

Information and Consent Form to Participate in a Research Study

Study Title: Exploring the Self-Diagnosis Experiences of Autistic Women at the Intersection of Gender and Autism.

Who is conducting this study?

Principal Investigators:

Yani Hamdani, Department of Occupational Therapy, University of Toronto & Azrieli Adult Neurodevelopmental Centre (Centre for Addiction and Mental Health)

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Co-Investigator, Primary Contact for Study Information:

Francis Routledge, Master's candidate, Rehabilitation Sciences Institute, University of Toronto,

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* This study is being conducted by Francis as part of their Master's degree.

Additional Co-Investigators:

Meng-Chuan Lai, Child and Youth Mental Health Collaborative at the Centre for Addiction and Mental Health, The Hospital for Sick Children, and Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada

Naomi Thulien, MAP Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute St. Michael's Hospital, Unity Health Toronto, and Dalla Lana School of Public Health, Division of Social and Behavioural Sciences, University of Toronto

Dear *Participant*,

My name is Francis Routledge, and I am a Rehabilitation Science Master's student at the University of Toronto. I am supervised by Dr. Yani Hamdani. We are conducting a study called "Exploring the Self-Diagnosis Experiences of Autistic Women at the Intersection of Gender and Autism."

We would like to invite you to take part in this research study. Before agreeing to take part in this study, it is important that you understand how you will be involved. This information and consent form provides you with information to help you make an informed decision to potentially participate in the study.

What is this study about?

The purpose of this study is to explore the self-diagnosis experiences of Autistic women. Autism research has historically focussed on childhood experiences of Autism and has been missing the voices and experiences of non-men. In this study, we are seeking to learn more about Autistic women's experiences with self-diagnosis, including what self-diagnosis means to you, how you arrived at self-diagnosis, and how your experiences as an Autistic woman have shaped your self-diagnosis.

Who funds this study?

This is a Masters' student thesis project based at the University of Toronto's Rehabilitation Sciences graduate program. Francis has received a graduate student from the Ontario Association on Developmental Disabilities (OADD) that includes a small portion of funds to be used for research.

What is the aim of this study?

This study aims to explore the self-diagnosis experiences of Autistic women.

Who can take part in this virtual study?

Eligibility for this study requires that participants have self-diagnosed as Autistic, identify as a woman, be 18 years of age or older, live in Ontario, and are able to communicate in English. Up to eight participants will take part in this study.

What will I be asked to do?

If you meet the inclusion criteria and consent to participate in this study, you will be invited to choose between two options to participate:

(1) Being interviewed by me (Francis) in a virtual interview. The interview will last approximately 40- to 60-minutes and will be recorded using Zoom, so that I don't miss anything important that you say. The interview will be scheduled at a date and time that is convenient for you. If you choose this option, I will send you information prior to the interview to give you an idea of topics we may discuss.

OR

(2) Completing an online open-ended questionnaire that you will have access to for two-weeks. You can revisit the questionnaire as many times as you want over these two-weeks. The questionnaire will take approximately 40- to 60- minutes to complete.

Some of the topics I would explore with you are about your understanding of self-diagnosis, your path to self-diagnosis as an Autistic woman, aims of self-diagnosis and demographic information. Our conversation or your written responses may include additional topics related to gender, clinical diagnosis, health services, discrimination, and systemic oppression.

If you choose to participate through interview, you can stop the interview at any point. If you choose to participate through online questionnaire, you can stop writing, answering questions, and accessing the document at any point.

If you require accommodations and/or have preferences on how you would like to participate, please let me know.

Examples may include:

For the virtual interview:

- Taking breaks throughout the virtual interview
- Turning our camera's off during the virtual interview

For the open-ended questionnaire:

- Changing the questionnaire font (example: changing the font from Calibri to Comic Sans)
- Changing the font colour (example: changing black font on a white background to grey font on a white background)

Are their benefits in participating in this study?

We cannot be certain that there will be direct benefits to you as a result of participating in this study. You may find it beneficial to share your experiences as a self-diagnosed Autistic woman. You may feel a sense of accomplishment participating in research that aims to deepen the understanding of self-diagnosis experiences of Autistic women.

Are their risks in participating in this study?

There is little risk anticipated to you as a participant in this study. You do not have to answer any of the researcher's questions. You can take a break or stop the interview at any time you wish or take a break or stop the questionnaire at any time you wish. It is possible that you could become upset sharing your experiences with topics such as self-diagnosis, gender, Autism,



clinical diagnosis, discrimination, health services, and systemic oppression. If this happens, we can stop the interview.

Compensation

As a token of our appreciation, you will be given a \$30 gift card to recognize your time commitment and as a thank you for your participation in the study.

What will happen to the information that I provide?

All information we collect will be kept in a locked cabinet and/or on a secure server at the University of Toronto. It will be kept confidential and accessed only by the research team members. At the end of the study, all information linked to your identity will be erased or deleted. All research data (de-identified meeting transcripts and online questionnaire) and other study information (consent forms) will be stored on the secure server for 5 years and then deleted. All other research data will be kept for 5 years per University of Toronto policy. No one outside of the research team will have access to your information. Your identity will not be shared without your express permission.

We will audio record the interview. These recordings will let us review the interview in more detail. All recordings will be typed out and the recordings will be destroyed. No names will be included in the typed documents. Participants will be given pseudonyms in all written and published work. When findings are published or presented in public, names and identifying features will not be used without your express consent.

If at any time you change your mind about participating in the study, you can ask that we withdraw your data. We will not be able to withdraw your data once we publish the study.

By agreeing to participate in this study, you have not waived any rights to legal recourse in the event of any research-related harms.

What if I have questions?

If you have any questions about the study at any time, you can contact me at francis.routledge@mail.utoronto.ca. If you have any questions about your rights as a research participant or have concerns about this study, contact the Research Oversight & Compliance Office (ROCO) at (416) 946-3273 or ethics.review@utoronto.ca. The REB is a group of people who oversee the ethical acceptability of research studies in accordance with the requirements of the federal and provincial government, as well as the University of Toronto.

We do not have any conflicts of interest to declare. We thank you for taking the time to consider this study.

Thank you for your consideration to potentially participate in this study.



Research Consent Form - Study Participation

Exploring the Self-Diagnosis Experiences of Autistic Women at the Intersection of Gender and Autism.

By signing this form, I confirm that:

- I have read the participant information letter.
- I have had the opportunity to ask questions about the study and my questions have been answered to my satisfaction.
- I have been told my participation in the study is voluntary.
- I have the right to withdraw my participation from the study at any time.

Would you like to receive a summary of the results of this study upon completion?

Yes. Please send me a summary at this email address _____

No.

I _____ have received *verbal consent* from _____ on
(Name of person obtaining consent) (Name of Participant)

_____ to participate in this study.
(Date)

(Signature of person obtaining consent)

(Date)



Research Consent Form – Consent to Share Email for Gift Card Payment

Exploring the Self-Diagnosis Experiences of Autistic Women at the Intersection of
Gender and Autism.

By signing this form, I confirm that:

- I give permission for my email address to be used to receive a \$30 gift card.
- I understand that a company outside of and unaffiliated with the University of Toronto will have my email for the purposes of distributing and redeeming the gift card.
- I understand that my email will be stored for five-years by the University of Toronto researchers for record keeping-purposes.
- The purpose of the gift card will not be included on the e-gift card.

Please send my e-gift card notification to the following email address:

(Signature of participant)

(Date)