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Report: Investigating Personal Identity Development in Persons with Autism Spectrum Disorder (ASD)

Thank you for your invaluable contribution to the study entitled, '*Investigating Personal Identity Development in Persons with ASD*', conducted at Wilfrid Laurier University. We hope you find this report interesting and enjoyable to read.

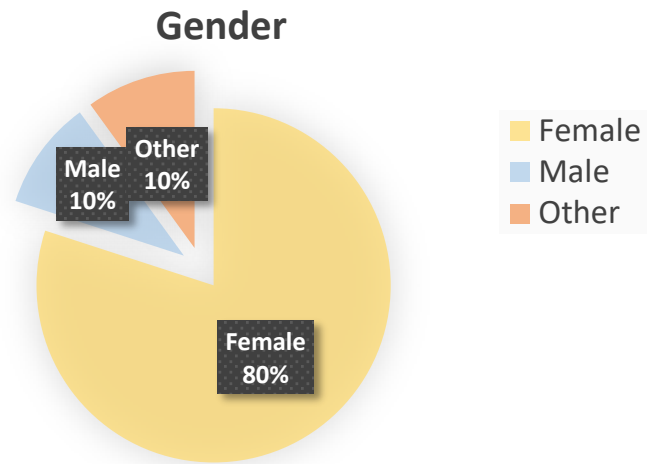
About the Participants

Participants were recruited through online community groups focusing on autism awareness (e.g., Facebook, Reddit, etc.), and through referrals (i.e., participants had the option to send the survey link to anyone they thought would be interested in also participating). Participants were required to self-disclose a formal diagnosis of Autism Spectrum Disorder (ASD) or Asperger's Syndrome, or self-identify as having ASD/Asperger's Syndrome in order to participate. A total of 333 people participated in this project; however, 146 participants were removed from analyses for not passing an attention check, and an additional 12 were removed for providing incomplete information (i.e., left more than 50% of the survey blank).

In addition, 17 participants were removed from analyses for self-disclosing an 'Other' gender of their choice (e.g., agendered, transgendered, non-binary, hybrid gender, etc.), as the number of participants was too few to conduct reliable analyses. In the future, researchers may wish to focus solely on the non-binary experiences of autism in order to gain a more thorough understanding of the various ways in which autism impacts the lives of this diverse group of people.

Finally, given that there were only 17 males – and 17 non-binary participants – the statistical analyses were conducted solely with females, as there were too few male and non-binary participants to conduct reliable analyses. Consequently, the final sample size used for statistical analyses, of which all were female, was 140.

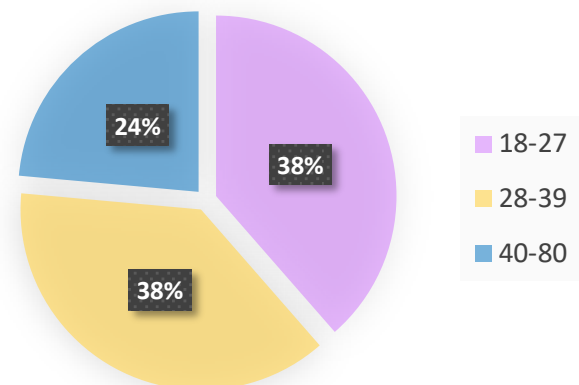
Gender. Overall, there were more females than males in the study; approximately 80% of the participants were female, 10% 'Male' and 10% indicating 'Other'.



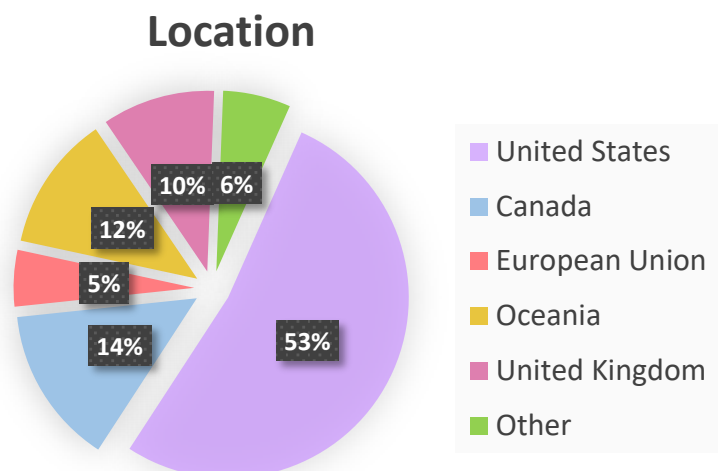
Age. Age of participants ranged from 18 – 80 years, with an average age of 33 years. For males, the average age was 30; for females, the average age was 33; lastly, for 'other' (e.g., non-binary), the average age was 32.

Age of Female Participants

Female Age Groups. Female participants were grouped into three age ranges: 18-27 years, 28-39 years, and 40-80 years. This was done for the purpose of examining age differences amongst the female participants.



Location. Of the participants who self-disclosed their location, 53% were located in the United States; 14% located in Canada; 16% located in the European Union (including the UK), 12% located in Oceania, and 5% located in other areas (e.g., Chili, Brazil, etc.). Please see the graph labeled **Location** for a visual representation of these numbers.

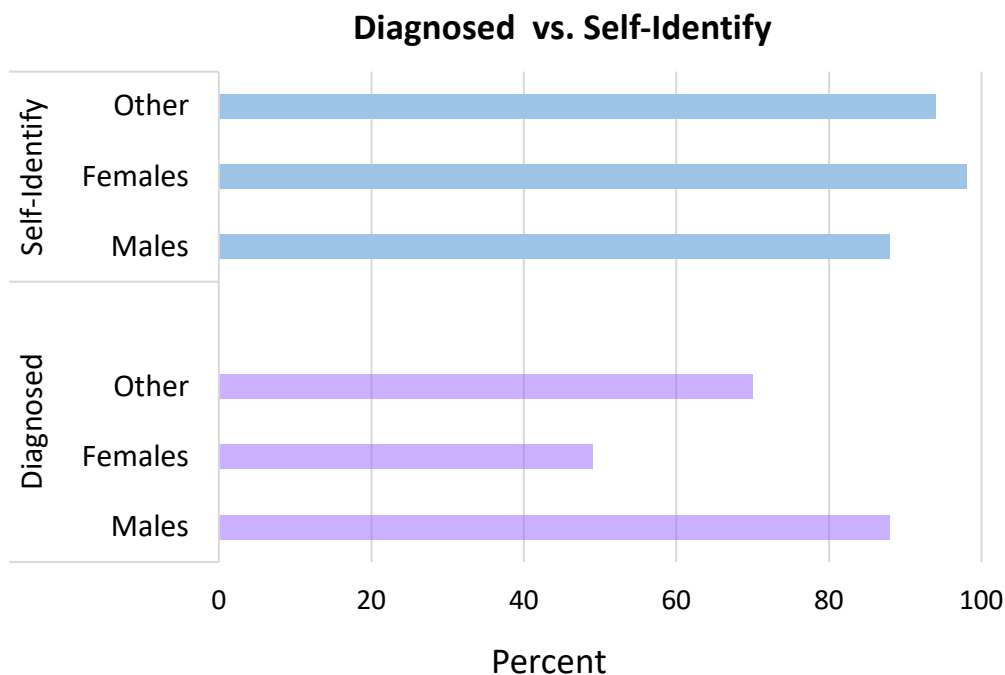


Feeling Different

One goal of this study was to investigate whether people with ASD feel different from others, and if so, at approximately what age did this feeling begin to manifest. Consequently, participants were asked to read a short vignette that depicted an individual's experience of feeling different from others at a very young age (see Attwood, 2006, p. 23 for Claire Sainsbury's account of her memory as a child with undiagnosed Asperger's Syndrome, which was used as the vignette in this study). After reading the vignette, participants answered an open-ended question asking them if they had experienced something similar to the vignette, and to describe that experience in as much detail as possible. Please note that participants provided consent to use their written responses. The responses were coded for common themes and are presented throughout this report.

Diagnosed With ASD. Nearly half of all female participants (49%) reported that they had been diagnosed with ASD. In contrast, 88% of the male participants, and 70% of the 'other' (e.g., non-binary) participants reported that they had previously received an ASD diagnosis. When examining female participants by age, 54% of females aged 18-27 reported a diagnosis of ASD, 38% aged 28-39, and 58% aged 40-80 also reported that they had previously received an ASD diagnosis.

Self-Identifying With ASD. Approximately 95% of the female participants self-identified as having ASD. In contrast, 88% of the male participants, and 94% of the non-binary participants self-identified as having ASD. Please see the graph labeled **Diagnosed vs. Self-Identify** for a visual representation of those who self-identify with ASD against those who have been officially diagnosed with ASD.

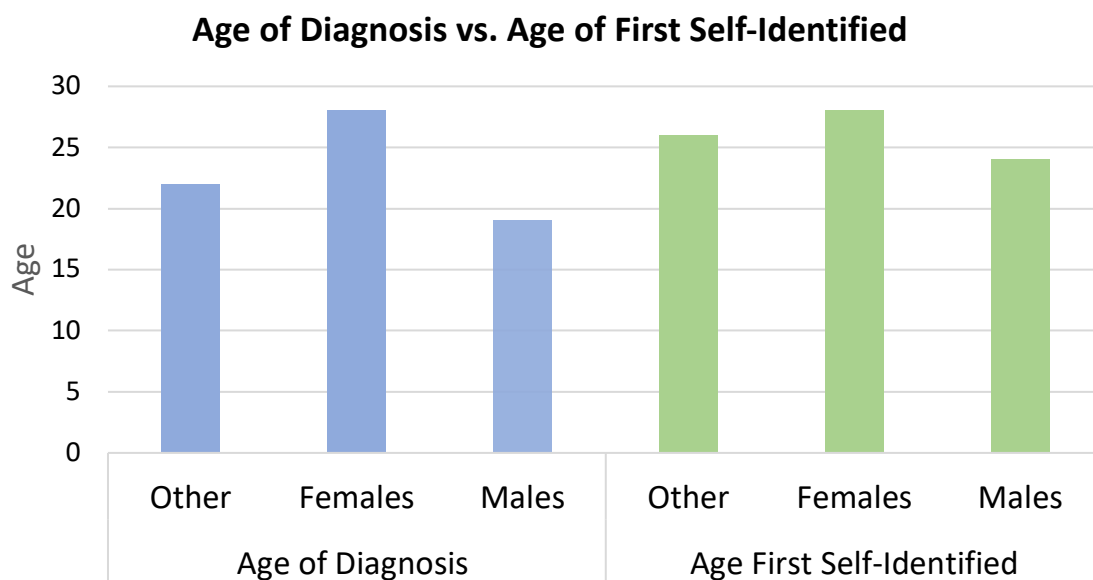


Feeling Different: ‘Other’ Respondents. Nearly all of the non-binary participants agreed with the vignette, saying that they too felt different from others from a very young age, and in some cases, for “as long as [they] could remember”. Many of the responses centered around childhood experiences at school, including difficulties making friends, being teased and bullied by other classmates, sensory difficulties, and high levels of depression during adolescence. Additionally, many respondents mentioned that they did not know exactly why they felt so different, and that this feeling of being different was very pervasive, even from a young age.

One participant described this sense of feeling different via a short anecdote: *“I decided early on that I could not be human. I was either a faery child or from another planet. I wondered how my parents got me but was afraid to ask. I lay in bed at night quietly weeping, wishing my real people would come take me home.”* Many participants spoke about learning how to ‘pass’ as neurotypical (e.g., mimicry) to avoid being bullied, and in some cases, in an effort to make friends. Another spoke about the damaging effect that acting normal at such a young age can bring, by remarking: *“Since I started acting normal at a young age I no longer know who I am (or was) but have now become fused with the fake identity.”*

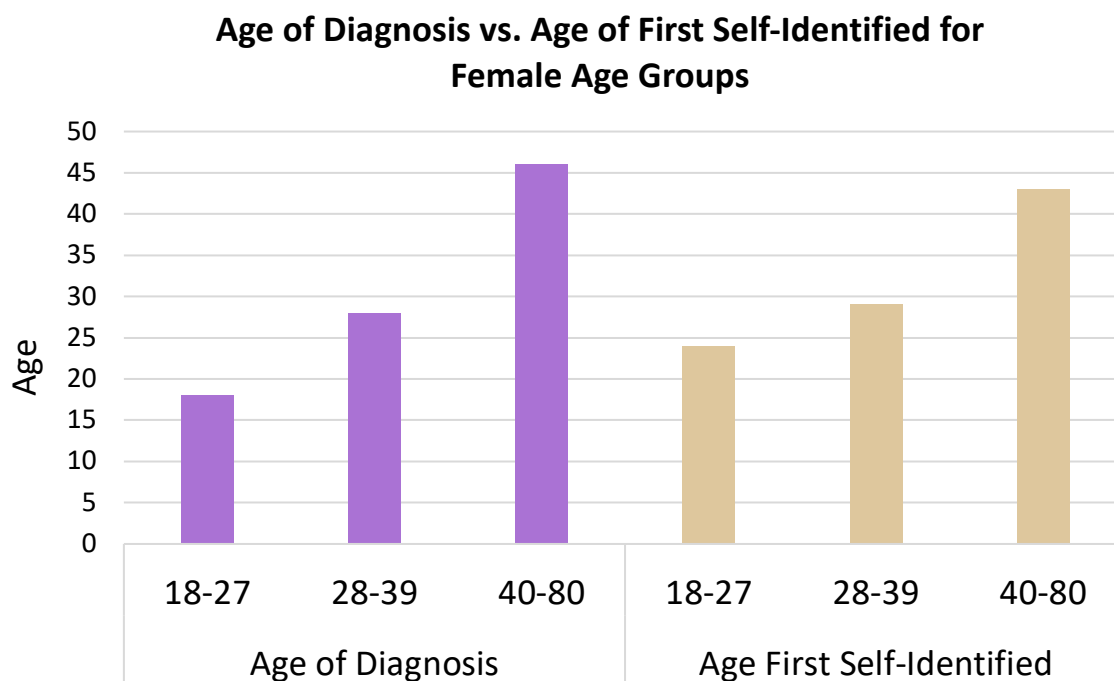
Age of Diagnosis. On average, male participants were diagnosed with ASD at the age of 19. For females, this age was 28, and for non-binary genders, age of diagnosis was 22.

Self-Identifying Age. On average, male participants began self-identifying as autistic at 24 years. In contrast, females began self-identifying at 28 years, and non-binary participants began self-identifying at the age of 26. Please see the graph below.



Feeling Different: Male Respondents. In general, most of the male respondents had less agreement with the vignette, as fewer of them indicated that they had felt exceptionally different from others during childhood and beyond. Most of the time, if a male respondent did feel different from others, they tended to not be bothered by this feeling of difference. Many of the male respondents mentioned that as children they usually were part of a group of friends, and if they were not, they tended to not be bothered by the isolation that this lack of friendship is likely to bring. Additionally, a large portion of the male respondents mentioned that they had been bullied at school during childhood, and, in a few cases, had trouble making friends, or finding a significant other once they were older. One respondent related his childhood experiences to certain number properties that he had learned during school math class: *"Analogically I identified myself as an infinitely repeating fraction in a world of non repeating numbers. I had to truncate or approximate myself to relate properly to others."*

Female Groups: Age of Diagnosis and Age Self-Identified. On average, females in the 18-27 age group were diagnosed with ASD at 18 years. Females in the 28-39 group were diagnosed, on average, at 28 years, and females in the 40-80 group were diagnosed at 46 years. In terms of the age at which these females began self-identifying as autistic, females in the 18-27 group began self-identifying at age 24, females in the 28-39 group began self-identifying at 29, and females in the 40-80 age group began self-identifying at age 43. Please see the graph, labeled **Age of Diagnosis vs. Age of First Self-Identified for Female Age Groups** for a visual representation of these numbers.



Mental Health and Psychological Well-Being for Female Age Groups

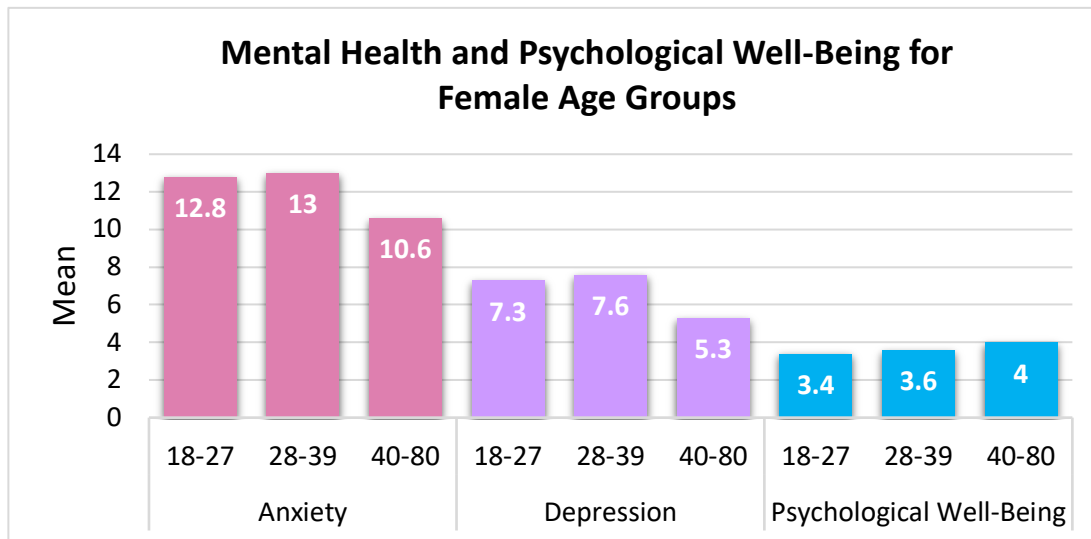
Mental Health. For this study, levels of anxiety and depression were also measured, as research suggests high comorbidity with ASD and anxiety and depression. For female participants, those in the 40-80 age group showed significantly lower levels of anxiety and depression, as compared to females in the 18-27 and 28-39 age groups.

Feeling Different: Female Respondents (18-27). Nearly all female respondents between the ages of 18-27 agreed with the vignette, stating that they felt (and continued to feel) different from others. One participant said: *"I remember asking my parents if I was an alien or an angel when I was four years old because I felt so strange and foreign."* In some cases, this feeling first began during childhood, and in other cases, began in college or high school– sometimes it occurred all throughout their lives. However, some participants disagreed with the vignette by stating: *"I refused to acknowledge that I was different in any way. All I ever wanted was to be normal, I didn't realize back then that all I'd ever get was to imitate it."*

Many respondents spoke about having trouble making friends – sometimes, they became friends with whoever was around at the time, or because the friendships had been pre-arranged by someone (e.g., their mother). Many wished that they could experience intimate relationships, and some remarked that they had never been in one. Many spoke about being bullied and experiencing painful sensory difficulties (e.g., loud music, traffic, etc.). A common theme involved trying to pass as 'normal', as one participant remarked: *"I spent a lot of my teenage years reading etiquette books. Didn't know what was wrong with me, but I figured something must be for me to screw up 'socialization' so badly, so I read up on it."*

Finally, many respondents struggled with depression and anxiety: *"In University I found everyone made friends and I was somehow on the outside of everything. I've always felt like some kind of outsider or alien. This made me feel confused as to what was wrong with me, why I couldn't do what others could seemingly naturally. It affected me by manifesting as depression and anxiety, self harm, social isolation."*

Psychological Well-Being. Psychological well-being is related to positive functioning and biological health, and negatively related to negative functioning (e.g., depression). Psychological well-being encompasses six areas: autonomy (i.e., self-determination and independence), environmental mastery (i.e., participate and master one's environment successfully), personal growth (i.e., continuing to grow and develop as a person), positive relations with others (i.e., ability to foster trusting interpersonal relationships), purpose in life (i.e., belief one has purpose and intentions to achieve that purpose), and self-acceptance (i.e., holding positive attitudes about oneself). In this study, female participants in the 40-80 age group showed significantly higher levels of psychological well-being, as compared to females in the 18-27 and 28-30 age groups. These numbers are reflected in the graph below, labeled **Mental Health and Psychological Well-Being for Female Age Groups**.



Feeling Different: Female Respondents (28-39). Nearly all female participants in this age group agreed with the vignette. Sometimes, this feeling of being different occurred during young childhood (e.g., 4 years old), other times it developed over the course of their lives. One participant remarked, *"The other kids seemed completely alien to me and it was like I was a different species."* Many spoke about preferring to read or write stories, rather than socialize with others. Most also spoke about struggling to form and maintain friendships and romantic relationships: *"I felt like the friendship was happening to me rather than with me."*

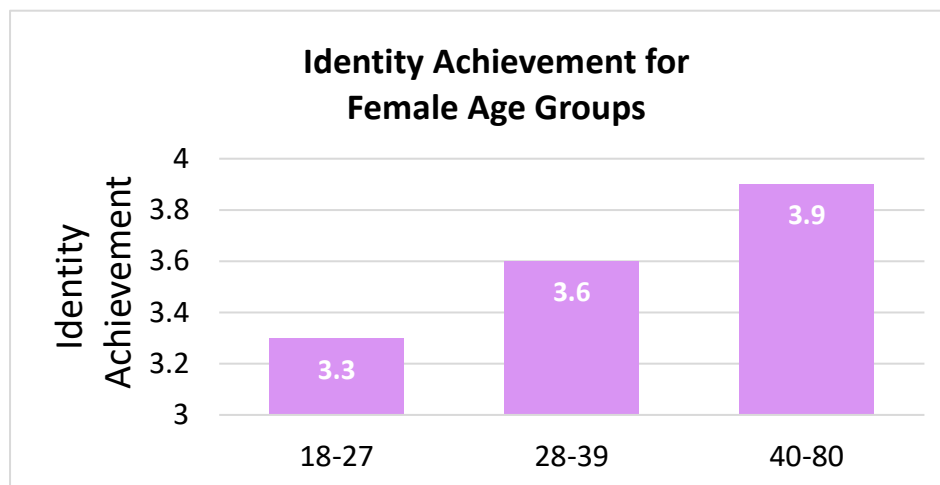
Bullying was another common theme, as one participant explained, *"Other children used my differences to harm me. That is when I came to understand that I am not normal. And that my differences are bad."* Another said something similar: *"I was bullied a lot and my parents discussed changing schools with me [...] but apparently (according to my mom) I told her it didn't matter, it would be the same at a new school, because it wasn't the other kids, it was me."* Low self-esteem and feelings of depression were also common.

Respondents spoke about learning to pass as neurotypical: *"If I have to go in public I do my best to adapt and put on a public appearance of what I perceive is normalcy and politeness, but at the end of the occasion I am drained and it honestly takes me a day to get over things [...]"* Another said: *"I think I am a very good chameleon so I've become ok in many social situations. [...] I've also taken soft skill classes meant for the workplace, but apply to many areas of life."* For some, learning about ASD changed their lives, as one participant wrote: *"Reading about ASD explained my entire history, my entire existence, my entire personality. I still burst into tears when I come across checklists or descriptions of what it's like to be neuro-atypical. It's a bizarre and tremendously beautiful thing, to finally feel understood."* Another remarked, after receiving her autism diagnosis: *"I'd rather be alone with my differences than suppressed of everything I am."*

Personal Identity Theory

A personal identity gives meaning, form, and continuity to life experiences. Through the interactions of one's psychological, biological dispositions, and social context, a person's identity "becomes defined, affirmed, and confirmed" (Kroger, 2002, p. 82). Erikson's theory of Psychosocial Stages (Erikson, 1963) suggests that personal identity initially develops during adolescence and young adulthood, when one attempts to incorporate all the various aspects of oneself into a personal identity (Erikson, 1968). It is thought that during adulthood, individuals will modify aspects of their identity in response to life experiences (e.g., choices about one's career, religion, politics, family, relationships, sex roles, etc.).

Identity Achievement. Marcia (1980) based his theory of identity development on two dimensions: exploration (i.e., a time of turmoil when old values/choices are re-examined and new alternatives explored), and commitment (i.e., a choice is made regarding an important identity question, like choosing a career). Those in the Achieved identity status have explored meaningful alternatives and made commitments to a self-relevant identity question. These individuals "know not only who they are, they know how they became that, and that they had a hand in the becoming" (Marcia, 1980, p. 34). In general, identity Achievement is associated with higher self-esteem (Butman & Arp, 1990), and high psychological well-being (Cakir, 2014). For the present study, females in the 40-80 age group showed a significantly higher level of identity Achievement, as compared to the other age groups. Please see the graph below for a visual representation of these results,



Female Respondents (40-80). The majority of females in the 40-80 age group agreed with the vignette, remarking that they too had felt different from others at different points throughout their lives. As before, sometimes this sense of feeling different occurred during childhood, other times it developed much later (e.g., college years). One participant stated: *"I've always known I am different than others. There was no one moment of realization that I remember."* Many respondents spoke about being voracious readers as children, struggling to make friends, and a few also mentioned trouble with forming and maintaining intimate relationships. Another main theme

centered on a desire to fit in with others: *"I remember thinking life should have come with some sort of rule book because I couldn't figure the rules out myself."*

A frequent theme centered on a desire to live authentically and to know oneself: *"I do not play roles, when it comes to relationships, but live authentically, and wish for my relations to do the same."* Another remarked, *"I worked very hard in my teens and 20s to figure out who I am, and what I need"*, and *"I did a lot of spiritual and religious exploration in my teens, and a lot of personal exploration in my 20s."* Additionally, *"It's been a long time through a lot of self searching and a bit of therapy that eventually led me to pursue an ASD diagnosis. I'm happy that I did, because it allows me a shield when I'm being particularly weird, and it's led me to understand myself better."*

Lastly, many spoke about the impact that receiving an ASD diagnosis made on their lives. For example, *"Now that I know my diagnosis, I can understand my differences and why I've had such trouble, but it doesn't make it any easier."* Additionally, *"I can understand a lot more about why my past has been the way it is, and now I know that it's not because I'm lazy or stupid or incompetent: I'm autistic, and that affects the way I perceive and interact with the world."* And finally, *"I believe the ASD has been all-pervasive in my life and has coloured all my relationships with people, intimate or not. It's impossible to separate one from the other (as in, the person from the condition)."*

Thank You

Your participation in this study has been very appreciated; without you, there would be no project! Thank you again for your time and willingness to participate. I hope you have enjoyed this report of our main findings. If you have any questions or comments, please feel free to contact me (Erinn Barry) at: buic9830@mylaurier.ca

Sincerely,

A handwritten signature in black ink that reads "Erin Barry". The signature is written in a cursive, flowing style.

Biosketches

This study would not have been possible without your invaluable participation. Thank you! We thought you might be interested in learning more about the individuals at Wilfrid Laurier University who put this study together. Here are the biographical sketches of Erinn Barry (principal investigator), and Dr. Nicola (Nicky) Newton (supervisor).

Erinn Barry will be graduating with a BA in Psychology (Concentration: Research Specialist) with a minor in Philosophy, from Wilfrid Laurier University, in June 2018. Based on her personal experience of being diagnosed with ASD in her mid 20s, she is particularly interested in researching possible gender differences in symptom presentation of high-functioning autism, and the proposed female autism phenotype. Her undergraduate honours thesis, conducted in 2016-2017, examined a possible link between personal identity formation and autism traits. The current study extended this research into a new domain of persons diagnosed with (or self-identify as having) ASD. Erinn will be pursuing an MA in developmental psychology at Wilfrid Laurier University in September 2018.

Dr. Nicky Newton is an Assistant Professor of Psychology at Wilfrid Laurier University (WLU), and director of the Personality and Development in Adulthood (PanDA) lab. She received her PhD in Personality and Social Contexts psychology from the

University of Michigan, Ann Arbor, in 2011, and came to WLU in 2015. Nicky's research focuses on how social roles (such as marriage, parenthood, work, and retirement), social support, activity engagement, and gender are related to personality development in adulthood.

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