



Broad Phenotype Children with Autism in Kent, Surrey, and Sussex: Developing a Self-Report Questionnaire Prioritising Individual Self-Care



Sussex Community
NHS Foundation Trust

Sophie McGrevey, Sussex Community NHS Foundation Trust

Public Summary:

Referrals for autism assessment have been increasing in recent years. This means that waiting times are longer for families, and children and young people are struggling to get the support they need. This also means that the number of autistic children and young people we think there are is not correct. We need a better understanding of the true number of autistic children and young people so that we can provide better support for them.

This research aimed to understand what autism looks like in Kent, Surrey, and Sussex (KSS) to better help autistic children and young people. To do this, we asked schools about the number of autistic children in their school and interviewed autistic children and young people to find out about the support they need.

Questionnaire data from Special Educator Need Coordinator (SENCOs) working across 21 primary and secondary schools in KSS revealed an autism prevalence of around 6%.

Qualitative interviews highlighted that the autistic young people most frequently reported needing small provisions in the classroom, like access to fidget toys, breaks and something as simple as teachers speaking slowly and clearly, and that these small provisions would really make a big difference in their school experience.

These findings allow us to better understand the prevalence of autistic children and young people in schools and their support needs, which can better inform services, like schools, to provide support for those who cannot access support through traditional means, like an Education, Health and Care Plan (EHCP), or cannot access autism NHS services due to waiting lists.



Public and Community Involvement:

This project has had input from my trust's local Young Person's Advisory Group (YPAG) throughout its duration. I have attended the YPAG 3 times, each contributing to different stages of the research. In the first meeting, the young people gave feedback on participant information sheets, feedback including font, presentation and the overall readability of them, which were incorporated into the final versions. The second meeting saw the young people give feedback on methodology, i.e., the interview schedule, as well as provided useful recommendations for recruitment with young people and schools. The third and final meeting involved looking back at their input throughout the project, as well as going through some anonymous chunks of qualitative data from interviews so that they could have a go at qualitative analysis, so their thoughts about what the data means can be written up and published.

Dissemination:

This project has allowed me to disseminate findings both nationally and internationally. I have presented at the ARC KSS Research Week in 2023 and 2024, at the British Association for Community Child Health (BACCH) Annual Scientific Meeting in Glasgow this year, as well as presenting posters at Research Week 2023, BACCH 2023, Sussex Clinical Academic Conference 2024 in Brighton and the European Public Health Conference 2024 in Lisbon. These opportunities have allowed me to publish some of this work, such as my poster prize at Research Week 2023 being published in the *Advanced Journal for Professional Practice* and my abstract for the European Public Health Conference being published in their journal.

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These opportunities have been monumental in my research skills and have prepared me for a career in academia.

Impact and Implementation:

Throughout data collection, participants have commented on the impact of my research for them. One parent said "my children have expressed a strong desire to share their experiences, stories, and challenges with the community. They are eager to raise awareness about autism and educate others about their unique perspectives. I believe that their voices and stories have the power to inspire and empower others" about their child being involved in research and that it is important for them to have opportunities to take part in research. One SENCo said "We really enjoy taking part in research that we are sure will eventually support the way we support some of our most vulnerable students", which shows that SENCos can see that research like this project has an impact in helping young autistic people. Also, when disseminating at conferences, such as BAACH, fellow researchers and colleagues at different NHS trusts have reach out to find out more and how they could do something similar in their local area, showing that my research has impacted others to conduct similar work.

Publications

<https://doi.org/10.1093/eurpub/ckae144.1324>

<https://doi.org/10.22024/UniKent/03/ajpp.1192>

What next?

Take these findings further to develop a quality-of-life measure specifically for autistic children and young people.