

# Children and Young People's Mental Health, Neurodevelopment, Neurodiversity and Special Educational Needs and Disabilities Community of Research Practice



Monday 26<sup>th</sup> September 2022



In September, the Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS) held an in-person, community of practice event on Children and Young People's Mental Health, Neurodevelopment, Neurodiversity and Special Educational Needs and Disabilities (SEND), at the University of Sussex.

Chaired by Becca Randell, Implementation Manager for the Starting Well, ARC KSS, and Dr Ian Male, Director of Research at Sussex Community Foundation Trust, the event brought together more than 40 delegates from different academic institutions, voluntary and community organisations, as well as NHS England, to learn about research projects in the region, share best practice and identify research gaps.

# Agenda

10:30 - 10:45	Capturing the voice of CYP: Digital Storytelling
10:45 - 11:15	What are our perceptions of the experiences of Neurodiverse and SEND CYP and their families?
11:15 - 11:35	Coffee Break
11:35 - 12:00	South East NHSE Overview including a Q&A session
12:00 - 12:50	What gets in the way of undertaking research in CYP Mental Health, Neurodiversity, Neurodevelopmental, SEND in Kent, Surrey and Sussex? How can we break down these barriers?
12:50 - 13:30	Lunch
13:30 - 14:30	Showcasing research across Kent, Surrey and Sussex
14:30 - 15:30	World Café- Showcase research, promoting collaboration to build future funding bids and building research capacity / Coffee Break
15:30 - 15:45	Feedback from World Café
15:45 - 16:00	Closing and next steps

# Capturing the voice of CYP: Digital Storytelling

Devyn Glass, ARC KSS Research Fellow, presented the "Our Stories" project which was conducted with the Autism Community Research Network Sussex (ACoRNS) at the University of Sussex in collaboration with University of Southampton. Digital stories were produced by autistic young people to show "how I feel..." at secondary school. The videos were shown to delegates where the young people used the 'Just Right approach' of using colour zones to communicate their thoughts and feelings.



For more information contact [Devyn Glass](#)

# South East NHSE Overview including a Q&A session



**David Keaveney-Sheath**, Strategic Senior Case Manager for NHS England, gave an overview of the Learning Disabilities & Autism Programme in the South-East. David outlined the ‘case for change’ for neurodiverse children and young people, their families and supporters.

He discussed the current national and regional strategies and the opportunities for collaboration that come out of the All-age Autism Strategy 21-26 and stressed the need to work collaboratively to ensure that transformation and improvement projects are co-produced by neurodiverse people, their families, clinicians, commissioners and researchers, to design and deliver evidence-based practice consistently and at scale.

*"It was a privilege to meet so many clinicians and researchers working, so passionately, to improve the lives of neuro-diverse children. The LDA programme are excited to work with the KSS ARC community of research practice to deliver on our programme priorities and improve the service the NHS offers neuro-diverse children, young people and their families."*



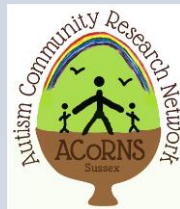
For more information, contact [David Keaveney-Sheath](#)

# Showcasing research across Kent, Surrey and Sussex



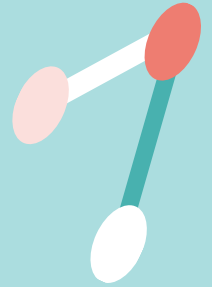
The afternoon began with a showcase of the different research projects going on in this field. We heard from:

- **Dr. Ann White**, Time for Autism
- **Gemma Kelly**, The Children's Trust (Tadworth)
- **Dr. Will Farr**, Sussex Community NHS Foundation Trust
- **Dr. Sarah Crombie**, Chailey
- **Prof. Nicola Yuill**, University of Sussex
- **Dr. Jess Eccles**, Sussex Partnership Foundation NHS Trust
- **Somnath Mukhopadhy**a, Brighton and Sussex Medical School



**Click on  
the  
relevant  
image to  
view the  
slides**

# What are your perceptions of the experiences of Neurodiverse and SEND CYP and their families ?



We asked people to respond to the above questions and have grouped the responses into the following categories:

## **Lack of support post-diagnosis**

“There is little information and support for children and their families when they become aware they may be neurodivergent”

## **Disjointed system to navigate**

“Systems don’t work together, difficult accessing education systems that don’t fit, difficult to navigate, need parents to advocate or may not get service”

## **Difficulty obtaining a diagnosis**

“Waiting time very long for diagnosis”

## **Different school experiences**

“Frequent experiences of late diagnosis and being in school environments that may not understand sensory and communication needs”

## **Feeling misunderstood and judged**

“Battling stigma and the population’s understanding”

To read all of the responses, please click [here](#)

# Resources

Please click on the resources you would like to view

1. [Digital storytelling slides](#)
2. [South-East NHSE Overview slides](#)
3. [Tangiballs Poster](#)
4. [E-Wellbeing Poster](#)
5. [Time for Autism flyer](#)
6. [The Eating and Drinking Ability Classification System implementation summary](#)
7. [Young people's advisory group and parent carer's group information](#)
8. [Galliver M, Gowling E, Farr W, et al. Cost of assessing a child for possible autism spectrum disorder? An observational study of current practice in child development centres in the UK. \*BMJ Paediatrics Open\* 2017;1:e000052. doi:10.1136/ bmjpo-2017 000052](#)
9. [Male I, Farr W, Reddy V. Should clinical services for children with possible ADHD, autism or related conditions be delivered in an integrated neurodevelopmental pathway? \*Integrated Healthcare Journal\* 2020;2:e000037. doi:10.1136/ ihj-2019-000037](#)
10. [Abrahamson V, Zhang W, Wilson PM, et al. Realist evaluation of Autism ServiCe Delivery \(RE-ASCeD\): which diagnostic pathways work best, for whom and in what context? Findings from a rapid realist review. \*BMJ Open\* 2021;11:e051241. doi:10.1136/ bmjopen-2021-051241](#)

# Contact



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[Starting Well: Children's Mental  
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