

Information Leaflet: Accessing Sexual and Reproductive Healthcare as an Autistic Person: A qualitative exploration on the experiences of Autistic people in Ireland.

Invitation Paragraph

You are being invited to participate in a research study about your experience as an Autistic person accessing sexual and reproductive healthcare services in Ireland. Questions will be focusing on accessibility and how being Autistic may or may not have impacted your care experience.

Participation is completely voluntary.

Please thoroughly review the information provided in this sheet and discuss it with others if you wish. If you have any questions or if anything is unclear, please do not hesitate to reach out (contact information will be provided at the bottom). We encourage you to take the necessary time to make an informed decision about your participation in this study.

What is the purpose of the study?

What is the study: We plan to study the experiences of Autistic people and to collect information relating to accessibility of sexual and reproductive healthcare services. Participants will only be asked about accessibility of these services and how those challenges or advantages effected their experience of the health care service. The aims of this study are to:

- 1.) examine what challenges Autistic people face when accessing sexual and reproductive healthcare services.
- 2.) determine if there are any positive aspects to their sexual and reproductive health care service experiences.
- 3.) determine if there are any factors of accessibility and service experience that are unique only to sexual and reproductive health care.

Why is it being done: There are several studies that show there are many barriers Autistic people face when accessing general healthcare. These challenges are compounded on when accessing sexual and reproductive healthcare services due to gender differences and the nature of the service. Autistic women are generally underdiagnosed/diagnosed later in life which poses a challenge to accessing healthcare in appropriate ways, as a diagnosis is often the first step to accommodations. It has also been shown that Autistic individuals tend to have higher rates of STDs and unplanned pregnancies than their peers, showing there is a gap in healthcare use which causes harm to the community.

Duration of Study: This study is being done as a dissertation for completion of a master's course at Trinity College Dublin, and therefore will be conducted from late June to September 2nd when the final report is submitted.

Why have I been chosen to participate?

We are interested in understanding Autistic people's experiences of accessing sexual and reproductive healthcare.

You are invited to participate in this study if you have a diagnosis of Autism or self identify as Autistic, are comfortable communicating verbally in English, do not have a co occurring Intellectual Disability, and have ever accessed any kind of sexual and reproductive health care service.

We are hoping to have 8 participants in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information leaflet to keep and asked to sign a consent form.

If you decide to take part you are still free to change your mind up until August 15th 2024 and without giving a reason. There will be no penalty and you will continue to receive the same service/member experience from the organisation you were recruited from, as they will not know who did or did not chose to participate.

What will happen to me if I take part?

Taking part in the study will involve a face-to-face interview that can be either in person or online. The interviews will last no longer than 1 hour but duration is up to the participant and how much you wish to share. The location of the interviews is flexible and can be discussed to find a suitable location. A classroom in the Arts Building at Trinity College Dublin is available as an option for in person interviews.

Topics discussed will include:

- accessibility questions pertaining to sensory issues or accommodations during sexual and reproductive service use.
- communication issues or accommodations during appointments or while making appointments.
- your overall experience with the service and how Autism may or may not have impacted your experience.

Please note that the following topics will **not** be included:

- Your sexuality or sexual history.
- Your medical status or history.
- What specific sexual and reproductive healthcare service you used and why.

With your permission the interviews will be audio recorded, no video, so that transcripts can be made and those will be anonymised. The raw audio recordings will be securely stored on a Trinity College Dublin OneDrive on a local machine on campus to help ensure its protection. The raw data will be deleted after results of the dissertation report are confirmed by the exam board. The anonymised transcripts will be kept for no more than two years after the end of the course which ends when the dissertation results are confirmed, as required by TCD. Best practice for data protection will be followed and all steps will be taken to securely store and retain personal data collected as part of this study. This data will not be shared with anyone else, nor will it leave the country or be given to any other institutions.

Data Privacy

Your Data Protection and Privacy Rights Under GDPR include:

- right of access; You can request access to your data at any time up until it is destroyed.
- right to rectification; You have the right to rectify your data if it is incorrect or incomplete
- right to erasure; You have the right to request your data is erased and to drop out of the study
- right to object to processing based on legitimate or public interest; You can limit the way your data is used by TCD.
- right to data portability; You can receive your data in structured, commonly used, and machine readable format.
- right to object to profiling or making decisions about individuals by automated means

If you have questions or concerns about your Data Protection rights you can contact the DPO below:

Email: dataprotection@tcd.ie

Post:

Data Protection Officer
Secretary's Office,
Trinity College Dublin,
Dublin 2,
Ireland

What are the benefits of taking part?

There will be no direct benefits to participants beyond being able to share their experiences, however we hope the results of the study will help us to understand further the unique challenges or positives Autistic people encounter when accessing sexual and reproductive healthcare as that is a vital part of health care.

What are the possible disadvantages and risks of taking part?

We have taken all measures to minimise any risk to you. All information will be treated confidentially.

Potential disadvantages may be discussion of sensitive topics, although it is unlikely as no questions will be asked about sensitive topics such as sexuality, medical status or history, or context questions as to what specific services were used and why. Mention of anything outside of what the questions ask is up to the participant and discussion of sensitive topics is not required to participate.

In the event of the interview triggering an emotional event, the interviewer will stop the session and provide you a list of relevant resources that you can contact.



Will my participation in this study be kept confidential?

Original audio recordings will be retained in a secure Trinity College Dublin OneDrive account on a local computer in a locked office on campus that only I, Adriana Guppy, and my supervisor, Micheal Feely, have access to, until after my degree has been conferred. A transcript of interviews in which all identifying information has been removed will be retained for a further two years after this.

Please note that by law we are obliged to report any inadvertent discovery relating to physical, emotional or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity.

What will happen to the results of this research?

The results of this research will be used to write my dissertation as part of the completion of my course, this paper may be published in the future as a journal article.

What do I do if I have any further questions?

If you have any questions, if anything is unclear, or you would like to participate, please contact either of us at the information below:

Student Researcher: Adriana Guppy

Email: Guppya@tcd.ie

Phone: +353 830284871

Supervisor: Micheal Feely

Email: Mfeely@tcd.ie