



# QUEST Newsletter

Follow-Up Issue 6, January 2019



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## HAPPY NEW YEAR!

Hello and Happy New Year! We have now come to the end of the third wave of the QUEST Follow-up project. Thank you to everyone for taking part in the study, we could not have done this without your support! The QUEST study started over 10 years ago, and has been one of the largest studies of emotional and behavioural difficulties for children with **Autism Spectrum Disorder (ASD)**.

## QUEST Follow-up at age 13-17—Findings so far...

### Changes Over Time

277 families from Bromley and Lewisham took part in the original QUEST study (at age 4-9 years). We followed up 211 of these at age 11-15 years, and have recently followed up 214 families at age 13-17 years.

The study has shown us how incredibly diverse ASD is, and that it is experienced very differently by families. However, on a group level we found:

- parent stress decreased over time
- parents report fewer behavioural problems as their children grow older.

Over the coming months, we will be looking at what predicts mental health outcomes in adolescence for individuals with ASD.

### Social Media Use

You may remember we surveyed some of the young people in mainstream schools about their social media use. :

- 76% said they use Youtube.
- 53% said they use Whatsapp
- 47% said they text
- 42% said they use Instagram
- 39% said they use Snapchat
- 34% said they use Virtual worlds/Online social gaming
- 33% said they use Facebook



We'll use this information to look at how social media use (and other factors) relate to experiences of cyberbullying.

### Brain Activity Finding

- At wave 2 (age 11-15) some young people will remember taking part in tasks that were designed to measure different aspects of cognitive functioning.
- One task measured the brain's response to changes in background auditory information (sounds).
- We looked at individual differences in sensitivity to small changes (e.g. changes in the pitch of a sound). Individuals with a range of learning abilities (from special and mainstream schools) took part.
- **We found that individuals with a more sensitive brain response had higher levels of emotional and behavioural problems.** This was also related to parent reports of increased sensory sensitivity.
- These results suggest that biological differences in how information related to sound, images and touch are processed may be important for understanding emotional and behavioural problems in young people with ASD.



### Physical Responses

- When people feel anxious and annoyed their heart rate often increases or their palms get sweatier. These physical responses are other ways of measuring how anxious people feel, as well as asking people how they are feeling, which we know can be difficult for young people with ASD. We measured the physical responses of 50 young people while they completed different tasks on a computer.
- At the moment, we're exploring whether these physical responses are linked to the different activities and how anxious the young person seemed to be or how anxious they or their parents said they normally are. We would like to find out whether this might be a useful way of measuring anxiety levels in young people with ASD.



## What have parents said about being involved in the study?

“I appreciate all the work your team do. It’s this type of research that can help create new strategies and interventions that can help those like my son, so thank you “



“Keep up the amazing work and Happy Christmas to the QUEST team”

“You might want to catch up with my son, the transition to adulthood was/is quite hard.”

## Prize draw

All wave 3 participants were entered into a prize draw, and 6 lucky winners were selected. Two families won Samsung Galaxy tablets, another two won £30 shopping vouchers and another two won £20 shopping vouchers. The winners have now been notified. Congratulations to those who won and thank you again for everyone's participation!



## What's next for QUEST?

The QUEST study will be continuing in 2019 - we'll be in touch with more on this later in the year.

We are always interested to hear how you are getting on, so please feel free to email us.

### Our contact details

It would help us greatly **if you could tell us about any change of address or phone number.**

Please contact: **Moriya Maccabee** (Research Assistant) By phone: 0207 848 0320 (Please leave a message if we don't answer and we'll call you back)

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