**Exploring the experience of BAME parents who have children with autism and co-morbid disorders: An Interpretative Phenomenological Analysis**

Participant Information Sheet

My name is Hana Richardson, and I am a postgraduate student studying MSc Child Development at University College London (UCL). I have also been working part-time at Tram House School since September 2020. I would like to invite you to be a part of my dissertation research project, which will explore Black Asian and Minority Ethnic (BAME) parents’ experiences of raising children who are autistic and may have additional diagnoses.

I very much hope that you would like to take part. This information sheet will try and answer any questions you might have about the project, but please do not hesitate to contact me if there is anything else you would like to know.

Many thanks for your time and consideration.

**Who is carrying out the research?**

I am the only researcher for this project and identify as Black British- Caribbean. The research will be supervised by Dr Andrew Holliman (Senior Teaching Fellow at UCL).

**Why are we doing this research?**

There is little research about how autism is experienced in BAME communities in the UK. Families in BAME communities face additional challenges, compared to their white British counterparts, and your insight into this is extremely valuable. This research could help to develop more culturally sensitive support in the future.

**Why am I being invited to take part?**

You are being asked to participate as you meet the inclusion criteria for the study. You are a parent who is part of a BAME community, who has a child with autism (and possibly additional diagnoses). All parents asked to participate has a child who attends Tram House school. As mentioned before, your insight is extremely valuable and it is a chance to tell your story.

**What will happen if I choose to take part?**

If you agree to take part, we can agree on a time convenient to you to carry out an interview at Tram House. The interview is expected to last approximately 45 minutes. During the interview you will be asked a series of questions about your experience of raising a child with autism, and also how being part of a BAME community has affected this experience. The interview will be audio recorded and transcribed for later analysis.

**Will anyone know I have been involved?**

All of the information from the interview will remain anonymous and kept confidential. When I write my dissertation, your name and identity will be anonymous. Your recorded interview will be deleted as soon as I have accurately transcribed the interview. The transcribed interview will then be saved in an encrypted folder for 10 years. Your demographic data will be deleted after I submit by dissertation (in September 2021).

**Could there be problems for me if I take part?**

I understand that the topic that we will be discussing may be sensitive. The interview questions that I will be asking have been approved by both UCL and the ethics committee at BeyondAutism.

There will be a sheet with a small list of questions with some background information i.e. “What is your ethnicity?” and “How old is your child with autism?”. You will be asked to complete this at the beginning of the interview. This information will be used for context for the interview and demographic data, which will be used in my dissertation.The interview will include questions like:

Had you heard of the term “autism” prior to your child’s diagnosis?

How do you think being a member of the BAME community influences your experience?

You do not have to answer any question that you do not want to. You can take breaks during the interview or ask to terminate the interview at any time. You also have the right to withdraw from the study after the interview, which means that none of your data will be used in my dissertation. You have until **Friday 28th May 2021** to do so. This can be done by sending me an email (which will be at the bottom of the information sheet and debrief sheet if you wish to participate).

**What will happen to the results of the research?**

The information you provide will be combined with the experiences of other parents from Tram House to identify patterns in the answers provided: these will then be discussed in my dissertation research project. My dissertation will be submitted to UCL and may be read by the senior leadership team at Tram House school. There is also a possibility that this research will be published by a science journal. I intend for the research to be published, and hope that it will allow people to gain more of an insight into your experience and hope bring about change in the autism community. This research could help to develop more culturally sensitive support in the future whether that be during the diagnostic stage or later on. As mentioned above your name and identity will remain anonymous.

**Do I have to take part?**

It is entirely up to you whether or not you choose to take part. I hope that if you do choose to be involved then you will find it a valuable experience. There will be no repercussions if you choose not to take part.

**Data Protection Privacy Notice**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This ‘local’ privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information from research studies can be found in our ‘general’ privacy notice for participants in research studies here.

**Contact for further information**

If you have any further questions before you decide whether to take part, you can reach me at [**qtnvhkr@ucl.ac.uk**](mailto:qtnvhkr@ucl.ac.uk)**.**

If you would like to be involved, please complete the following consent form and return to my university email address: [**qtnvhkr@ucl.ac.uk**](mailto:qtnvhkr@ucl.ac.uk) **by Friday 30th April 2021.**

This project has been reviewed and approved by the UCL IOE Research Ethics Committee.

Thank you very much for taking the time to read this information sheet.