

CONSENT FORM for Youth with ASD

Project title: Challenges and Facilitators During Transition to Adulthood of Adolescents with Autism Spectrum Disorder (ASD)

Lead researcher:

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Introduction

We invite you to take part in a study being conducted by Dr Ghanouni and her team at Dalhousie University. Choosing whether or not to take part in this research is entirely your choice. If you do not want to participate in our project, there will be no impact on the services you receive. The

information below tells you about what is involved, what you will be asked to do and about anything you might experience. In this project, we would like to explore if access to services as you get older is more difficult and why that might be. We have defined this transition period to be between the ages of 15-25. By 25, the brain is fully developed and an individual is considered an adult. What we mean by services includes broad spectrum of resources including education, employment, health care services, etc.

If you have any questions about this study, please email us at resasd2@dal.ca. Please ask as many questions as you like. If you think of questions later, please contact Dr. Ghanouni.

Purpose and Outline of the Research Study

To provide smoother transition to adulthood for families of individuals with ASD, we need to have a better understanding of perceptions, priorities, and experiences of young people, their parents/family members, and their healthcare service providers. We do not know a lot about what individuals with ASD experience during transition to adulthood. Given the unique needs of individuals with ASD compared with any other types of disorders, looking at the process of transition to adulthood among this population is important.

The purpose of this project is to uncover barriers and facilitators related to services during the transition to adulthood of adolescents with ASD. We hope to include at least 20 participants, from across Canada, to share with us their perspectives and comments on services during transition of individuals with ASD to adulthood. These participants will be a mix of young people living with ASD, their parents, and healthcare service providers.

Who Can Take Part in the Research Study

You may participate in this study if you identify yourself as a youth diagnosed with ASD, are able to communicate or verbal, and are 15-25 years old.

What You Will Be Asked to Do

Individuals will express their interest in participating to the research team through phone or e-mail. You will receive an e-mail or mailed Letter of Initial Contact describing the project and your potential role. When participation is confirmed through initial conversation with our team over Skype, email, or phone, you will be sent a copy of the consent form prior to the interview. Informed consent will be obtained in writing at the outset by the research team.

You will be involved in a 60-minute individual interview, at a time that works for you face to face, over phone, or Skype. We will ask you some questions to tell us about challenges you experience and factors to support you as you get older. Interviews will be audio- recorded on a password-protected recorder. We will also distribute a questionnaire to collect demographic information via paper or online link, whichever feel easier for you.

Possible Benefits, Risks and Discomforts

Participating in the study might not benefit you, but we might learn things that might benefit others. Your ideas will help us to have better understanding about experiences of transition among adolescents with ASD and how best to support them.

The risks associated with this study are minimal as there are no known risks for attending the interview or completing the demographic questionnaire online or on paper. If you feel uncomfortable answering any interview question, you are free to not answer and skip that question.

Given that our interview questions are broad, we do not anticipate emotional distress. However, if this happens, we will pause the interview and ask you if you would like to continue. In this situation, we can also direct you to talk to autism associations for potential resources that they can provide.

Compensation / Reimbursement

To thank you for your time, we will give you a gift card (e.g., Amazon, based on your preference) valued at \$30, after the interview is over. If you decide you do not want to complete the interview, we can stop at anytime, and you will still receive the gift card.

How your information will be protected:

Study data and audio recordings will be encrypted and stored on password-protected computers. All names and identifiable information will be removed, and pseudonyms or study ID will be used. We will use participants quotes, without identifying information. Audio-recordings will be stored on password-protected recorders and then securely deleted once transferred to an encrypted file. Any study information is only accessible by the research team and will not contain any identifying information. Data will be destroyed after 7 years after publication. Hard copies of field notes, transcripts, and any other print documents will be stored in a locker at Dalhousie University. We will not disclose any information about your participation in this research to anyone and all information will be kept confidential. An exception to confidentiality is the duty to disclose to proper authorities any reported abuse or neglect of a child/youth.

Information that you provide to us will be kept private. Only the research team at will have access to this information. We will describe and share our findings in presentations and journal articles. We will be very careful to only talk about group results so that no one individual will be identified. This means that ***you will not be identified in any way in our reports***. The people who work with us have an obligation to keep all research information private. Also, we will use a participant number (not your name) or a pseudonym chosen by you in our written and computer records so that the information we have about you contains no real names. All your identifying information will be securely stored. All electronic records will be kept secure in an encrypted file on the researcher's password-protected computer.

If You Decide to Stop Participating

You are free to leave the study at any time. If you decide to stop participating at any point in the study, you can also decide whether you want any of the information that you have contributed up to that point to be removed or if you will allow us to use that information.

Participants can share their concerns with the research team and/or withdraw the project at any time. You can e-mail us if you have any questions or would like to discontinue your participation in the project.

However, it will become impossible for us to remove data from the data set during analysis (within a month after completing the interview) or during publication.

How to Obtain Results

Participants who have indicated in the consent form their interest to receive a summary of findings will be sent a link and letter via e-mail. We will provide you with a short description of group results when the study is finished. No individual results will be provided.

Questions

We are happy to talk with you about any questions or concerns you may have about your participation in this research study. Please contact the research team at via email at resasd2@dal.ca or call 902.494.8434 at any time with questions, comments, or concerns about the research study. We will also tell you if any new information comes up that could affect your decision to participate.

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at (902) 494-1462, or email: ethics@dal.ca (and reference REB file # 20XX-XXXX).”

Signature Page

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I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to take part in an interview that will occur at a location acceptable to me, and that those interviews will be recorded, and that I will be asked to complete a demographic questionnaire online or on paper. I understand direct quotes of things I say may be used without identifying me. I agree to take part in this study. My participation is voluntary and I understand that I am free to withdraw from the study at any time, until analysis is completed.

Signature

Date

I agree that my interview may be audio-recorded [Please note that this is a requirement to be able to attend the study] Yes No

I agree that direct quotes from my interview may be used without identifying me Yes No

I choose the following pseudonym for myself if necessary:

Pseudonym

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