents about their experiences of their child's diagnostic process. Some expressed concerns about how staff wearing masks and distancing might affect the interaction. With permission, the team were able to access recordings of autism assessments carried out at a diagnostic clinic, some with and others without staff using PPE. The aim was to evaluate the standard of service.



The recordings were coded for warmth, responsiveness (both child and clinician), time and space, and balance of conversation between child and clinician, using a method from Nicola's previous [Zoom or Room project](#). Daisy found that there were slight reductions in warmth and responsiveness, but clinicians acted skilfully to adapt to the circumstances, e.g., giving children more space and time. Overall, the conclusion was that the service standard was maintained. This is a reassuring indicator for parents who may be worried about the impact of altered conditions for assessment.

From the interviews, Daisy produced a useful checklist for clinics evaluating their diagnostic processes. The checklist includes clarity in communication, support and resources, aftercare, recognition for concerns, need for personalisation and concerns around PPE or online assessments.

# mASCot

MANAGING AUTISM SPECTRUM CONDITION OURSELVES TOGETHER

mASCot is a Brighton and Hove-based parent-led group that aims to help connect families in similar situations who have an autistic child/children. mASCot aims to celebrate the diversity of the families in the group and to allow the children to be themselves. They host a variety of activities and groups for members to join. These include training sessions for parents to help them develop tools to deal with day-to-day issues they encounter. They also run coffee mornings, activities, and youth clubs for the young people to attend. Recently mASCot has teamed up with 'The Real Junk Food Brighton at The Gardener cafe', which is a 'pay as you feel' cafe. Every Monday between 11-3 pm it is run by volunteers from mASCot (both parents and young people).



We visited the Cafe recently and met Monica Marchi from mASCot and some of her team of young people volunteering at the cafe. Monica told us how the cafe is **a really inclusive and safe place where everyone is welcome** - which was definitely what we experienced. It gives young people the opportunity to learn different skills, including customer service, cooking and cleaning in a safe and nurturing environment. It also provides the opportunity to socialise and meet other people.



We spoke to three young people about the cafe and their volunteering experiences. Luca, who has been volunteering at the cafe for 7 weeks during his college lunch breaks, told us how the cafe has allowed him to learn many skills that will prepare him to go on to a paid job in a shop or cafe. Another young person hopes to learn and develop different skills before going on to study a media course at university. We also spoke to Rosie who has recently started volunteering at the cafe. She told us how she enjoys working in front of house in the cafe and making hot drinks - which were really nice.

We also spoke to Sarah Betts, the director of the Real Junk Food Project. She told us how she hopes the cafe can be a welcoming and inclusive space for everyone in the community, especially people who are socially isolated. The pay-as-you-feel system includes those who may be excluded by the high price tags of other coffee shops in Brighton. The cafe uses food rescued from supermarkets across Brighton and Hove and has fed 3000 people over the last month with 20 tonnes of saved food. The collaboration between Real Junk Food and mASCot is an inspiring and effective project, making a positive impact for the volunteers and customers who use the café, as well as reducing food waste.

# USING HIGH-TECH TOYS IN AUTISM DIAGNOSIS PROCESSES: THE TANGIBALL PROJECT

Autism diagnosis is an extensive and expensive process. Will Farr from the Sussex Community NHS Foundation Trust is working on developing a toy, Tangiball, that could be used to detect sensory dysfunction in young children being assessed for autism. This toy will capture data from the child's interactions with it and use this data to predict patterns of movement. This information could add insight and early indicators to the diagnostic process.

Will spoke at one of the regular meetings of the Children & Technology Lab (ChatLab) explaining the high costs of diagnosing autism, investigated by a project with Dr Ian Male. They found that in a review of 20 NHS trusts covering 600 participants the children had an average of 4 clinical appointments and 12 months wait from their first appointment. Will aims to develop a toy that may improve diagnosis procedures.

Research has shown that autistic children differ in the micro-movements they make, and sometimes handle objects in atypical ways (see research by Torres et al (2013) and Williams (2003)).

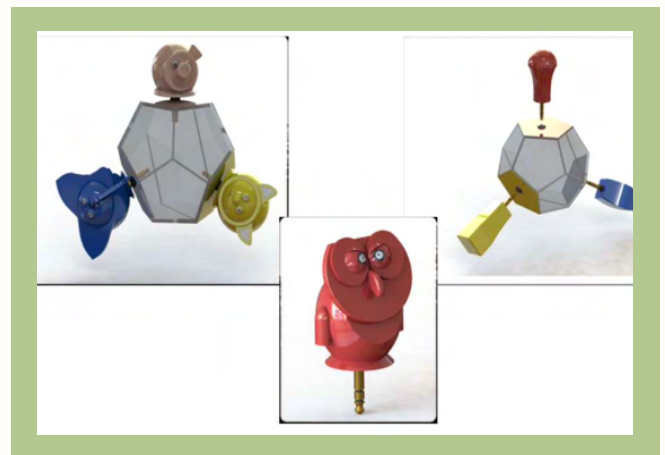
Torres et al (2013) explained how there is a difference in the micro-movements of those with ASC interacting with objects in their environment in comparison to those without ASC. Developmental processes that occur in typical development are disrupted in favour of activities with less specific goals. As these autistic children grow up they may continue to interact with objects in ways that are seen as repetitive or unusual.

A review by Williams (2003) found a wide variety of studies indicating differences in the development of autistic children's play in comparison to those without a diagnosis. Using an attractive toy for children to play with can be a more appealing way of getting an understanding of the children's behaviour and reactions.

Other 'smart toys' have been developed. For example, Rivera and colleagues (2016) looked

at how the development of smart toys might help to detect developmental delays. They created a prototype of a tower of cubes with sensory capabilities that collected information that could then be analysed to see if there was any form of behavioural differences distinctive to different developmental trajectories.

The Tangiball is in development: it consists of a colourful and textured ball that enables different keys with animal or character figures to be slotted into holes, providing different sensory feedback. Sensors around the ball detect and record the child's movements in fitting the keys into the ball.



# Meet Our Placement Students

At the end of the 2020 - 2021 academic year our previous placement students, Ethan Lam and Ailish Macinnes, finished their year-long placement with ACoRNs. Their placements were great successes, and we would like to thank them for the excellent contributions they made to ACoRNs in our first year. Both Ethan and Ailish are now completing their third-year projects under the supervision of Nicola Yuill.

Meet our two new ACoRNs placement students - Alice and Jemima are excited to be joining the ACoRNs team this year. As part of their placement, they run the Autism Reading Group, manage the social media, produce newsletters, updates, help with events, and are involved in our new autism-friendly university project.



**ALICE WHITE**

"I am an undergraduate psychology student at the University of Sussex. My interest lies in inclusive education. I am looking forward to getting involved in the various projects and events that ACoRNs Sussex is currently working on. I hope to pursue a career as an Educational Psychologist. So far in my placement I have enjoyed running the reading group and working on our blog posts - I have also found working on our proposals for an Autism-friendly university project really interesting."

"I am also an undergraduate Psychology student at the University of Sussex. I'm passionate about improving the inclusivity of education as well as learning how to carry out a successful research project. After completing my degree and some travelling, I hope to become an Educational Psychologist. So far, I've enjoyed learning more about how the website is managed. I'm really interested in the Autism-friendly university project and can't wait to see what it can achieve!"



**Jemima Matthews**

## We are now on Instagram!!

We have expanded our social media presence to now include Instagram. We are hoping to reach a greater range of people including more students and young people. We will be sharing all about our different research projects and events.

This will also be a great way to share updates on our new Autism-friendly University Project. Follow us at @acorns\_sussex



## Autism Friendly University Project

Alice, Jemima & Ethan have been working with Nicola Yuill, Sophie Anns and a group of other students to produce a proposal for a new Autism-friendly University Project. The project aims to make the university more accessible and inclusive. We are pleased to share we have received funding from the connector program to run this project, led by students with lived experience of autism. Previous placement student Ethan will also be investigating the experiences of autistic students at the university for his third-year project.

# Autism Reading Group

Our monthly reading group gives people the opportunity to share their views on different topics related to autism. We're still running them on Zoom, which has helped some people to get along without the need to travel further than their computer screen!

At our first meeting of the year, we discussed the autism diagnosis gap between girls and boys. We discussed how girls commonly mask their traits and as a result may go undiagnosed till they are teenagers or even into adulthood. We talked about the need for more work to improve awareness and shift stereotypes. It leaves the question: What more can be done to improve teacher training on autism?

Our second meeting tackled the curious topic of interoception - even finding out what it is: it is your sense of what is going on within your body - for example, hunger, thirst, and sensations of warmth and cold. There is fascinating work on how interoception may differ for autistic individuals, and maybe ways of using awareness of bodily states to manage anxiety. A great example is the current work of Professor Sarah Garfinkel, who has developed an intervention that aims to reduce anxiety by improving interception. The intervention is all centred around listening to your heart. There's more on this on our [blog](#). Want to join us next time? Just email: [acorns@sussex.ac.uk](mailto:acorns@sussex.ac.uk) to join our mailing list.



## Research Updates

Nicola Yuill is supervising 6 third year project students this year, who are all carrying out really interesting research.

Lucy Williams is investigating the role of digital stories in changing people's knowledge and attitudes about autism. Lucy's questionnaire will present a range of questions and statements about autism before and after seeing various digital stories. Responses will then be analysed to see how they have changed. Simon Humphries project will be working with Devyn Glass on the 'Our Stories Project'. He will use thematic analysis to evaluate the experiences of the young people who are making Digital Stories, as well as to look at the views of other professionals who the Stories are shared with.

Amber, Ailish and Ella will be analysing interviews with parents of children who have Wiedemann-Steiner Syndrome, looking at common behaviour patterns and diagnostic experiences in this little-researched genetic disorder. They hope to have a trip to Great Ormond Street Hospital to speak to Dr Wendy Jones, who mapped the chromosomal difference causing WSS.



### Get in touch

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*Intercepting surplus food to  
feed people*

*Supporting local autistic young  
people and their families*

*Working together to bring you*

# **mASCot Mondays**

## **@The Gardener Café**

*Every Monday from 11am to 3pm at 50 Gardner St*

**Pay As You Feel**

**mASCot is an organisation who supports  
autistic young people.**

**We help run The Gardener on Mondays**

# **PLEASE BE KIND AND PATIENT**

**The Real Junk Food and mASCot celebrating diversity. Everyone welcome**

[www.asc-mascot.com](http://www.asc-mascot.com)

<https://www.realjunkfoodbrighton.co.uk>