

# Welcome



**ACoRNS**  
**Sussex**

MAR  
24

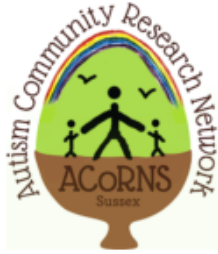
**Re-Imagining Healthcare in  
Autism**

by ACoRNS Sussex

[Follow](#)

Free

Nicola Yuill, Jacqui Shepherd & @acornsussex team  
Psychology/Education, University of Sussex



## About ACoRNS

The Autism Community Research Network Sussex (ACoRNS) is an initiative which seeks to improve the lives of autistic children and young people.

ACoRNS is a collaboration between Psychology and Education researchers at the University of Sussex and local autism stakeholders involved in education, health and social care services, who are interested in developing, researching, understanding, and sharing good practice in services used by autistic children and their families.

### Tweets by @ACoRNSussex



**ACoRNSussex**  
@ACoRNSussex



Our next Autism Reading Group is tomorrow at 4-5pm on the topic predictive coding and how this is involved in autism, email us at [acorns@sussex.ac.uk](mailto:acorns@sussex.ac.uk) to join this fascinating conversation [spectrumnews.org/features/deep-...](https://spectrumnews.org/features/deep-...)



**How autism may stem from p...**  
A 'predictive coding' theory of a...  
[spectrumnews.org](https://spectrumnews.org)



5h

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

@acornsussex

<https://www.acorns-sussex.org.uk/get-involved/>



@acornsussex



@acornsoton

## Get Involved

Attend our events: see twitter for announcements.

Follow us on twitter: [@acornsussex](https://twitter.com/acornsussex).

Check out our blog: <https://www.acorns-sussex.org.uk/blog/>.

Read our termly newsletter, with news and events, via our mailing list: email [acorns@sussex.ac.uk](mailto:acorns@sussex.ac.uk).

Take part in our Autism Reading Group (ARG: currently meeting online), where we join with our Southampton ACoRNS group to discuss issues in autism: email [acorns@sussex.ac.uk](mailto:acorns@sussex.ac.uk) and ask to be put on the ARG list.

We welcome everyone (and we recognise the categories listed below can overlap)

**Autistic people:** are at the centre of our work, we appreciate all autistic voices sharing first-hand experiences and ideas about how to make the world more accessible – help shape our agenda.

**Parents / carers:** meet other stakeholders, comment on and contribute to research, discover new practices, and share your own experiences of what has worked and what to improve.

**Professionals:** meet other stakeholders to share feedback on services, comment on and contribute to research, hear about autistic experiences and those of families, bring ideas for improvement and inspirations for new practices.

**Researchers:** gain wider perspectives from all stakeholders to inform, share and discuss research as well as helping to identify and shape research priorities.

**Students:** learn about current research, discuss papers in the reading group and learn more [about different career options.](#)

# Plan for today

4-4.10 Introduction

4.10-4.30 Videos Part 1

- [Time for Autism](#) – Stephanie Daley, Brighton & Sussex Medical School & parent
- *A Parent Perspective* – Samantha Holt, ChatLab, University of Sussex & parent
- Q&A [Oliver McGowan Mandatory Training for learning disability & autism](#) – Paula McGowan: parent campaigner
- 4.30 Breakout groups
- 4.45-5 Questions and feedback
- 5-5.15 Videos Part 2
- *Dental care and autism* – Jennifer Parry, Consultant in Paediatric Dentistry, Sussex Community Foundation Trust
- *Health experiences and challenges* - Ian Male/ Will Farr, Sussex Community Foundation Trust
- *Our Stories project*- Nicola Yuill, ACoRNS & ChaTLab, University of Sussex
- 5.15 Breakout groups
- 5.30 Questions and feedback followed by Next Steps

# Westminster commission on autism 2016

Recommendations:

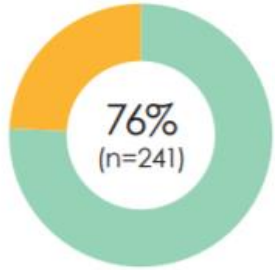
**Training** -- Inspection -- Data Collection -- Annual Health Checks --- Leadership -- **Resources**

**It is critical to improve access to healthcare for autistic people of all ages.**

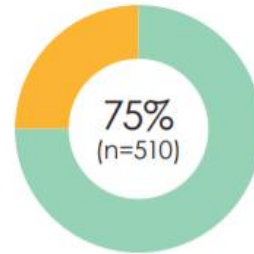
This population have increased health risks and reduced life expectancy, yet face multiple obstacles to accessing the same healthcare that other population groups enjoy. The knock-on effect of poor access to healthcare on physical and mental health, on employment and the economy, on quality of life and mortality, leads us to **request positive action now.**

[https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011\\_ncg-autism-report-july-2016.pdf](https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf)

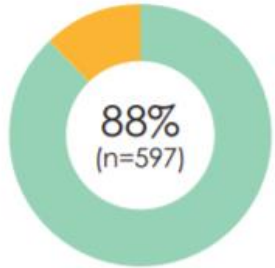
# Recommendations: Training and Resources



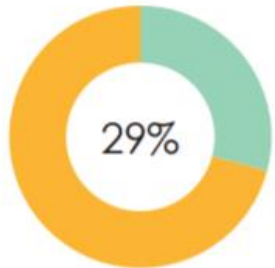
of autistic and parent-advocate survey respondents said **their doctor does not make any changes to meet their (or their child's) needs as an autistic person;**



of autistic and self-advocate and family-advocate respondents say they **would like help to understand what will happen when they go to the doctor or hospital.**



of all survey respondents **do not feel that health professionals understand the conditions which co-occur alongside autism;**



the Self-Assessment Framework shows only **29% of local areas rated themselves 'green' for having training available to all staff;** a decrease on statistics from 2013 when 38% rated themselves green<sup>13</sup>.

[https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011\\_ncg-autism-report-july-2016.pdf](https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf)

# Videos part 1

- [Time for Autism](#) –*Stephanie Daley, Brighton & Sussex Medical School & parent*
- *A Parent Perspective – Samantha Holt, ChatLab, University of Sussex & parent*
- Q&A [Oliver McGowan Mandatory Training for learning disability & autism](#) – *Paula McGowan: parent campaigner*

Followed by breakout, Q&A

# Videos part 2

- *Dental care and autism – Jennifer Parry, Consultant in Paediatric Dentistry, Sussex Community Foundation Trust*
- *Health experiences and challenges - Ian Male/ Will Farr, Sussex Community Foundation Trust*
- *Our Stories project- Nicola Yuill, ACoRNS & ChaTLab, University of Sussex*

Followed by breakout, Q&A



# Our Stories project

- Sarah Parsons, Hanna Kovshoff (Southampton) & Nicola Yuill (Sussex)
- Team of researchers, children, parents & professionals in health, education & social care settings
- Films and virtual walk-throughs: What's it Like? team (Autek Ltd)

<https://www.pals-society.com/whats-it-like>

- Co-constructing Digital Storytelling methods to support the transitions of autistic children
- What is a digital story? <https://autismtransitions.org/>
- Time for Autism:  
<https://www.bsms.ac.uk/research/neuroscience/cds/time-for-autism/time-for-autism.aspx>



Economic  
and Social  
Research Council

Interested  
in Time  
for  
Autism?



**COULD YOU HELP  
FUTURE DOCTORS  
LEARN ABOUT AUTISM?**

We are looking for families in Brighton and Hove and across Sussex to take part in a new education programme designed to teach medical students about autism.

Each family will be paired with two students from Brighton and Sussex Medical School who will visit them at home three or four times over the course of a year.

This is an exciting opportunity for children and young people on the autism spectrum and their families to share experiences and expertise with medical students, to help them provide better care in the future.

If you would like to know more, please contact:  
Alison Smith, Time for Autism Development Manager  
T: 07717 450954 / 01273 877896  
E: [sc-tr.timeforautism@nhs.net](mailto:sc-tr.timeforautism@nhs.net)  
[www.bsms.ac.uk/time-for-autism](http://www.bsms.ac.uk/time-for-autism)

<https://www.acorns-sussex.org.uk/get-involved/>



@acornsussex



@acornsoton

- Attend our events: see twitter for announcements.
- Follow us on twitter: **@acornsussex**
- Check out our blog: <https://www.acorns-sussex.org.uk/blog/>
- Read and comment on our termly newsletter, with news and events, via our mailing list: email **acorns@sussex.ac.uk**
- Take part in our **Autism Reading Group** (ARG: currently meeting online), where we join with our Southampton ACORNS group to discuss issues in autism: email **acorns@sussex.ac.uk** to be on the ARG list

# Next steps

- Feedback on this event: <https://forms.office.com/r/G7WGvRMrLx>
- Recording made available
- Blog summarising views and ideas
- Autism reading Group Tuesday 20th April 4-5pm on Zoom, topic: Autism and Imagination
- .....