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Participant Information Sheet

Hello, my name is Maria Downey. As part of my masters in psychological science research project under the supervision of Dr Cliódhna O'Connor in the School of Psychology, University College Dublin, I am looking at the experience of receiving a diagnosis of autism in adulthood.

Research study title: Before and after an adult autism assessment

What is this research about?

There are many barriers which prevent adults with autism from receiving a formal diagnosis such as financial factors, long waiting lists, misdiagnosis or even outdated ideas relating to gender. An increasing number of these adults are now seeking a diagnosis despite there currently being no direct route in the public health care system (HSE) for pursuing an adult diagnosis. This research aims to understand the practical and personal experiences of an adult receiving an autism diagnosis.

Why are we doing this research?

We hope that through this research the autism diagnosis process for an adult is captured. By recruiting adults who are waiting for an autism assessment and following up with them at a later date, post-diagnosis, it is anticipated that a more insight into their diagnosis experience is gained. It is hoped that this work will increase the scientific understanding the experience of receiving a diagnosis of autism in adulthood.

Why have you been invited to take part?

You have been invited to take part because you (a) are aged between 18-65 years old, (b) currently on a waiting list to get an autism assessment, and (c) have not been previously diagnosed as autistic (for example Asperger's syndrome during childhood). Please note that unfortunately participants over the age of 65, have ever been diagnosed with a global intellectual disability (e.g. Down Syndrome), are unable to give informed consent to participate, would have difficulty giving an interview in the English language, or live in a residential institution (e.g. prison, nursing home) are not able to participate in this study.

What will happen if you agree to take part?

If you agree, you will be asked to take part in two interviews with a member of the research team, one before your autism assessment and one after. Each interview will last around an hour and will be recorded. The aim of the interviews would be to gain insight into your experience of receiving an autism assessment

in your own words. The interview will take place at a convenient time for you, either through Zoom, phone call, email, or in person at UCD.

How will your data be used?

All the data will be collected and stored according to the General Data Protection Regulation. We would like to record the interview with you so that we have an accurate record of everything you said. Afterwards, the interview will be typed out and the recording will be deleted. Your interview transcripts will be combined with those of the other people who take part in the study. We will analyse the data to look for similarities and differences in people's experiences of the assessment process. The results will be published in peer-reviewed journals so other researchers can learn about our findings.

How will we protect your privacy?

Your name will only appear on the consent form that you sign. The consent forms will be stored securely and separately from all other data. Your name will not be written on the interview transcript, so there will be no way to identify you from the material. If you mention any potentially identifying information during the interview (e.g. name of town or health professional), we will delete this. All the information you provide will be kept confidentially, in an encrypted, password-protected computer. Only the researchers will have access to the research data. Quotes from the interviews may be used in publications or conference presentations, but there will be no way to identify the identity of any participant. No third party (e.g. service providers) will be informed that you took part in the study or what you said in the interview. The only circumstance in which we would breach confidentiality is if a participant discloses information that makes us concerned for their or others' safety. In such a case, we are legally obliged to report this to the statutory authorities.

What are the benefits of taking part in this research study?

While there will be no direct benefit from taking part, studies like these may help guide future autism research and practice. By taking part in this study, you will help improve the understanding of the experience of receiving a diagnosis of autism in adulthood and raise awareness of the challenges and benefits that can come with that.

Please note that the interviewer is not a practicing clinician and is not able to provide any clinical advice. The interview is not meant to be therapeutic and will not have any implications for your autism assessment.

What are the risks of taking part in this research study?

There are no serious risks associated with participation in this study. Some people might feel uncomfortable speaking about their experiences of autism and the assessment process. You are under no obligation to disclose any information that you feel uncomfortable discussing. If you believe that talking about your experiences of autism and the assessment process might cause you distress, you are advised not to participate in this study. Contact details for some relevant support organisations are provided below.

Can you change your mind at any stage and withdraw from the research study?

Yes – this is entirely voluntary. There is no obligation on you to take part in the study. There will be no negative repercussions from this and no one else will be made aware of your choice not to participate. If you do decide to participate, you can end the interview at any time. If you do change your mind during the interview, you can request that we delete the data you have already provided. However, after the interview

has finished, it will not be possible to facilitate later requests to remove your data because participants' names will not be stored with their data.

How will you find out what happens with this project?

You can contact the researchers (see details below) in the future to get information on any publications and presentations.

If you have any further questions, please contact:

Head researcher: Maria Downey, (maria.downey@ucdconnect.ie), School of Psychology, UCD

Supervisor: Dr Cliódhna O'Connor (cliodhna.oconnor1@ucd.ie), School of Psychology, UCD

Thank you for taking the time to read this information sheet. If taking part in the study has raised any concerns regarding your mental health, you might wish to consider contacting your usual mental health team (e.g. GP, counsellor) or one of the following support organisations:

50808 | <https://text50808.ie> | Text HELLO to 50808

YourMentalHealth.ie | <https://www2.hse.ie/mental-health/> | 1850241850

LGBT Helpline | <https://lgbt.ie/lgbt-helpline-opening-hours/> | 1890 929 539

Samaritans | www.samaritans.org | 116 123

Jigsaw | www.jigsaw.ie | 01 472 7010

Pieta House | <https://www.pieta.ie/contact/> | 0818 111 126

Bodywhys – The Eating Disorders Association of Ireland | www.bodywhys.ie | 1890 200 444

Thriving Autistic | <https://www.thrivingautistic.org> | support@thrivingautistic.org