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SELF-REPORTED SEXUALITY AMONG WOMEN WITH AND WITHOUT  
AUTISM SPECTRUM DISORDER (ASD)

A Dissertation Presented

by

HILLARY HURST BUSH

Submitted to the Office of Graduate Studies,  
University of Massachusetts Boston,  
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

June 2016

Clinical Psychology Program

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## ABSTRACT

### SELF-REPORTED SEXUALITY AMONG WOMEN WITH AND WITHOUT AUTISM SPECTRUM DISORDER (ASD)

June 2016

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Directed by Assistant Professor Abbey Eisenhower

Autism spectrum disorders (ASD) – characterized by deficits in social interaction and communication, and restricted and repetitive behaviors, interests, and activities – increasingly are being diagnosed in individuals of all ages. However, as children on the autism spectrum enter adolescence, self-report research on ASD and sexuality is currently limited to 14 empirical, peer-reviewed articles, misconceptions are prevalent, and professionals remain underequipped to support their sexuality needs. The goal of the current study was to expand the current knowledge base by exploring multiple aspects of sexuality (including relationship and family status, gender identity, sexual history, sexual orientation, sexual desire, sex education exposure, sexual behavior, sexual satisfaction, sexual victimization, and sexual awareness) and

well-being (including symptoms of ASD, sensory sensitivity, depression, anxiety, and social anxiety) in a sample of 18-30 year old women with and without ASD. To capture a wide range of experiences, female-bodied individuals with more fluid gender identities (e.g., agender, genderqueer) and transfeminine women were invited to participate too. Overall, 248 individuals with ASD and 179 individuals without ASD ( $N = 427$ ) self-reported on their experiences by completing a 20-minute online survey. Results showed a wide range of sexuality-related identities and experiences among women with ASD. Of note, a surprisingly high percentage of participants with ASD reported having a genderfluid identity, a sexual minority identity, and at least one lifetime incidence of sexual victimization. When compared to a non-ASD sample, participants on the autism spectrum reported higher levels of gender fluidity, sexual minority identity, and sexual victimization, and lower levels of romantic partnerships, sexual desire, sexual behavior, sex education exposure, and sexual awareness, including consciousness and monitoring; participants in both groups reported comparable levels of sexual satisfaction. Relations across sexuality-related variables, and between sexuality-related and non-sexuality-related variables, within the ASD and comparison groups also were assessed and many significant correlations were observed. The discussion focuses on how these findings expand the current knowledge base, and how they might inform the work of researchers and clinicians, and support the romantic partners, family members, and friends involved in the lives of young people with ASD.

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I would like to thank everyone who contributed to the current study, including individuals who took the time to participate, who went out of their way to publicize the study, and who took the time to provide me with helpful feedback and advice. This project would not be possible without your sincere efforts. In particular, thanks are due to Eva Mendes of the Asperger/Autism Network (AANE).

The current study was generously funded by the Society for the Psychological Study of Social Issues Grants-in-Aid Program, the Doctoral Dissertation Research Grant Program at UMass Boston, and the Department of Psychology at UMass Boston.

With my whole heart, I would like to thank my husband, Devon, my mother, Louise, and my grandmother, Neska, for their unwavering love, support, and

understanding throughout my years in graduate school. Finally, I would like to dedicate this work to the memory and spirit of my father, Peter, who passed away before I had the chance to realize and explore the interests reflected in this work. His enthusiastic pursuit of his interests and his brave willingness to forge a new path in the world are qualities that I seek to emulate.



## NOTE ON LANGUAGE

There is currently a range in terminology that is used to describe autism and autism spectrum disorders. “Asperger,” “Aspie,” “Autistic,” “autism,” “autism spectrum,” “autism spectrum disorder,” “spectrum,” “typically developing,” and “neurotypical” are among the many terms I encountered while conducting this study. Terminology around autism is a complicated and political issue, and it becomes all the more challenging when researchers (who often do not have autism) use words and terms that are different from how individuals on the autism spectrum describe themselves and their experiences. In the absence of a definitive consensus, it was necessary to make difficult decisions in the preparation of this dissertation.

In this dissertation, I have elected to use the term “autism spectrum disorder” (“ASD” for short) when describing participants on the autism spectrum. This language was selected to capture both individuals with an Autistic identity and those with an Asperger identity, and to reflect that participants may have one but not both of these identities. Also, “ASD” is consistent with the DSM5 and with the current conventions of clinical psychology. However, “ASD” may be inconsistent with how individuals on the autism spectrum, including participants in the current study, might describe themselves. I have chosen to use the term “comparison” when describing participants not on the autism spectrum. The decision not to use the terms “typically developing” or “neurotypical” to describe participants without ASD is partly due to the fact that other aspects of neurodevelopment, beyond ASD, were not assessed, and largely due to the vagueness of these terms.

The language used to discuss autism continues to evolve. This research was conducted in a discrete moment of time, and the language used here, while thoughtfully chosen at the time, is likely to become outdated in the near future.

## TABLE OF CONTENTS

ACKNOWLEDGMENTS .....	vi
NOTE ON LANGUAGE.....	viii
LIST OF TABLES.....	xiv
LIST OF FIGURES .....	xvi
CHAPTER	Page
1. INTRODUCTION .....	1
Sexual Identity Development Theory and Implications for . the ASD Population .....	3
Sexuality, ASD, and Young Adulthood.....	6
How Sexuality and ID Literature Informs the Current Study	8
The Need for Self-Reported Sexuality Research .....	11
Sexuality, Gender, and Women with ASD .....	16
Sexual History and Behavior and Individuals with ASD .....	21
Sexual Attraction, Sexual Orientation, and Individuals with ASD.....	23
Sexual Interest and Desire and Individuals with ASD.....	28
Sex Education and Individuals with ASD .....	30
Sexual Satisfaction and Individuals with ASD .....	34
Sexual Victimization and Individuals with ASD.....	36
Sexual Awareness and Individuals with ASD .....	38
Internalizing Symptoms and Individuals with ASD .....	41
Sensory Symptoms and Individuals with ASD.....	47
2. CURRENT STUDY.....	49
Specific Aims.....	49
Specific Aim 1: To describe the experiences of women across multiple aspects of sexuality.....	49
Specific Aim 2: To identify potential differences in aspects of sexuality between women with and without ASD.....	49
Hypothesis 1.....	50
Hypothesis 2.....	50
Hypothesis 3.....	50
Hypothesis 4.....	50
Hypothesis 5.....	50

Hypothesis 6.....	50
Hypothesis 7.....	50
Specific Aim 3: To understand how sexuality-related variables are associated with each other, and with key demographic variables, ASD symptoms, internalizing symptoms, and sensory symptoms.....	50
Specific Aim 4: To explore whether internalizing symptoms and sensory symptoms moderate the relation between ASD symptoms and aspects of sexuality for women with ASD.....	51
Hypothesis 8.....	51
Hypothesis 9.....	52
3. RESEARCH DESIGN AND METHODS .....	53
Design .....	53
Participants.....	53
Inclusion criteria .....	53
Subgroup criteria.....	54
Participant characteristics .....	55
ASD group characteristics .....	58
Procedure .....	59
Piloting.....	59
Recruitment of ASD group participants .....	59
Recruitment of comparison group participants.....	62
Data collection for ASD and comparison group participants.....	63
Fraudulent responding and study changes .....	64
Participant screening .....	65
Measures .....	66
Sexuality-related variables.....	67
Sexual history.....	67
Sexual orientation .....	67
Sexual desire .....	67
Sex education exposure.....	68
Sexual behavior.....	68
Sexual satisfaction .....	70
Sexual victimization.....	70
Sexual awareness .....	71
Non-sexuality-related variables .....	71
Demographics .....	72
Autism symptoms .....	72
Sensory symptoms .....	73
Depressive symptoms .....	74

Anxiety symptoms .....	75
Social anxiety symptoms .....	76
Qualitative items and analysis .....	76
4. RESULTS .....	79
Data Processing Procedure .....	79
Normality analyses.....	81
Analyses for potential covariates .....	82
Between-group comparisons on demographic variables .....	82
Comparisons between demographic variables and continuous variables.....	84
Tests of Specific Aims .....	87
Specific Aim 1: To describe the experiences of women across multiple aspects of sexuality.....	87
Relationship and family status .....	88
Gender identity.....	89
Sexual history.....	90
Sexual orientation .....	92
Sexual desire .....	93
Sex education exposure.....	94
Sexual behavior.....	95
Sexual satisfaction .....	97
Sexual victimization.....	98
Sexual awareness .....	98
Specific Aim 2: To identify potential differences in aspects of sexuality between women with and without ASD.....	99
Relationship and family status .....	100
Gender identity.....	101
Sexual history.....	102
Sexual orientation .....	103
Sexual desire .....	104
Sex education exposure.....	104
Sexual behavior.....	106
Sexual satisfaction .....	109
Sexual victimization.....	109
Sexual awareness .....	110
Specific Aim 3: To understand how sexuality-related variables are associated with each other, and with key demographic variables, ASD symptoms, internalizing symptoms, and sensory symptoms.....	110
Exploratory factor analyses on the item level.....	114

Exploratory factor analyses on the total score level ..	123
Specific Aim 4: To explore whether internalizing symptoms and sensory symptoms moderate the relation between ASD symptoms and aspects of sexuality for women with ASD.....	126
Moderating effects of internalizing symptoms .....	128
Moderating effects of sensory symptoms .....	134
Exploratory Qualitative Analyses .....	138
Impact of ASD on sexuality.....	138
Rationale for participating .....	142
Subgroup Analyses .....	143
4. DISCUSSION .....	146
ASD Sample Characteristics.....	146
Sexuality and Well-Being Among Young People With And Without ASD.....	147
Relations Between and Across Sexuality-Related and Non-Sexuality-Related Constructs.....	155
Strengths and Limitations .....	160
Future Research Directions.....	164
Clinical Applications .....	166
APPENDIX	
A. INFORMED CONSENT FORM.....	168
B. INFORMED CONSENT QUIZ.....	170
C. LIST OF RESOURCES FOR PARTICIPANTS .....	171
D. ONLINE BATTERY .....	175
REFERENCES .....	198

## LIST OF TABLES

Table	Page
1. Demographics of ASD ( $n = 248$ ) and Comparison Groups ( $n = 179$ ).....	55
2. Breakdown of Continuous Missing Data for ASD and Comparison Groups .....	80
3. Frequencies of Sexual Behaviors Among Participants with ASD	95
4. Descriptive Statistics and Between-Group Differences for Major Continuous Variables.....	99
5. Differences in Sexual Behaviors Between ASD and Comparison Groups.....	107
6. Differences in Sexual Victimization Between ASD and Comparison Groups .....	109
7. Partial Correlations Between Sexuality and Non-Sexuality Related Variables for ASD Group .....	111
8. Partial Correlations Between Sexuality and Non-Sexuality Related Variables for Comparison Group.....	112
9. Factor Loadings and Communalities Based on a Factor Analysis with Oblimin Relation for 39 Sexuality-Related Items (ASD Group).....	117
10. Factor Loadings and Communalities Based on a Factor Analysis with Oblimin Relation for 35 Sexuality-Related Items (Comparison Group) .....	121
11. Factor Loadings and Communalities Based on a Factor Analysis with 6 Total Scores on Sexuality-Related Constructs (ASD Group).....	124
12. Factor Loadings and Communalities Based on a Factor Analysis with 6 Total Scores on Sexuality-Related Constructs (Comparison Group) .....	126

13. Codes Identified in Participants’ Responses Regarding Study Participation ..... 142

14. Descriptive Statistics and Between-Group Differences on Major Continuous Variables for Participants in ASD Group With and Without a Formal Diagnosis ..... 145



## LIST OF FIGURES

Figure	Page
1. Structural Equation Model to Test Potential Moderating Effects of Internalizing Symptoms on the Relation Between ASD Symptoms and Global Sexuality.....	129
2. Structural Equation Model to Test Potential Moderating Effects of Internalizing Symptoms on the Relation Between ASD Symptoms and Sexual Satisfaction.....	131
3. Decomposition of Interaction Effect Between Autism Symptoms and Internalizing Symptoms in Predicting Sexual Satisfaction.....	133
4. Structural Equation Model to Test Potential Moderating Effects of Sensory Symptoms on the Relation Between ASD Symptoms and Global Sexuality.....	135
5. Structural Equation Model to Test Potential Moderating Effects of Sensory Symptoms on the Relation Between ASD Symptoms and Sexual Satisfaction.....	137

## CHAPTER 1

### INTRODUCTION

Autism spectrum disorders (ASD) are heterogeneous neurodevelopmental disorders characterized by deficits in social interaction and communication, and restricted and repetitive behaviors, interests, and activities (APA, 2013). Multiple sources have reported a dramatic increase in the incidence of ASD, with the Centers for Disease Control and Prevention (CDC) currently estimating the rate of diagnosis at 1 in 68 children (2014). While epidemiological research on rates of ASD diagnosis among adults remains limited, there is emerging evidence that ASD may be as prevalent among adults as it is among children (Brugha et al., 2011). Regardless of one's ability or disability identity, sexuality is, to varying degrees, common to all human lives. Sexuality is defined by the World Health Organization (2002) as:

... a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships.

While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (p. 5)

In light of the statistics provided by the CDC and the definition provided by the WHO, it is evident that ASD touches the lives of many individuals and that sexuality is even more far-reaching, arguably impacting every human life. However, research that addresses ASD and sexuality simultaneously, from the perspective of individuals themselves on the autism spectrum, is limited.

A comprehensive PsychINFO search shows that there are approximately 160 peer-reviewed articles that focus on the sexualities of individuals with ASD. However, only 14 of these articles include sexuality data reported by individuals with ASD themselves, as opposed to parent- or caregiver-reported data. While measures have been taken to address this wide gap in the scientific literature – researchers and clinicians such as Isabelle Henault (2005) have published books largely based on their clinical experiences of helping young clients with ASD navigate sexuality issues, and advocates including Sarah Hendrickx (2008) and Mary and Jerry Newport (2002), have written books on the topic of ASD and sexuality – these resources are not, and do not claim to be a substitution for systematic, empirical research.

While the current literature on ASD and sexuality is limited in size, it possesses some notable strengths, including the representation of women on the spectrum (e.g., Gilmour, Schalomon, & Smith, 2012; Ousley & Mesibov, 1991), the use of self-report

sexuality measures designed specifically for participants with ASD (e.g., Stokes & Kaur, 2005), and the assessment of multiple aspects of sexuality, including behaviors, orientation, knowledge, desire, arousal, functioning, and more (e.g., Byers, Nichols, & Voyer, 2013; Byers, Nichols, Voyer, & Reilly, 2013; Gilmour et al., 2012). The current study builds upon the methodology of these existing studies, and makes a unique contribution to the ASD and sexuality literature by measuring multiple aspects of sexuality and well-being among young women, including transfeminine women and female-bodied individuals with more fluid gender identities, between 18 and 30 years old.

In the following literature review, both sexual identity development theory, and empirical findings from the self-report ASD and sexuality literature will be discussed. Findings from other bodies of research, including the other-report ASD and sexuality literature, the intellectual disability (ID) and sexuality literature, and mainstream (non-ASD) sexuality literature will be discussed, as relevant.

### **Sexual Identity Development Theory and Implications for the ASD Population**

It is important to understand how developmental theories have influenced current understanding of sexual identity. While sexual identity is understood to be a development process for all individuals, much of the existing sexual identity development theory is focused on individuals who identify as sexual minorities and, implicitly, individuals who do not have disabilities (Diamond, 2006). This focus on sexual orientation is to the exclusion of other aspects of sexuality, including desire, behaviors, and attitudes and beliefs, which are likely to contribute to one's sexual self-concept. Nonetheless, sexual

identity development theory plays a role in how human sexuality is currently studied, and is important to review here.

The 1969 Stonewall Rebellion in New York City is widely considered a turning point in the awareness and recognition of individuals who have a sexual minority identity, including those who identify as gay, lesbian, or bisexual (Patterson, 1995). Following this historic event, focus increased on the experiences of sexual minorities, and much like Carol Gilligan (1982), who criticized developmental theory for generalizing research on the experiences of men to women, theorists began to criticize the developmental and sexuality research to date that overwhelmingly focused on the experiences of heterosexuals (Patterson, 1995). In 1979, Vivian Cass presented the first sexual identity development model for individuals who identify as gay or lesbian. This model contained six linear stages: (1) identity confusion (feeling confused and questioning whether one might be gay); (2) identity comparison (accepting that one might be gay and self-isolating); (3) identity tolerance (accepting that one is likely gay and seeking out others who have that identity); (4) identity acceptance (feeling positive about gay identity and increasing contacts with the gay community); (5) identity pride (immersing oneself in gay culture and minimizing contact with heterosexual people); and (6) identity synthesis (integrating sexual orientation with other aspects of personal identity). Since Cass's (1979) work, stepwise models for gay and lesbian identity development have been presented by other theorists, and "sexual identity development" has come to be defined as the process through which sexual minorities acknowledge their sexual orientation and integrate it into their self-concept in a positive manner (Diamond,

2006). It is important to note that self-awareness and understanding of one's own sexuality, awareness of others' thoughts and feelings, and accessing communities are all implicit requirements for moving through the stages of sexual identity development presented by Cass (1979), and that these activities may be difficult for someone who presents with the social, communicative, and behavioral challenges of ASD. It may be the case, however, that participation in vibrant online ASD communities, including Wrong Planet and the Aspergers "subreddit," facilitates these activities and the process of sexual identity development for people on the autism spectrum.

While it is helpful to acknowledge the existing theories on sexual identity development and how they have informed contemporary sexuality research, it is important to note that the leading models were based exclusively on the experiences of individuals without ASD, and thus may not generalize to the ASD population. Further, the goal of the current study is not to develop and offer a sexual identity development theory for women with ASD. As Diamond (2006) noted, current research on sexual identity development generally examines the experiences of both men and women, uses qualitative and longitudinal methods, considers cultural and interpersonal contexts, and devotes more attention to sexual fluidity and change over time. The cross-sectional and quantitative nature of this study makes it poorly equipped to answer these questions. However, the design of the current study is consistent with the leading contemporary studies on ASD and sexuality, which take a broad approach to understanding sexual identity and facets of sexuality – far beyond sexual orientation – that is also consistent with the definition of sexuality offered by the World Health Organization (2002).

## **Sexuality, ASD, and Young Adulthood**

Young adulthood is well-documented as an important period of identity development, and of normative social and sociosexual development (Tolman & McClelland, 2011). However, the symptoms and associated features of ASD may inhibit the capacity of individuals with ASD to form a variety of friendships and relationships, including those that have the potential to become sexual (Henault, 2005). Social impairments associated with ASD may include difficulty relating to others and understanding what they are thinking, difficulty with social and emotional reciprocity, and difficulty understanding the social motivation behind normative behaviors, like personal hygiene routines (Nichols, Moravcik, & Tetenbaum, 2008). Communication impairments may include difficulty starting and maintaining conversations, difficulty interpreting verbal and non-verbal communication cues, and overusing stereotypic, idiosyncratic, or repetitive language (APA, 2000); in turn, these can negatively impact the ability of individuals on the autism spectrum to form new relationships and to detect others' interest in them (Henault, 2005). Behavior impairments may include restricted or repetitive behaviors, adherence to non-functional rituals or routines, and very specific and narrow interests (APA, 2000); these too can impede one's ability to foster sexual relationships (Sullivan & Caterino, 2008).

In addition to social and communication difficulties, many individuals on the autism spectrum have hyposensitivity or hypersensitivity to sensory stimuli (Myles et al., 2004); while previously an associated feature and not a diagnostic criterion, sensory sensitivities were included as a sub-criterion under restricted, repetitive behaviors in the

*DSM-V* (APA, 2013). Having a dislike of certain smells, tastes, and textures can negatively impact physical and interpersonal expressions of sexuality, and enjoyment of solo and partnered sexual activity. Also, patterns of “black or white” thinking are sometimes observed in individuals with ASD, which can lead to rigid beliefs and rules around sexuality (Nichols et al., 2008). In a recent study by Byers, Nichols, Voyer, and Reilly (2013) with participants on the autism spectrum with previous romantic relationship experience, ASD symptoms were found to be negatively correlated with sexual satisfaction and sexual arousability, but unrelated to level of sexual knowledge, positive beliefs about sexuality, or desire for sexual activity within the relationships. While these findings provide empirical support for the idea that the features of ASD may make healthy sexuality challenging to achieve, other research consistently has shown that many individuals on the autism spectrum are interested in romantic and sexual relationships, and engage in a range of sexual behaviors (Gougeon, 2010; Hendrickx, 2008; Sullivan & Caterino, 2008).

The current study focuses on the sexualities of young women with ASD, as well as transfeminine women and female-bodied individuals with more fluid gender identities; however, the current ASD and sexuality literature is overly focused on the experiences of adults, including participants with a very broad range of ages (e.g., Byers, Nichols, Voyer, & Reilly, 2013; Konstantareas & Lunskey, 1997). This partly may be due to standards of research ethics in some countries, including the United States, where participants must be at least 18 years of age in order to provide informed consent; it may also be due to parents’ concerns about allowing their younger children with ASD to



participate in sexuality research (e.g., McCarthy, 1998). The inclusion of participants with a wide range of ages may also reflect the difficulty of recruiting individuals with ASD to participate in sexuality studies and in turn, the need for broad inclusion criteria. The distinctions between adolescence, young adulthood, and adulthood are not well-defined in the sexuality and disability literature; however, socioemotional development is frequently a longer developmental process for individuals with ASD than for individuals without ASD, and it is possible that adults with ASD may face some of the same challenges around sexuality as adolescents and young adults with ASD (Nichols et al., 2008). Support for this idea comes from Bernert's (2011) ethnographic work, in which participating direct support providers noted how some adult women engaged in behavior often associated with teenagers with disabilities (e.g., having a string of short-term relationships). Further, blurry boundaries around developmental stages may be present due to heterogeneity among individuals with ASD, particularly in regard to education status, employment status, and living situation, which are frequent markers of developmental stages within the typical literature. While ASD and sexuality studies with a wide range of adult participants are certainly informing, this practice is problematic because sexuality is a developmental process; less can be learned from studies that do not differentiate between ages or that focus on adulthood, by which time a great deal of development has already occurred.

### **How Sexuality and ID Literature Informs the Current Study**

The existing literature on sexuality and disability focuses heavily on the experiences of individuals with mild to moderate ID, and less so on those with ASD. ID,

which has replaced the outdated term “mental retardation,” is defined as having an intelligence quotient (IQ) around 70, and having significant impairment in adaptive behavior, which includes a range of conceptual, social, and practical skills, all present prior to age 18 (American Association of Intellectual and Developmental Disabilities, 2011). A considerable percentage of individuals with ASD also have ID: recent studies have estimated this rate to be 38 percent (CDC, 2012) and other studies report that it is even higher. In this sense, some of the literature on ID and sexuality may be relevant for individuals with ASD (who also have ID), due to overlapping populations. However, it also can be deduced that the majority of individuals with ID do not have ASD and therefore, may not face the same barriers to sexuality and sexual expression (Gougeon, 2010; Roeyers & Thys, 2012). People with ID frequently have global delays but do not generally exhibit the specific social, communicative, and behavioral impairments as individuals with ASD. Thus, individuals with ID are generally more adept than those with ASD at establishing rapport with others, reading social cues, and navigating the social spaces in which they can meet potential partners.

While differences exist between individuals with ID and individuals with ASD that limit the generalizability of sexuality research findings from one population to the other, there are some key ways in which the sexualities of these two groups overlap. For example, both ID and ASD populations have been influenced by decades of harmful misconceptions about their sexualities, including the idea that all people with disabilities are childlike, asexual, and not at all interested in sex, and the contradictory belief that all people with disabilities are sexually deviant and dangerous (Dotson, Stinson, & Christian,

2003). Moreover, many individuals with either ID or ASD have cognitive profiles that interfere with their ability to learn sexuality information; these young people also may experience a “peer void” and lack opportunities to learn socially (Gougeon, 2010; Nichols et al., 2008). Finally, people with ID and to a lesser extent, people with ASD, often receive housing and employment supports from human service agencies following their transition from special education to adult services, at or before age 22. This means that direct support providers are often highly involved in their lives, and how these individuals (and human services agencies on the whole) approach sexuality carries major implications for the people they serve (Bazzo, Nota, Soresi, Ferrari, & Minnes, 2007).

It is important to note here that with the emergence of the neurodiversity movement, many individuals identify as Autistic or autistic (as opposed to a “person with ASD”) and view ASD as a human variation (like sex or gender), as opposed to a disability or disorder to be remedied (Ortega, 2009). While alignment with neurodiversity was not explored directly in the current study, many participants incidentally shared (e.g., through open-ended survey responses and email communications with the Principal Investigator (PI) that they identified with this movement. It is likely that some people would disagree with autism being compared to ID, or other disabilities; however, in their open-ended responses, which are explored in the current Results chapter, some participants discussed the impact of harmful misconceptions and negative societal attitudes about their attempts to find partners and to assert their sexuality. While the current study attempts to be consistent with neurodiversity values and respectful of the views of study participants, the overlapping experiences between individuals with ID and

individuals with ASD – particularly around navigating damaging stereotypes and misconceptions about their sexuality – demonstrate the relevance of reviewing the ID and sexuality literature when learning about ASD and sexuality.

### **The Need for Self-Reported Sexuality Research**

Until recently, other-reported studies have been disproportionately represented in ASD and sexuality research, including research on individuals of different ages with ASD. The importance of gathering information from individuals with disabilities themselves is highlighted by the work of Gaudet, Pulos, Crethar, and Burger (2002), who found that among individuals with traumatic brain injury and related cognitive issues, ratings of one's own sexuality correlated only weakly with ratings provided by family members. Findings like these show that it is insufficient to rely exclusively on other-report data, particularly when research procedures can be adapted to facilitate self-report among individuals with ASD. The first study to include sexuality data provided by individuals with ASD themselves was completed by Ousley and Mesibov in 1991. To date, there are only 14 sexuality research studies in which data were collected directly from participants with ASD. This research is likely limited due to multiple factors, including a long-standing belief that people with disabilities do not have healthy sexualities, ethical concerns around collecting sensitive data from vulnerable populations, and methodological concerns, namely doubt that people with ASD can self-report in a reliable and valid manner (Gougeon, 2010). However, several contemporary studies – namely those by Mehzabin and Stokes (2011); Gilmour et al. (2012); and Byers, Nichols, and Voyer (2013) – have collected quantitative sexuality data from individuals with ASD

in a successful and valid manner. They did so by carefully choosing brief, simply-worded questionnaires that were unlikely to cause confusion or be misinterpreted by participants with ASD. Where necessary, the authors added or slightly changed the language of these questionnaires (e.g., adding a parentheses with language to clarify what “oral sex” is) to make them more suitable for their participants with ASD. The studies by Gilmour and colleagues (2012); Byers, Nichols, and Voyer (2013); Byers, Nichols, Voyer, and Reilly (2013); and Byers and Nichols (2014) each used online questionnaires to recruit their samples and to collect data; these studies provide the methodological foundation for the current study.

A review of the current literature on ASD and sexuality has shown that self-reported studies tend to explore many aspects of sexuality (e.g., sexual behaviors, experiences, desires, knowledge, attitudes) instead of just one. Studies of this nature include Ousley and Mesibov’s (1991) groundbreaking study, which compared sexual knowledge, sexual interest, and sexual experience between individuals with ASD and individuals with mild to moderate ID, as well as other studies conducted by Konstantareas and Lunsby (1997); Mehzabin and Stokes (2011); Gilmour and colleagues (2012); and Byers, Nichols, and Voyer (2013). In the current study, the following aspects of sexuality were assessed: history, orientation, desire, exposure to sexual education, experience and behavior, satisfaction, victimization, and awareness. While the majority of these constructs have been examined in ASD samples, particularly through the two recent studies of Byers, Nichols, and Voyer (2013), and Byers, Nichols, Voyer, and Reilly (2013), sexual awareness is a construct that has not yet been measured within an

ASD sample. In addition to the specific target population, the inclusion of this multifaceted variable, including sexual consciousness and sexual monitoring, represents a unique contribution of the current study to the existing literature.

In comparing self-reported sexuality studies to the other-reported sexuality studies that, until recently, dominated the ASD and sexuality literature, an interesting observation emerges. While the self-reported sexuality studies described above tend to take a holistic approach to sexuality, other-reported sexuality studies tend to focus narrowly on sexual and sexualized behavior (e.g., Hellemans, Roeyers, Leplae, Dewaele, & Debouette, 2010; Van Bourgondien, Reichle, & Palmer, 1997), as well as emphasizing more taboo experiences, including stalking (Stokes, Newton, & Kaur, 2007), fetishes (Dozier, Iwata, & Worsdell, 2011; Raelmuto & Ruble, 1999), and gender dysphoria (Gallucci, Hackerman, & Schmidt, 2005). While these studies are certainly informative and provocative, and underscore the fact that individuals with ASD may need specialized education and support from others in order to develop healthy sexualities, they also do not adequately represent the wide range of sexualities experienced by individuals with ASD. Further, their presence in an underdeveloped body of literature arguably may inflate beliefs around the occurrence of sexual problems and deviance within the ASD population. Additionally, depending on the type of sexuality information that researchers wish to obtain, other-report methods provide a significant limitation as caregivers, parents, and others may not know the answers. For example, in Hellemans, Colson, Verbraeken, Vermeiren, and Deboutte's (2007) study on sexual behaviors among men with ASD, the participants (residential staff members) responded to a high number of

items with “unknown”; had these young men had been asked the items directly, it is likely that more detailed information would have been obtained. Ultimately, to gain a more balanced understanding of what sexuality means for young women with ASD, the current study exclusively used self-reported measures to gather data directly from the source.

The concerns of parents and teachers around addressing sexuality with young people with ASD are well-documented (Ballan, 2012; Kalyva, 2010; Nichols & Blakeley-Smith, 2010). For example, parents have feared that talking about sexuality might lead to deviant behavior, or an inflated interest in sex (Ballan, 2012). It is reasonable to expect that some of these concerns may pose a barrier to young people with ASD receiving parental permission to participate in sexuality research studies, in which they may be asked about their sexualities in an open, frank, and detailed manner. To date, in only one study, completed by Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen (2014), has self-report sexuality data been collected from participants under 18 years old (participants were young men, with and without ASD, between 15 and 18 years old). It is helpful to note that Dewinter and colleagues (2014) conducted their research in the Netherlands, where cultural attitudes toward both ASD and sexuality are different from those in the United States and Canada, where much of the ASD and sexuality research has been completed to date.

While research on the after-effects of participating in sexuality research among individuals with ASD is relatively unexplored, a groundbreaking study by Thomas and Kroese (2005) on the impact of participating in a sexuality research study among

adolescents with mild ID may carry positive implications for sexuality research participants with ASD. The findings of Thomas and Kroese's (2005) study helped to debunk previous rumors about individuals with disabilities participating in sexuality research, as the vast majority of both male and female participants did not show any outward signs of embarrassment during the structured interview (74%) and none showed any negative sexual behavior or talk following the interview. While a minority of participants initially showed some signs of embarrassment (11%) and some showed mild embarrassment throughout the interview (14%), everyone completed the interview in full, despite the interviewer offering to stop. Further, the researchers found that 17% of participants appeared to be positively affected by their participation; this was demonstrated by making positive comments about the research study to their teachers and peers. While these findings are promising and hopeful for researchers who plan to conduct sexuality studies with developmentally vulnerable populations, it is important to remember that the participants in Thomas and Kroese's (2005) study had ID, not ASD, and that the findings may not hold true for youth on the autism spectrum. For instance, individuals with ASD may be less able than those with ID to experience or to communicate feelings of embarrassment or distress; further, the ways in which young people with ASD may communicate embarrassment are likely idiosyncratic or subtle, and may not be detected by a researcher who does not know them intimately.

Taken together, the need for self-reported sexuality research among young people with ASD is evident, and provides the best opportunity to learn about multiple facets of sexuality, including the experience of navigating ASD and sexuality simultaneously,



without overly focusing on a single aspect (i.e., behavior), or on deficits. While there are risks that accompany conducting personally sensitive research with any population, emerging research findings suggest that individuals with disabilities are not negatively impacted by participating in sexuality research, when that research is conducted in a sensitive, non-stigmatizing, and person-focused manner. In fact, there even may be some benefits of participating in sexuality research, as some participants may welcome the opportunity to discuss their experiences in a confidential, validating setting.

### **Sexuality, Gender, and Women with ASD**

Currently, males are diagnosed with ASD much more frequently than females, at a rate of nearly five to one (CDC, 2012). As a result, women with ASD constitute a minority group within a minority group. Previous research has identified gender differences in ASD: boys with ASD tend to have higher IQ than girls, while girls with ASD may show greater skills related to communication, attention, and creativity (Nichols et al., 2008). A recent study by Solomon, Miller, Taylor, Hinshaw, and Carter (2012) assessed both autism symptoms and internalizing symptoms (e.g., anxiety, depression) among boys with ASD, girls with ASD, and girls without ASD. In terms of ASD symptoms, the researchers found that girls with ASD were comparable to boys with ASD, and were dissimilar from girls without ASD. As they approached adolescence, girls with ASD were at an increased risk for internalizing symptoms relative to both boys with ASD and girls without ASD. In light of the emerging differences between males and females on the spectrum – especially around communication skills and internalizing symptoms, which can impact greatly interpersonal functioning and in turn, sexual

functioning – one must exhibit caution when generalizing the findings of sexuality studies with mixed gender samples to only females or males with ASD. This underscores the need for more research with female-only ASD samples, in addition to more ASD and sexuality research in general, in order to understand and serve the needs of young women on the spectrum.

While research that focuses exclusively on the sexualities of women with ASD is limited, an overall strength of the current sexuality and ASD literature is the inclusion of female participants in self-report quantitative studies. It is possible that researchers, who were progressive enough to recruit individuals with ASD to self-report on their sexualities, were also cognizant of the overrepresentation of males in previous, other-report studies on disability and sexuality (Gougeon, 2010). However, the inclusion of women with ASD is promising, but insufficient: some self-report quantitative studies included males and females with ASD, as well as males and females with ID, and focused more heavily on differences between diagnostic groups instead of on potential gender differences (e.g., Konstantareas & Lunskey, 1997; Lunskey & Konstantareas, 1998; Mehzabin & Stokes, 2011). It is challenging to distill information specifically about the sexualities of women with ASD in studies with small sample sizes, and in which they are grouped with women with ID, or men with ASD, for analysis. For example, Ousley and Mesibov (1991) found that women with ID and women ( $n = 10$ ) with ASD ( $n = 10$ ) reported comparable levels of sexual experience as their male counterparts, but also that they showed less interest in sexuality and dating than men. While it is unclear as to which group of women (ID versus ASD) was driving this finding, it is interesting nonetheless

and requires careful consideration. It suggests that a mismatch may exist for some women between their level of sexual interest and desire, and their sexual behaviors; the same is likely true for some men, albeit in the opposite direction. If women with disabilities are engaging in more sexual activity than their level of desire and interest in sex would otherwise indicate, then it is important to understand their reasons for doing so, and to provide sociosexual education and empowerment training, as needed. Findings like these underscore the need for additional research, to guide intervention, specifically for women with ASD.

Gilmour and colleagues (2012) were among the only researchers to recruit a large, mixed-gender sample and also to focus on the sexualities of younger women with ASD. They found that young people with ASD (mean age = 28.9 years) were significantly more likely than controls without ASD (mean age = 23.2 years) to report same-sex desire, behavior, and orientation on domains of the *Sell Scale of Sexual Orientation*; this finding was particularly pronounced for women with ASD. To date, there appears to be only one study that has examined the sexualities of women with ASD in a single-sex sample containing women with ASD, their mothers, and controls (Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer, 2007). The results of this study showed that, relative to women without ASD, women with ASD reported significantly lower rates of heterosexuality (67.9% versus 97.3%), and significantly higher rates of bisexuality (13.2% versus 1.6%), and asexuality (17.0% versus 0.0%). Research designs like these, which included large samples of women on the spectrum, are needed not only to learn

more about the bases of these differential findings around sexual orientation, but also to learn more about the sexualities of women with ASD in general.

A surprising finding in Ingudomnukul and colleagues' (2007) study was the high percentage of women with ASD (53.7%), relative to controls without ASD (37.9%), who had identified as a "tomboy" during childhood. While unexplored further in that study, this finding suggested that women with ASD may be less likely to relate to traditional female gender roles, and possibly may be more fluid in their gender identities. This contributed significantly to the decision to include transfeminine women and female-bodied individuals with more fluid gender identities, in addition to cisgender women, and to inquire about gender in an open-ended format in the current study. While anecdotal evidence (e.g., postings in online ASD communities) suggests that women with ASD indeed are more likely to endorse a more fluid gender identity, the construct of gender identity remains relatively unexplored in the empirical ASD and sexuality research to date. Bejerot and Eriksson (2014) attempted to address this gap, and to test Baron-Cohen's (2002) "extreme male brain theory of autism," by measuring gender identity, androgynous behavior in childhood, gender typicality, among other constructs, in an adult sample of Swedish men and women, with and without ASD. Consistent with Ingudomnukul and colleagues' (2007) findings, Bejerot and Eriksson (2014) found that women with ASD, relative to women without ASD, were more likely to have identified as a tomboy when young; further, they found that women with ASD were less likely to have a cisgender identity, but also that both men and women with ASD were comparable to controls without ASD in their ratings of gender typicality. Drawbacks of this study

included a small sample size (50 individuals with ASD and 53 individuals without ASD), and reliance on the gender binary (i.e., participants were asked exclusively about their identification with male and female roles, without the option of being able to identify as other genders). Both Ingudomnukul and colleagues' (2007) and Bejerot and Eriksson's (2014) emerging findings on gender identity among individuals with ASD signaled the importance of assessing gender identity in an open-ended fashion in the current study.

To date, no qualitative study has focused exclusively on sexuality and women with ASD; however, a recent study has provided valuable insight as to what it means to be both a sexual woman and a woman with a disability. Bernert (2011) interviewed 14 women with ID, ranging in age from 18 to 89 years, and three main themes emerged: functioning within disability-centered environments (e.g., day programs, group homes) without having a well-developed disability identity (the majority of participants either denied, or expressed uncertainty around their disability status), having a relatively better-developed adult identity encompassing expectations for sexual autonomy, and experiencing sexual limitations due to protective policies and programs, largely instilled by their families and human service agencies. All of the participants reported experiencing a paradox: each *depended* on family members and/or direct supportive providers in order to be *autonomous*, particularly in regard to forming and maintaining interpersonal and sexual relationships. For example, a participant relied on direct support providers for transportation to visit her partner's apartment, and other participants relied on social spaces, which were organized and maintained by direct support providers, in order to socialize and to meet potential partners. Related to this finding, many

participants felt that their human service agencies were not meeting their needs, and that they wanted more support to expand their social spheres.

A major concern raised in the same study is that women with ID, who often are aware of the systemic and contextual barriers meant to “protect” their sexualities, may engage in unhealthy or unsafe strategies to access their sexualities (e.g., a woman having sex in a shed at her day program because her partner was not allowed to visit her at home). Bernert (2011) also highlighted the vulnerability of women with ID, which is possibly an unfortunate by-product of the increased visibility and inclusion of people with disabilities in mainstream society:

Of concern, community inclusion, increased independence, and elevated visibility resulting from integration can amplify the vulnerability of persons with intellectual disabilities. This increased vulnerability is evident for women...  
(p. 129).

The themes and concerns raised by Bernert’s (2011) sample are largely relevant for women with ASD, who are also more visible in the community than ever before, and who often receive supports – and experience barriers – from family members, friends, partners, and/or direct support providers.

### **Sexual History and Behavior and Individuals with ASD**

Sexual behavior entails a wide range of behaviors and activities with romantic or sexual intent, including but certainly not limited to holding hands, hugging, going on a date, kissing on the mouth, touching one’s genitals or someone else’s, oral sex, vaginal intercourse, and anal intercourse (Wish, McCombs, & Edmonson, 1980). Frequently,

studies on sexuality among ASD samples consider solitary sexual activities (e.g., masturbation, looking at pornography) as well as partnered sexual activities (e.g., Byers, Nichols, Voyer, & Reilly, 2013). Sexual behavior is frequently measured in a checklist format, and for sake of brevity, history and current activities are sometimes assessed simultaneously with the same measure. Also, measures such as the *Sexual Behavior Scale* (Stokes & Kaur, 2005), have been designed specifically to assess sexual history and behaviors with individuals with ASD. In this way, sexual history and behavior are different from other sexuality variables, which are typically measured using scales and questionnaires designed and normed for non-ASD populations. Within the ASD and sexuality literature, sexual history and behavior are relatively well-studied aspects of sexuality.

In studies with other-reported data (e.g., provided by a direct support provider in a residential setting), findings consistently show that the vast majority of individuals with ASD show an interest in sexuality and masturbate, but dramatically fewer show interpersonal or dyadic sexual behaviors (Hellemans et al., 2007; Van Bourgondien et al., 1997). These findings are consistent with those of some self-reported studies, including Mehzabin and Stokes's (2011) study, in which young adults with ASD reported both fewer sexual experience and fewer socio-sexual behaviors relative to young adults without ASD. Relative to individuals with mild to moderate ID, in addition to typical individuals, people with ASD have self-reported lower rates of sexual experience (e.g., Konstantareas & Lunskey, 1997; Ousley & Mesibov, 1991). Gender differences in rates of interpersonal sexual activity have not been observed among adults with ASD (Ousley &

Mesibov, 1991); however, some studies suggest that men with ASD are more likely than women with ASD to masturbate (Byers, Nichols, Voyer, & Reilly, 2013). However, in a number of these studies, variability in sexual experience within the ASD sample was noted; also, the earliest self-reported studies on ASD and sexuality had very small ASD samples (fewer than 30 participants). In a recent study with a large community sample of adults with ASD ( $n = 82$ ) and without ( $n = 282$ ), no differences in sexual experience, as measured by Trotter and Alderson's (2007) *Sexual Experience Questionnaire*, were observed between groups (Gilmour et al., 2012). The current study replicated this method of assessing sexual history and behavior among individuals with and without ASD.

### **Sexual Attraction, Sexual Orientation, and Individuals with ASD**

While initial ASD and sexuality research made the implicit assumption that individuals with disabilities were heterosexual – if sexual at all – increasing research has revealed diversity in sexual orientation among individuals on the spectrum (e.g., Bejerot & Eriksson, 2014; Gilmour et al. 2012). Sexual attraction involves feeling sexual desire toward others, and it is a key aspect of sexual orientation, a multidimensional construct capturing identity, attraction, and behavior in relation to one's own and others' genders (Priebe & Svedin, 2013). "Heterosexual," "bisexual," "gay," and, "asexual," are frequently used labels to describe sexual orientation; however, there are many ways in which people conceptualize their sexual orientations and this is by no means an exhaustive list. While sexual attraction and sexual orientation are related – sexual attraction is a component of sexual orientation, as defined by Priebe and Svedin (2013) and others – they are ultimately different constructs because the genders of the



individuals to which one feels sexually attracted are not necessarily the genders associated with one's sexual orientation (e.g., a woman might identify as gay, and occasionally feel sexually attracted to men). "Sexual minority" is a contemporary term to refer to individuals who have a sexual orientation other than heterosexual.

Although there are an increasing number of online communities for LGB individuals on the spectrum, as well as personal accounts by self-advocates with ASD who identify as LGB (e.g., Daniel Tammet, Wendy Lawson), no empirical study to date has explored exclusively the experiences of sexual minorities on the spectrum. Nonetheless, larger quantitative studies have begun to yield more comprehensive information on the rates of sexual minority status within the ASD population. A recent study compared aspects of sexuality, including sexual knowledge, experiences, and orientation, between adults with ASD living in the community and adults without ASD in the general population (Gilmour et al., 2012). Compared to individuals without ASD, participants on the autism spectrum reported significantly lower levels of heterosexual interest, behavior, and orientation, and significantly higher levels of gay, bisexual, and asexual interest, behavior, and orientation on the *Sell Scale of Sexual Orientation* (Gonsiorek, Sell, & Weinrich, 1995); this was especially pronounced for women with ASD. In spite of these proportionally higher rates of sexual minority status among individuals with ASD, the majority of participants with and without ASD were shown to have heterosexual interests and behaviors. A limitation of Gilmour and colleagues' (2012) study was the lack of distinction between sexual attraction and sexual orientation; the researchers did not appear to ask participants about their sexual orientations in their

own words, and instead used attraction and behavior statistics as a proxy for orientation. This limitation was addressed in the current study by using an open-ended question to ask participants about their sexual orientation, in their own words.

The findings of Gilmour and colleagues (2012) are largely consistent with those of an earlier study, which looked specifically at the sexual orientation of women with ASD, their mothers, and women without ASD (Ingudomnukul et al., 2007). The women with ASD reported relatively high rates of bisexuality and asexuality, at 13.2% and 17%, respectively. These findings around sexual minority status were elevated compared to those of another study, in which sexual orientation was assessed among 32 adults with ID of different etiologies, including two participants with ASD (Bedard, Zhang, and Zucker, 2010). In this study, it was found that a majority of individuals with ID identified as heterosexual (87%), followed by bisexual or questioning (9.7%) and gay (3.2%). The rates of sexual minority status reported by Ingudomnukul and colleagues (2007) and Bedard and colleagues (2010) also were elevated compared to those yielded by recent, mainstream United States studies. For example, recent studies using census data consistently show that between 3 and 4 percent of the mainstream population identifies as gay, lesbian, bisexual, or transgender (Gates, 2012; Gates & Newport, 2013). While preliminary research findings do suggest that proportionally more individuals with ASD than ID identify as sexual minorities, and that proportionally more individuals with ID than individuals without ID identify as sexual minorities, it is important to interpret these findings with caution. Studies on sexual orientation among individuals with ID or ASD are few in number, some are limited by small sample sizes, and as discussed previously,

some confound sexual orientation with other constructs. However, these findings must be regarded nonetheless, and research continued in order to understand and support the sexual orientation of individuals with ASD.

In addition to studying rates of sexual minority status within the ASD and ID populations, research has also explored the attitudes of individuals with ASD toward same-sex sexuality and behaviors. The findings of an early self-report study on the attitudes and beliefs of adults with ID and adults with ASD showed that both groups showed more internalized heterosexism (i.e., judgment of same-sex sexual behaviors) than individuals without ASD or ID (Lunsky & Konstantareas, 1998). For example, only 29 percent of individuals with ASD or ID “approved” of two men kissing compared to the 82 percent of the typical sample; a similar pattern was observed for two women holding hands (74% versus 94%), two men embracing (55% versus 90%), and two women getting married (35% versus 82%). It is important to note that these studies were conducted in the late 1990s, and since then, same-sex marriage has been legalized in a number of states, sexual minorities have been portrayed more frequently and positively in the media, and while there is still much to accomplish, the general public slowly has become more accepting of sexual minorities. This is evidenced by increasing rates of acceptance toward same-sex marriage by U.S. citizens, which rose from 37% in 2003 to 56% as of March 2013 (Washington Post-ABC News). In light of these shifting beliefs, it would be helpful to replicate the research on the attitudes and beliefs of individuals with ASD toward LGB relationships and sexual behavior, to see if these have shifted as well. Along these lines, a recent study by Dewinter and colleagues (2014) showed that

adolescent boys with ASD showed more tolerant attitudes toward same-sex sexual behavior than their peers without ASD. The beliefs and attitudes of individuals with ASD toward sexual minorities are particularly important to understand, in light of the recent findings that suggest that proportionally more individuals with ASD than those without ASD identify as sexual minorities, and that inconsistencies between education, beliefs, and behaviors have been associated with risky sexual behavior in other youth populations (Kirby, Laris, & Roller, 2007).

Gilmour and colleagues (2012) explored a couple of the leading theories that help to explain the heightened rates of same-sex sexual desire, behavior, and orientation that they observed among their participants with ASD. The first theory has to do with desirability effects: individuals with ASD may be more likely to endorse same-sex sexual behaviors and sexual minority status – or, less likely to deny them – than individuals without ASD because of reduced concern about being stigmatized or judged by others on the basis of their responses. The second theory is based on Baron-Cohen's (2002) extreme male brain theory of autism, and has more biological and empirical support. Briefly stated, this theory posits that ASD in both males and females is the result of abnormally high prenatal levels of testosterone, the primary male sex hormone. These heightened testosterone levels, particularly in the brains of females, may account for the higher rates of sexual interest in females reported by women with ASD (Gilmour et al., 2012; Ingudomnukul et al., 2007). More research on ASD and sexual orientation is needed, including epidemiological studies with large community samples, as well as

neurobiological studies to identify the mechanism through which ASD and sexual minority status, particularly in women, may be linked.

### **Sexual Interest and Desire and Individuals with ASD**

Sexual interest and desire are relatively well-represented constructs in the ASD and sexuality literature; in fact, they were among the main outcomes of interest in the first self-report sexuality study of its kind among individuals with ASD (Ousley & Mesibov, 1991). In comparing groups of adults with ASD and ID, males in each diagnostic category reported greater sexual interest than the corresponding females. Overall, however, male and female participants with ID reported only marginally higher rates of sexual interest than males and females with ASD; this served as emerging evidence to debunk the myth that people with disabilities, and particularly those with ASD, are not interested in sexual activity with others. The authors also measured sexual experience and found that participants with ID reported significantly more sexual experience than individuals with ASD; they suggested that the mismatch between sexual interest and sexual experience could be a source of frustration and feelings of isolation for individuals with ASD. Research using similar quantitative methods to study the experiences of individuals with ID or ASD from a range of ages (16-46 years old) yielded consistent findings: no significant differences in sexual desire were observed between the ID and ASD groups (Konstantareas & Lunskey, 1997). These researchers also assessed the sexual knowledge of participants with ASD, and found that sexual interest was positively correlated with both sexual knowledge and sexual experience. It is important to note that

their study design was correlational, not experimental, and their findings did not support the notion that increased sexual knowledge *causes* increased sexual desire and behavior.

A limitation of these early studies on sexual interest and desire among individuals with ASD was the lack of a non-ASD comparison sample. While studies by Ousley and Mesibov (1991) and by Konstantareas and Lunskey (1997) demonstrated that individuals with ASD showed sexual desire and interest, the findings of these studies could not speak to any differences between people with and without ASD. More recent research with an ASD sample and a comparable non-ASD sample showed that adults with ASD reported similar numbers of sexual experiences as adults without ASD, and that strong correlations between sexual desire and sexual experience occurred within each group (Gilmour et al., 2012). Further, Gilmour and colleagues (2012) found that individuals with and without ASD reported comparable rates of “breadth of sexuality” (number of sexual partners and desired number of sexual partners) and of “strength of sexuality” (frequency of sexual behaviors and strength of sexual interest). Also, recent research without a non-ASD comparison sample has demonstrated clearly that adults with ASD experience sexual desire (Byers, Nichols, & Voyer, 2013; Byers, Nichols, Voyer, & Reilly, 2013).

Beyond the peer-reviewed literature, author Sarah Hendrickx conducted mixed-methods research on ASD and sexuality, which she published in *Love, Sex, and Long-Term Relationships: What People with Asperger Syndrome Really Want*. Hendrickx (2008) used the Internet to recruit 36 adult men with ASD, 4 adult women with ASD, and 27 adult women without ASD, who either currently or previously had a partner with

ASD. The vast majority of participants identified as heterosexual. Hendrickx found a great deal of variation in the extent to which males and females with ASD experienced sexual desire and how they explored it. To different degrees, participants with ASD endorsed engaging in the following activities: watching pornography, masturbating, fantasizing, calling phone sex hotlines, soliciting sex workers, and engaging in partnered sexual activity, including partners with and without ASD. Consistent with Gilmour and colleagues' (2012) findings, a minority of participants reported being asexual and having very little to no interest in sexuality, either by themselves or with others. This minority previously has been magnified, distorted, and overrepresented in sexuality and disability literature (Gougeon, 2010). Overall, while Hendrickx's (2008) qualitative findings shed light on an underrepresented aspect of disability and sexuality research, and did so through less frequently utilized methodology, it is important to interpret them with caution, as she completed her study without IRB involvement or approval, and did not discuss the threats to validity and reliability of her work. Of note, Hendrickx's (2008) findings, which suggested great variability in sexual desire among individuals with ASD, and significant dissimilarity from adults without ASD, were inconsistent with Gilmour and colleagues' (2012) findings. In light of the mixed literature on sexual desire among individuals on the autism spectrum, continued research is needed.

### **Sex Education and Individuals with ASD**

The idea that individuals with ASD of all ages have sex education needs is widely acknowledged and undisputed (e.g., Koller, 2000; Nichols & Blakeley-Smith, 2009; Sullivan & Caterino, 2008). However, this is more easily stated than implemented. While

recent studies have demonstrated that individuals with ASD benefit from sexuality education and intervention, including Social Stories to teach sexuality topics (Tarnai & Wolfe, 2008) and narrative therapy for sexual trauma victims with ASD (Van Najnatten & Heestermans, 2012), disagreement exists around how and when information about sexuality should be presented to individuals on the autism spectrum, and who should provide it (Ballan, 2012). These concerns exist alongside well-documented apprehensions by parents and teachers around addressing sexuality with young people with ASD (Ballan, 2012; Kalyva, 2010; Nichols & Blakeley-Smith, 2009). For example, a mother in Ballan's (2012) study articulated a concern, likely shared by other parents of children with ASD, around teaching her son about sexuality and human anatomy:

What if I tell my son it is a penis and for the next 10 months, his fascination is with his penis instead of a computer game or train? What if he talks about his penis all day and to everyone he meets? (p. 680).

Similarly, many parents who participated in Ballan's (2012) qualitative study expressed concern that their children would engage in masturbation as a repetitive behavior, in place of their current behaviors, such as hand flapping. These are valid concerns, and unfortunately, not enough research exists to date around sexuality education outcomes for individuals with ASD to allay these fears.

The lack of exposure to appropriate sex education for women on the autism spectrum is compounded by "peer voids" (Nichols et al., 2008), or the lack of opportunity to glean information about sexuality and relationships from same-age friends. Overall, the gaps in sexuality education for young people with ASD is truly unfortunate, as sex



education has been associated with many healthful outcomes among young women without ASD, including decreased vulnerability for sexual victimization (Rowe, Jouriles, McDonald, Platt, & Gomez, 2012), and delayed onset of partnered sexual activity and increased practice of safe sex (Lindberg & Maddow-Zimet, 2012). Henault (2005) and others posit that lacking sex education for women with ASD may contribute to less positive sexuality outcomes, such as increased vulnerability to unfavorable sexual encounters, and decreased satisfaction with one's sexual identity, which are sometimes observed in women with ASD.

Findings around levels of sexual knowledge, a measurable outcome of sex education exposure, among individuals with ASD are mixed: earlier self-report studies suggested that individuals with ASD may lack exposure to sex education and age-appropriate sexual knowledge (e.g., Konstantareas & Lunsky, 1997; Ousley & Mesibov, 1991), while some more recent studies have suggested that people on the autism spectrum have comparable levels of sexual privacy knowledge (Mehzabin & Stokes, 2011) and sexual vocabulary knowledge (Gilmour et al., 2012) as peers without ASD. However, another recent study, conducted by Brown-Lavoie, Viecili, and Weiss (2014), showed that adults (19-43 years old) with ASD had significantly lower *perceived* sexual knowledge, as well as *actual* sexual knowledge, relative to age-matched controls without ASD. The findings of this study also suggested that individuals with ASD have comparable numbers of overall sources of sexual knowledge as their non-spectrum peers, but fewer numbers of social sources, such as parents, friends, or peers (Brown-Lavoie et al., 2014; Mehzabin & Stokes, 2011). In Brown-Lavoie and colleagues' (2014) study, the

Internet was the most frequently cited source of sexuality knowledge among individuals with ASD (57%), followed by educational brochures (40%), magazines (36%), television and radio (30%), teachers (26%), peers (21%), romantic partners (14%), support workers (13%), pornography (12%), parents (11%), and religious figures (5%). These findings corroborated Nichols and colleagues' (2008) hypothesis, which suggested that individuals with ASD – particularly women – are more likely to experience “peer voids,” and in turn, have fewer social opportunities for learning about sexual matters.

Sexuality and disability researchers and educators continually state the necessity of sexuality education for people with ASD not only to prevent against negative outcomes (i.e., victimization), but also to enhance and promote healthy development (Nichols & Blakeley-Smith, 2009). In the only self-report study to date that has examined sexual victimization among individuals with ASD, the increased risk of victimization associated with being on the autism spectrum was partially mediated by actual (as opposed to perceived) sexual knowledge. Indeed, appropriate and accessible sex education is critical to provide to all individuals with ASD. To this end, several manuals have been published over the past 10 years to guide professionals in imparting this knowledge. These include Henault's (2005) *Asperger's Syndrome and Sexuality: From Adolescence Through Adulthood*, and Davies and Dubie's (2012) *Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges*. Additionally, Hatton and Tector (2010) conducted a qualitative study with four adults with ASD to guide their development of a new sex education curriculum for young people on the

autism spectrum; they concluded that the topics of “clean and dirty,” touch and personal safety, “public and private,” health, masturbation, menstruation, relationships of different kinds, relationships that might include sex, and sense of self were essential to include. It is evident that resourceful, research-informed guides for teaching sexuality information to students with ASD exist. However, the aforementioned intervention programs focus specifically on the education needs of individuals on the autism spectrum with average intelligence or higher, and they have not been empirically validated. It remains unclear how, and to whom, these programs are being delivered. An important goal of the current study was to assess the sources of sexuality education that young women with ASD have at their disposal and their level of satisfaction with these sources. It is hoped that current findings will lay the groundwork for the development of a new sexuality education intervention program for women and female-bodied individuals with ASD, which could be tested and validated through a future randomized controlled study.

### **Sexual Satisfaction and Individuals with ASD**

While many authors interested in the sexualities of individuals with ASD have commented on sexual satisfaction and dissatisfaction within this population (e.g., Henault, 2005; Lawson, 2005; Newport & Newport, 2002), few studies to date have gathered empirical, self-reported data on sexual functioning and satisfaction from individuals with ASD. For her book, Hendrickx (2008) collected qualitative and quantitative data from adults with ASD, and from adults without ASD but who had romantic and sexual partners with ASD. She found that while the majority of the participants with ASD were interested in sex, many reported facing multiple barriers to

having the kind of sex lives they desired. Other resources for individuals on the autism spectrum and their partners have reported that up to 50 percent of relationships in which one partner has ASD and the other does not are not sexual (Aston, 2003). Related to this finding, Hendrickx (2008) found that 60 percent of her participants were dissatisfied with their sex lives, and that those participants in relationships often experienced significantly more or significantly less sexual desire than their partners. These findings suggest that individuals with ASD may be at heightened risk for sexual dissatisfaction, including those in sexual relationships, and that research is necessary in order to identify ways to remediate this risk.

Byers and Nichols (2014) and Byers, Nichols, Voyer, and Reilly (2013) constitute the only research teams to date that have collected and reported empirical data on sexual satisfaction among adults with ASD, as opposed to citing anecdotal evidence, or measuring other sexuality constructs, such as sexual behavior and sexual desire, and then drawing conclusions based on discrepancies observed between these variables. To measure sexual satisfaction within their ASD sample, Byers, Nichols, Voyer, and Reilly (2013) used the brief *Global Measure of Sexual Satisfaction* (Lawrance et al., 2011). Sexual satisfaction was found to be positively associated with being in a romantic relationship, and negatively associated with level of ASD symptoms. Sexual satisfaction was found to be a predictor of overall sexual well-being for individuals on the spectrum. Also, men reported greater sexual satisfaction than did women in this study, although in Byers and Nichols' (2014) follow-up study, few gender differences were observed across different domains of sexual satisfaction. A drawback of the fine work of the Byers

research team is the absence of a non-ASD control sample, which could have shed light on how sexual satisfaction, among many other sexuality variables, may differ between people with and without ASD. The current study took a similarly holistic approach to human sexuality, and included a brief, multidimensional self-report measure of sexual satisfaction and dissatisfaction (i.e., respecting that the absence of satisfaction does not indicate dissatisfaction, and vice versa).

### **Sexual Victimization and Individuals with ASD**

Many authors and researchers are sensitive to the vulnerability of individuals with ASD to sexual victimization, largely due to the communication and social interaction deficits that characterize ASD (Henault, 2005; Nichols et al., 2008). This vulnerability is present for individuals with other disabilities too; in fact, research on sexual victimization is even more developed for ID populations than it is for ASD populations (e.g., Burke, Bedard, & Ludwig, 1998; Senn, 1988; Sobsey, 1988). The risk of sexual abuse is a serious matter for young people with ASD, because social isolation can make individuals even more vulnerable to sexual abuse, and communicative impairments and limited sexuality education or knowledge may cause them to be less likely to recognize it as abuse, to report it, and to be taken seriously by others when it does occur (Nichols et al., 2008). What is currently known about sexual victimization and the ASD community is largely informed by studies with child ASD samples: a recent study reported the rate of sexual abuse to be as high as 16.6% percent for youth on the spectrum (Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin 2005), which is significantly higher than the reported rate of 9% for children without ASD (U.S. Department of Health and Human Services,

2011). Further, these statistics are likely underestimates of the true prevalence of sexual victimization within the ASD population. Within non-spectrum samples, girls are significantly more likely to be sexually abused than boys (Finkelhor, Hotaling, Lewis, & Smith, 1990), and childhood sexual abuse is associated with a high risk of revictimization in late adolescence and young adulthood, among other negative sexuality outcomes (Lalor & McElvaney, 2010). These are very serious issues, and it is unclear whether these patterns also hold true for females with ASD.

Due to the unique symptoms of ASD, a “gray area” exists around sexual victimization: authors such as Henault (2005) have noted that some women with ASD have multiple sexual partners in the absence of monogamous or committed relationships. While this may be desired and sought out by some women, and by itself certainly does not constitute sexual victimization or exploitation, it may reflect different sexual preferences and choices, or it may reflect a lack of communicative or interpersonal effectiveness skills. This idea is supported by the findings of existing studies that hint at the possibility of sexual victimization among women with ASD, pointing to mismatches in their reported levels of sexual desire and interest, and their reported levels of sexual behavior (Ousley & Mesibov, 1991).

A recent study by Brown-Lavoie and colleagues (2014) is the only self-report study to date on sexual victimization among adults with ASD. Adults on the autism spectrum reported significantly higher rates of sexual victimization, including unwanted sexual contact, sexual coercion, and rape, than the adults in the non-spectrum comparison sample. More than three-quarters (78%) of the ASD sample in this study reported at least

one lifetime instance of sexual victimization, compared to 47% of controls; further, individuals with ASD were almost 3 times more likely to report unwanted sexual contact, 2.7 times more likely to report sexual coercion, and 2.4 times more likely to report having been raped (Brown-Lavoie et al., 2014). In terms of gender, both men and women on the spectrum reported comparable rates of sexual victimization, although significant differences were observed between men with and without ASD, and women with ASD and without ASD. These groundbreaking findings provide empirical support to a critical issue within the ASD community. It is important for educators, therapists, and other professionals who support individuals with ASD to be aware of this issue, as well as the warning signs of sexual victimization. The current study contributes to the literature not only by replicating these findings in a unique sample, including women with and without ASD, but also by examining the relations between sexual victimization and other aspects of sexuality.

### **Sexual Awareness and Individuals with ASD**

To our knowledge, the construct of sexual awareness, defined as the tendencies to think and reflect about the nature of one's sexuality, to be aware of the sexual impression one makes on others, to think about sex often, and to be assertive in the sexual aspects of one's life (Snell, Fisher, & Miller, 1991), has not been studied directly within an ASD sample. In the most recently published self-reported ASD and sexuality studies, however, Byers, Nichols, and Voyer (2013), and Byers, Nichols, Voyer, and Reilly (2013) examined sexual anxiety and sexual cognitions, which share some conceptual similarity with sexual awareness. Specifically, Byers, Nichols, and Voyer (2013) studied sexual

arousability and anxiety simultaneously in their study of single adults with ASD. Participants were asked to rate a series of sexual situations (e.g., “When you have intercourse with a partner”) in terms of both how arousing and how anxiety-producing they would find the situation to be. They also assessed internal beliefs about sexuality with the *Sexual Cognitions Checklist* (Renaud & Byers, 2011). In this questionnaire, participants were asked to rate how often they considered different sexual situations as being positive (e.g., “Having sex with an anonymous stranger”). Byers, Nichols, Voyer, and Reilly (2013) examined these constructs in their related study of sexuality among adults with ASD who have significant relationship experience. Across the ASD samples (single adults, and adults with relationship experience), sexual anxiety was negatively correlated with sexual desire and frequency of sexual behaviors, and positively correlated with level of ASD symptoms and sexual problems. Positive sexual cognitions were strongly positively correlated with levels of sexual desire and frequency of sexual behaviors, but unrelated to participants’ age, relationship status, or level of ASD symptoms. Interestingly, among participants with relationship experience, men with ASD were more likely than women with ASD to endorse positive sexual cognitions (Byers, Nichols, Voyer, & Reilly, 2013). This suggests that variability exists among individuals with ASD in regard to their anxieties and cognitions around sexuality.

In light of Byers, Nichols, Voyer, and Reilly’s (2013) findings, as well as previous studies that suggest that people with ASD may have less relationship experience and sexual experience relative to individuals with ID and without disabilities (e.g., Ousley & Mesibov, 1991), but significantly higher levels of anxiety symptoms (e.g., Lai



et al., 2011), it is likely that individuals with ASD – especially women – may be susceptible to feeling uneasy around matters of sexuality. Further, limitations around perceiving others' thoughts and emotional experiences (i.e., theory of mind) can contribute to missed opportunities for relationships, as well as uneasiness around connecting with others on a sexual level (Henault, 2005). These feelings may relate to how people with ASD view themselves sexually, and how they think about sexuality in general. In addition to sexual anxiety and sexual cognitions, Byers, Nichols, Voyer, and Reilly (2013) examined sexual self-esteem, another construct similar to sexual awareness, using the self-esteem subscale of the *Sexuality Scale* (Snell & Papini, 1989). This brief scale assesses the extent to which individuals view themselves positively as a sexual partner. While sexual self-esteem was found to be positively associated with relationship status (individuals with ASD currently in romantic relationships reported higher levels of sexual self-esteem than single individuals with ASD) and negatively correlated with level of ASD symptoms, it correlated only weakly with other sexuality-related variables (Byers, Nichols, Voyer, & Reilly, 2013). This interesting finding suggests that sexual self-concept may function independently from sexual performance and satisfaction, and may function differently for individuals on the autism spectrum than for individuals without ASD.

Overall, the current study was informed by, and expanded upon the existing work of the Byers research team around internal experiences related to sexuality. Instead of examining positive cognitions, attitudes and beliefs, or sexual self-awareness, however, the current study focused on the construct of sexual awareness, in an attempt to be

relatively more objective, and to contain less value judgment on sexuality topics. The construct of sexual awareness has more to do with exactly that – awareness – than it has to do with assessment or self-judgment. The inclusion of sexual awareness represents a significant contribution of the current study to the existing literature.

### **Internalizing Symptoms and Individuals with ASD**

The concept of “internalizing” symptoms, as opposed to “externalizing” symptoms, was presented initially by Thomas Achenbach in 1966 as a way of further classifying psychiatric symptoms in children. Since then, internalizing symptoms have been widely studied across clinically and culturally diverse populations, including individuals of all ages with ASD. Internalizing symptoms are characterized by self-directed, internal states, and include many symptom clusters, including depression, anxiety, and anxiety-related symptoms (e.g., somatic symptoms, trauma-related symptoms, obsessions, compulsions). In the current study, participants’ levels of depression, anxiety, and social anxiety, and their relations with sexuality outcomes, were of particular interest.

Consistently, individuals with ASD of all ages have been shown to have clinical levels of internalizing symptoms, and more symptomatology than individuals without ASD (e.g., Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Simonoff et al., 2008). Also, in the typical population, females are more likely to have internalizing symptoms than males, a pattern that emerges during adolescence and persists through adulthood (e.g., Nolen-Hoeksema, 1990). Solomon et al. (2012) hypothesized that girls and female adolescents with ASD might be at heightened risk for internalizing symptoms, in light of

the observed vulnerabilities of individuals with ASD, relative to individuals without ASD, and females, relative to males, to develop these symptoms. To this end, they assessed both autism symptoms and internalizing symptoms among boys with ASD, girls with ASD, and girls without ASD. In terms of ASD symptoms, the researchers found that girls with ASD were comparable to boys with ASD, and were dissimilar from girls without ASD. As they approached adolescence, girls with ASD were at an increased risk for internalizing symptoms relative to both boys with ASD and girls without ASD. However, Lai et al. (2011) pointed out that many studies on gender differences in ASD presentation, including internalizing symptoms, did not match male and female participants with ASD on the basis of age or IQ, a significant limitation. Lai et al. (2011) sought to address this shortcoming by testing a wide range of symptoms in an age- and IQ-matched sample of 83 men and women with ASD, with average intelligence or higher. The majority of participants reported very high levels of anxiety, depressive, and obsessive-compulsive symptoms; however, no significant differences in symptomatology were observed between men and women. Exploring gender differences in ASD is not an aim of the current study, in light of the women's focus; however, Lai et al.'s (2011) findings suggested that high levels of internalizing symptoms would be observed within the current sample.

In regard to depression specifically, relatively few studies have examined self-reported depressive symptoms among adolescents, young adults, and adults with ASD and average intelligence or higher. Instead, the literature appears to focus on parent-reported depressive symptoms of their children and adolescents with ASD (e.g., Brereton,

Tonge, & Einfeld, 2006; Kim et al., 2000; Simonoff et al., 2008). To date, no self-report questionnaire or screening instrument exists to measure depressive symptoms, such as a pervasive feeling of unhappiness, loss of interest in activities, and eating and sleeping difficulties, specifically in individuals with ASD. In the absence of such a measure, there is some precedent for using self-report depression questionnaires validated with individuals with learning disabilities, as well as with individuals without ID, among individuals with ASD, with average intelligence or higher (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). The main drawbacks of using questionnaires designed for non-spectrum individuals with an ASD sample is that some features of ASD may mask the symptoms of depression, including appetite/feeding changes, sleep changes, decreased interest in activities, and psychomotor retardation (Stewart et al., 2006); moreover, individuals with ASD may have difficulty interpreting and responding to questions about their subjective states and internal experiences. However, in the current absence of self-report questionnaires specifically for individuals with ASD, the use of measures validated with typical, non-spectrum samples is an acceptable practice.

In addition to depression, anxiety is frequently observed among young people with ASD. Anxiety is characterized by behavioral symptoms (e.g., avoiding situations and people that are likely to cause uneasiness or worry), cognitive symptoms (e.g., worry), and somatic symptoms (e.g., increased heart rate, stomachaches, headaches). 1961), falling most frequently in the “moderate anxiety” range. 2008). Similar to assessing depression, no self-report measure exists yet to measure the anxiety symptoms specifically of individuals with ASD. However, as is the case with measuring depression,

there is precedence for using anxiety questionnaires developed for non-spectrum populations, such as the *Beck Anxiety Inventory* (Beck et al., 1961). In fact, anxiety symptoms are so frequently observed in individuals with ASD that Kerns and Kendall (2013) reviewed the existing ASD and anxiety literature to help determine whether anxiety disorders should be considered as comorbid or co-occurring with ASD, or actually a core element of ASD. While they do not offer a definitive answer on the matter, they do note that individuals with ASD more frequently show “atypical” anxiety symptoms (e.g., restrictive and repetitive behaviors that may overlap with symptoms of Obsessive-Compulsive Disorder, or OCD) that are less frequently observed among individuals without ASD.

In Lai et al.’s (2011) community sample of adults with ASD, the majority of participants (63.6% of males, and 72.4% of females) reported clinically significant levels of anxiety symptoms on the *Beck Anxiety Inventory* (Beck, Ward, Mendelson, Mock, & Erbaugh, 1971). There is some evidence that individuals with ASD without ID, compared to individuals with ASD with ID, may be more susceptible to anxiety symptoms, potentially by way of their verbal skills and adaptive behavior; in other words, some symptoms of anxiety require verbal skills and some degree of behavioral autonomy (Sukhodolsky et al., 2008).

Anxiety symptoms also have been studied qualitatively among individuals with ASD. For example, Trembath, Germano, Johanson, and Dissanayake (2012) conducted focus groups with young adults with ASD (9 men, 2 women), from which three themes emerged: sources or triggers of anxiety, experiences or consequences of anxiety, and

strategies for coping with anxiety. Although this study did not explore anxiety in regard to romantic relationships or sexuality, one male participant did endorse engaging in risky behavior to curb his anxiety, particularly in social situations:

I feel anxious. Like at parties, I feel very uncomfortable, so I have to drink lots of alcohol. I also tried marijuana because someone gave it to me as a birthday present and that actually reduced my anxiety, but it is illegal and, also, I don't have access to it anymore so, yeah, but that's not in Australia. (p. 221).

This quote illuminates the at-risk nature of the young adult ASD population; the findings of Trembath and colleagues (2012) warrant the need to assess for other potentially risky behaviors, including sexual ones, in relation to anxiety among young people on the spectrum.

Researchers have noted some of the shared behavioral symptomatology of ASD and social anxiety disorder, a specific type of anxiety disorder that specifically involves fear of social situations, interacting with others, and negative evaluations by others (White, Bray, & Ollendick, 2012). Recent studies suggest that about one-half of children and adolescents with ASD, with average intelligence or higher, show clinically significant levels of social anxiety symptoms (Kuusikko et al., 2008; Bellini, 2004). Within non-ASD samples, social anxiety symptoms have been associated with poorer sexuality outcomes, including reduced sexual satisfaction in relationships, reduced sexual pleasure, reduced feelings of connectedness during sexual activity, and, for women, frequency of sexual activity (Kashdan et al., 2011; Montesi et al., 2013). However, no

study to date has examined the relation specifically between social anxiety symptoms and sexuality outcomes among individuals with ASD.

In addition to social anxiety symptoms, depression and anxiety symptoms have been studied in relation to sexuality outcomes. For example, a bidirectional relation has been observed between depressive symptoms and sexual functioning: depressive symptoms appear to predict problems with sexual functioning, and problems with sexual functioning appear to predict negative feelings about oneself and other depressive symptoms (Atlantis & Sullivan, 2012). The research findings on anxiety and sexuality are a bit more mixed: while some studies suggest that anxiety may either increase women's sexual arousal or not impact it at all (e.g., Palace & Gorzalka, 1990), other studies with clinical samples (e.g., women with panic disorder and women with OCD) show that women with anxiety disorders are more likely than women without anxiety disorders to report low sexual desire and decreased frequency of sexual contact (Van Minnen & Kampman, 2000). Until recently, research on internalizing symptoms and sexuality was exclusively limited to non-spectrum populations; however, Byers, Nichols, Voyer, and Reilly (2013) measured anxiety and depressive symptoms among their sample of single adults with ASD. Surprisingly, they did not observe high rates of internalizing symptoms within their sample, and found that these symptoms were similarly low across adults with significant relationship and sexual experience and those without it. The current study contributes to the existing literature by measuring depression, anxiety, and social anxiety symptoms among young women with and without ASD; additionally, the current study

sheds light on relations between internalizing symptoms and multiple dimensions of sexuality, and whether these relations differ for women with and without ASD.

### **Sensory Symptoms and Individuals with ASD**

Sensory symptoms, including hypersensitivity and hyposensitivity to sight, smell, touch, hearing, and taste, and special sensory interests, are widely documented among people of all ages with ASD, particularly children (Kientz & Dunn, 1996; Leekam, Nieto, Libby, Wing, & Gould, 2007). There is emerging evidence that hyposensitivity to sensory stimuli is most frequently observed in individuals with ASD, followed by hypersensitivity and special sensory interests, or sensory-seeking behavior (Ben-Sasson et al., 2009). While prevalent, empirical research around sensory symptoms within the ASD population was limited for a period of time; in fact, it was only with the publication of the *DSM-V* (APA, 2013) that sensory symptoms were upgraded to a diagnostic sub-criterion under restricted and repetitive behaviors and interests as opposed to an associated characteristic (but not a diagnostic criterion), as they were characterized in the *DSM-IV-TR* (APA, 2000). Level of cognitive functioning appears to be a confound when comparing sensory symptoms between individuals with ASD and other populations: children on the autism spectrum who have average intelligence or higher have been shown to have markedly more sensory symptoms than children with similar IQs, without ASD, although these differences are much smaller between children with ASD and ID, and children with ID, without ASD (Freeman et al., 1981). In addition to level of cognitive functioning, age also may play a role in the presentation of sensory symptoms among individuals with ASD: Leekam et al. (2007) found that younger individuals with



ASD, and individuals with ASD and ID were more likely to show oral and visual sensitivities than older individuals with ASD, and individuals with ASD with average intelligence or higher. These findings suggested that it would be very likely that participants in the current study would report heightened sensory symptoms; this was further supported by a recent finding that adult women with ASD reported greater lifetime sensory symptoms relative to adult men with ASD (Lai et al., 2011). However, to our knowledge, no study to date has examined the relation between sensory symptoms and sexuality outcomes within either ASD or non-spectrum samples; this is an additional contribution of the current study to the literature. As suggested by authors with ASD interests (e.g., Nichols et al., 2008), it is hypothesized that sensory symptoms will moderate the relation between ASD, both in terms of symptoms and diagnostic status, and sexuality outcomes.

## CHAPTER 2

### CURRENT STUDY

#### **Specific Aims**

**Specific Aim 1: To describe the experiences of women with ASD across multiple aspects of sexuality.** Consistent with previous studies on self-reported sexuality among adults with ASD, the current study takes a broad approach to considering sexuality. A battery of questionnaires was used to assess different aspects of sexuality, including history, orientation, desire, exposure to sexual education, behavior, satisfaction, victimization, and awareness, in a quantitative manner. Data were collected exclusively online, consistent with the recent studies on self-reported sexuality among adults with ASD (e.g., Byers, Nichols, & Voyer, 2013; Byers, Nichols, Voyer, & Reilly, 2013; Gilmour et al., 2012). It was anticipated that women with ASD would report a wide range of sexual identities and experiences.

**Specific Aim 2: To identify potential differences in aspects of sexuality between women with and without ASD.** In addition to exploring how young women with ASD describe their sexualities, another main goal of the current study was to compare the experiences of women with and without an autism spectrum identity. A

comparison sample of women without ASD was recruited for the current study. The following hypotheses were tested:

***Hypothesis 1.*** Women with ASD will be more likely than women without ASD to identify as sexual minorities.

***Hypothesis 2.*** Women with ASD will report comparable rates of sexual desire as women without ASD.

***Hypothesis 3.*** Women with ASD will report less exposure to sexual education, and less satisfaction with sexual education received, relative to those without ASD.

***Hypothesis 4.*** Women with ASD will report less sexual behavior than women without ASD.

***Hypothesis 5.*** Women with ASD will report lower rates of sexual satisfaction than individuals without ASD.

***Hypothesis 6.*** Women with ASD will report higher rates of sexual victimization, relative to women without ASD.

***Hypothesis 7.*** Women with ASD will report lower rates of sexual awareness, including sexual consciousness and sexual monitoring, relative to women without ASD.

**Specific Aim 3: To understand how sexuality-related variables are associated with each other, and with key demographic variables, ASD symptoms, internalizing symptoms, and sensory symptoms.** A main goal of the current study was to understand the correlates of sexuality for young women with and without ASD. To this end, correlational and other comparative analyses were performed to test the relations among sexuality-related variables, demographic variables, ASD symptoms, internalizing

symptoms, and sensory symptoms; these were conducted separately for the ASD and non-ASD groups, then compared. Also, to determine whether the sexuality-related variables could be condensed into meaningful sexuality factors, exploratory factor analyses were performed within groups, then compared.

**Specific Aim 4: To explore whether internalizing symptoms and sensory symptoms moderate the relation between ASD symptoms and aspects of sexuality for women with ASD.** Internalizing symptoms, including anxiety and depression, are frequently present in adolescents and adults with ASD (e.g., Lai et al., 2011). Females with ASD, relative to males with ASD and females without ASD, are at increased risk of internalizing symptoms during adolescence (Solomon et al., 2012); this vulnerability may persist into young adulthood. While sexuality research among typical populations has shown that internalizing symptoms can negatively impact sexual functioning, and vice versa (Atlantis & Sullivan, 2012), the relation between internalizing symptoms and sexuality is not yet well-understood for individuals with ASD. The final goal of the current study was to use structural equation modeling to test whether ASD symptoms interacted with internalizing symptoms or sensory symptoms to predict sexuality outcomes. The sexuality outcomes, as identified in tests of Specific Aim 3, were “global sexuality,” a factor pulling from sexual desire, behavior, consciousness, and monitoring variables, and sexual satisfaction. The following hypotheses were tested:

***Hypothesis 8.*** Internalizing symptoms will moderate the relation between ASD symptoms and sexuality outcomes.

***Hypothesis 9.*** Sensory symptoms will moderate the relation between ASD symptoms and sexuality outcomes.

## CHAPTER 3

### RESEARCH DESIGN AND METHODS

#### **Design**

The current study used survey and cross-sectional methodologies. While the vast majority of the data collected were quantitative, the battery included several open-ended, qualitative items. Data were collected exclusively through online, self-report questionnaires; the battery was hosted by PsychData, a secure electronic website.

#### **Participants**

**Inclusion criteria.** Individuals were eligible to participate in the study if they met the following inclusion criteria: (1) identified as a woman, or reported a more fluid gender identity (including, but not limited to agender, transgender, genderqueer, and non-binary); (2) were between the ages of 18 and 30, inclusive; (3) English language proficiency, as the survey was offered in English only; and (4) computer access and literacy, as the survey was offered online exclusively. Several screening items, which appeared before the informed consent form (see Appendix A), were included in the

online battery to redirect individuals who did not meet the age and gender inclusion criteria.

In addition to meeting the inclusion criteria described above, all participants were required to complete a 5-item “quiz” after reviewing the informed consent form, before proceeding with the online battery. These items followed a true-or-false format, and were related to information contained in the informed consent form (e.g., “This survey contains direct questions about different aspects of sexuality.”) The informed consent quiz is included in Appendix B. Virtually every participant scored at least 60% on the quiz, with the vast majority of participants (99%) answering all of the items correctly.

In addition to the informed consent quiz items, participants also were asked to complete five attentional items throughout the battery. These were very simple prompts (e.g., “Type the word RED in the box,”) and their purpose was to assess participants’ level of attention and awareness of the instructions contained in the battery. The overwhelming majority (99%) of participants retained for analyses ( $N = 427$ ) completed each of these items in a satisfactory manner. No participant was removed from analyses solely on the basis of performance on these attentional items.

**Subgroup criteria.** To be included in the ASD group, participants needed to meet the following criteria: (1) score of seven (clinical cutoff) or higher on the *Autism-Spectrum Quotient* (AQ-10, Allison, Auyeung, & Baron-Cohen, 2012); and (2) self-identify as having ASD. For this study, a formal diagnosis was not required for inclusion in the ASD subgroup. This was an intentional decision to account for the fact that individuals, particularly women, with mild forms of ASD are underdiagnosed, that a

diagnostic evaluation requires financial resources (e.g., medical insurance, disposable income) that not everyone may have, and that one does not need a formal diagnosis to identify as having ASD, or to experience the impact of ASD symptomatology, for better or worse, on aspects of daily life. Overall, 248 individuals comprised the ASD group.

To be included in the comparison sample, participants needed to meet the following criteria: (1) score of six or below (below clinical cutoff) on the AQ-10; (2) not have a formal diagnosis of ASD; and (3) not self-identify as having ASD. Overall, 179 individuals comprised the comparison group.

**Participant characteristics.** Table 1 presents the key demographic characteristics of the ASD and comparison groups.

Table 1

*Demographics of ASD (n = 248) and Comparison Groups (n = 179)*

<u>Variable</u>	<u>ASD Group</u>	<u>Comparison Group</u>
Age*	23.2 years ( <i>SD</i> = 3.7)	21.8 years ( <i>SD</i> = 3.5)
Racial identity		
White	89%	81%
Black	0%	1%
Asian	2%	4%
Latino/a	2%	3%
Multiracial	5%	8%
Indigenous	1%	1%
Other	1%	1%



Nationality\*

United States (native born)	56%	76%
United States (immigrant)	4%	2%
Canada	10%	6%
United Kingdom	11%	5%
Australia/New Zealand	4%	3%
Other (European)	14%	6%
Other (non-European)	1%	4%

Student status\*

Full-time	42%	60%
Part-time	13%	6%
Not a student	45%	35%

Employment status\*

Full-time	15%	24%
Part-time	23%	30%
Not employed	61%	46%

Neither student nor employed*	24%	12%
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Household income

< \$5,000	11%	10%
\$5,001 – \$10,000	9%	4%
\$10,001 – \$20,000	11%	11%
\$20,001 – \$30,000	11%	11%
\$30,001 – \$40,000	12%	17%

\$40,001 – \$50,000	9%	7%
\$50,001 – \$60,000	7%	7%
\$60,001 – \$70,000	7%	3%
\$70,001 – \$80,000	5%	3%
> \$80,000	16%	24%
Education level		
Some high school	4%	3%
High school diploma	25%	22%
Some college	35%	41%
Associate's degree	5%	3%
Bachelor's degree	23%	22%
Advanced degree	8%	9%
Housing status†		
Live alone	18%	16%
Live with romantic partner	23%	24%
Live with roommate(s)*	18%	29%
Live with parent(s)*	41%	31%
Live with child/children	5%	3%
Live with sibling(s)	11%	13%
Live with other relative(s)	4%	3%
Other	7%	10%
Relationship status*		
Single	52%	50%

In a relationship	23%	35%
Engaged	4%	4%
Married	9%	8%
Polyamorous	7%	1%
Other	5%	1%
Has child(ren)	6%	5%
Has relative with ASD	31%	21%

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\* Denotes a statistically significant difference between groups at the  $p < .05$  level. These differences will be explored in more detail in the Results section.

† Percentages across subcategories do not add up to 100% because they are not mutually exclusive (e.g., a participant might live both with parents and siblings).

***ASD group characteristics.*** Approximately two-thirds (64%) of the ASD sample reported having received a formal diagnosis of ASD. Of these, 59% reported a diagnosis of Asperger Syndrome, 30% reported a diagnosis of Autism Spectrum Disorder, 14% reported a diagnosis of autism, 8% reported a diagnosis of Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), and 4% reported other, related diagnoses (e.g., “classic autism); these percentages add to over 100% due to some participants receiving more than one lifetime diagnosis. The average age of diagnosis was strikingly high, at 17.9 years ( $SD = 6.5$  years; range = 3-30 years, median = 19 years). Participants with a formal diagnosis were most frequently diagnosed by a clinical psychologist or therapist (49%), followed by a psychiatrist (27%), an interdisciplinary team or multiple professionals (6%), a neuropsychologist (6%), a neurologist (3%), or a

pediatrician or general practitioner (3%). Six percent of participants were unsure as to who had diagnosed them.

## **Procedure**

All procedures described below were approved by the Institutional Review Board (IRB) of the University of Massachusetts Boston.

**Piloting.** Prior to large-scale data collection, all battery items were piloted with six individuals. These individuals included four women with ASD between the ages of 18 and 30, one woman without ASD between the ages of 18 and 30, and one woman with ASD over the age of 30. The last individual, while not meeting the inclusion criteria for the current study, was included in the pilot sample due to her identities as a parent, and as being on the autism spectrum without having a formal diagnosis. Of the five participants who met the gender and age criteria for the current study, four gave permission for their data to be included in the final sample.

The pilot participants served as consultants for the current study, and provided timely feedback on up to three versions of the online battery. Feedback included wording and terminology recommendations, and improving the clarity of certain items. The pilot participants were recruited through a local ASD support organization, and through the PI's personal network. Each pilot participant received \$50 in Amazon credit to thank her for her time and involvement in the study. The piloting procedure took approximately three weeks.

**Recruitment of ASD group participants.** The recruitment of individuals with ASD was prioritized, and individuals on the spectrum completed the current study

between July and December, 2014. The PI took multiple steps to publicize the current study and to recruit participants. These included multiple online and in-person methods. The first recruitment procedures included the PI purchasing a domain name ([www.umbwomensstudy.com](http://www.umbwomensstudy.com)) and building a website to provide basic information to potential study participants. The PI also created a Facebook page ([www.facebook.com/umbwomensstudy](http://www.facebook.com/umbwomensstudy)) dedicated to the current study. These measures were taken to increase the online presence of the current study, to provide potential participants with relevant information so that they could make an informed decision regarding participation, and to give potential participants multiple ways to contact the PI with any questions.

Further online recruitment methods included contacting leaders of advocacy and support organizations for individuals with ASD and their families. These included, but were not limited to, the Asperger/Autism Network (formerly the Asperger Association of New England, or AANE), the Asperger Women's Association, the Portland Adult Asperger Support Group, Pathfinders for Autism, multiple local chapters of the Autistic Self-Advocacy Network, and multiple local chapters of the Autism Society of America. Many of the leaders and administrators of these organizations expressed support for the current study, and were willing to share information with their members. The PI also contacted a number of U.S. college and university disability services centers (e.g., Ross Center at the University of Massachusetts Boston, Disability Services at Wellesley College), as well as colleges and universities with programs specifically for students with ASD (e.g., College Success Program at Eastern University, Asperger Initiative at

Mercyhurst University) and sought their help distributing study information to potential participants. The PI also contacted different research and clinical groups (e.g., Aspire at Massachusetts General Hospital, Autism Consortium at Harvard Medical School), many of whom agreed to post study information on their websites. The PI also attempted to share study information directly with individuals with ASD by posting links to the study website on message boards and forums dedicated to ASD issues. These included, but were not limited to, the *Aspergers* forum on Reddit ([www.reddit.com/r/aspergers](http://www.reddit.com/r/aspergers)), Wrong Planet ([wrongplanet.net](http://wrongplanet.net)), Aspie Central ([www.aspiecentral.com](http://www.aspiecentral.com)), and the Asperger and ASD UK Online Forum ([www.asd-forum.org.uk/forum](http://www.asd-forum.org.uk/forum)). The PI sought approval from online message board moderators before posting study information, as the majority of these message boards were specifically for individuals with ASD, not members of the research community. Overall, the PI contacted approximately 130 support organizations, 10 research organizations, and 20 universities, and posted messages on five different online message boards.

It was also the case that individuals unaffiliated with the study or the PI made considerable efforts to publicize it; this included posting links to the study website on personal blogs and tumblr accounts. While the PI neither encouraged nor discouraged individuals from this activity, these efforts to publicize the study ultimately became a powerful recruiting tool.

In addition to these online activities, which comprised the vast majority of the efforts to recruit individuals with ASD, the PI made the following additional recruiting attempts: visiting two support groups for women with ASD at a local support and

advocacy organization, attending a local conference dedicated to ASD issues, and publicizing the current study in the program book of a conference specifically for young people with ASD.

Of the 248 participants retained for the ASD sample, they reported learning about the study in the following ways: tumblr (39%), other message board or email list (15%), Internet search (12%), Facebook group (11%), friend or personal contact (8%), Reddit (5%), support organization (5%), study website (3%), and other social media (2%).

**Recruitment of comparison group participants.** The recruitment of the comparison sample took place in October through December, 2014. This recruitment followed the same strategies as the large-scale recruitment of the ASD sample as to maximize similarities between the two groups across the following identities, each with the capacity to influence experiences around sexuality: age, race, nationality, student status, and living situation. The two groups were largely comparable across these domains; similarities and differences between groups, and how these were associated with sexuality- and non-sexuality-related variables, are discussed in detail in the next chapter.

Like the ASD sample, comparison sample participants were recruited primarily through online methods. These included posting the study on the Reddit forum Sample Size, an international online community and message board for people interested in survey methodology, posting the study on the Boston Craigslist website, and purchasing Facebook advertisements targeted to individuals who met the age and gender criteria for the study. Comparison sample participants also were recruited through the study website

and the study Facebook page. Further, a sizable minority of the comparison sample participants reported learning about the current study through friends' social media posts (i.e., tumblr posts), which were not made directly by the PI.

Of the 179 participants retained for the comparison sample, they reported learning about the study in the following ways: tumblr (33%), Facebook advertisement or group (29%), Internet search (18%), Reddit (8%), friend or personal contact (7%), message board or email list (3%), and Craigslist (2%).

**Data collection for ASD and comparison group participants.** Individuals who followed a link to the online survey were first required to answer several questions to verify their eligibility for the study, in terms of age and gender identity. If participants met the inclusion criteria, then they proceeded to the informed consent form (see Appendix A). The informed consent form contained a link to a document containing a link to a list of resources related to women's sexuality and ASD, in case they wanted to receive support around any of the topics or issues to be raised in the battery. This document appears in Appendix C. Given the online nature of the current study, the requirement of a written signature for informed consent was waived. However, after reviewing the form and clicking the "continue" button, participants were required to complete five "quiz" items related to informed consent, discussed previously in this chapter. Upon completion of these items, they were permitted to access the battery. At the end of the battery, participants were asked to indicate whether they were interested in receiving a summary of study findings and if they were interested in being contacted for future research opportunities. If the participants answered affirmatively to either question,



then they were asked to provide whichever pieces of contact information (i.e., name, email address, phone number) that they felt comfortable sharing. This contact information was saved separately from the data collected through the battery.

The survey was designed to take approximately 20 minutes to complete for individuals with ASD; this estimation was informed by online resources on survey methodology (e.g., Versta Research, 2011), as well as by feedback garnered from the pilot participants. Among participants in the ASD sample, the median length of time required to complete all aspects of the battery was 20 minutes; for participants in the comparison sample, it was 19 minutes.

**Fraudulent responding and study changes.** In the early stages of the current study, the PI intended to compensate study participants on an individual basis. Grant funding was secured to compensate each participant, regardless of ASD status, with \$10 in Amazon credit upon completion of the survey. However, shortly after the online battery was made publically available, the PI found very high rates of fraudulent responding. These were evident through very short completion times (i.e., the survey was being completed in under a minute, when it had been designed to take about 20 minutes), poor data quality, and multiple survey attempts from the same IP address. It is strongly suspected that this occurred due to the individual compensation structure.

After consulting with the University of Massachusetts IRB, Information Technology, and other researchers with online survey experience, the PI decided to convert the current study into a volunteer study, and not to compensate participants on an individual basis. Instead of receiving monetary compensation, participants were offered

the chance to receive a summary of findings at the conclusion of the study. The decision to make this study a volunteer study significantly increased data quality, and significantly decreased rates of fraudulent responding. It did not appear to have a negative impact on participant recruitment.

**Participant screening.** Multiple steps were taken to ensure high data quality in the current study. All fraudulent responses, described above, were identified and removed from analyses. Individuals who attempted to take the battery, but did not meet age and gender inclusion criteria, as well as individuals who indicated that they met these criteria, but did not attempt the battery, also were removed from analyses. Next, data from individuals who met inclusion criteria and attempted the survey, at least partially, were reviewed. Sixty-nine participants were removed from analyses due to significant missing data (i.e., at least 20% of constructs missing) and 10 additional participants were removed because they failed to respond to key items (e.g., whether or not they identified as being on the autism spectrum); potential differences between survey attempters and those retained for the final sample were explored and are presented at the beginning of the next chapter. Thirteen responses were removed from analyses because the participants had attempted the survey multiple times, as evidenced by repetitions in IP address. Finally, participants were screened for eligibility for either the ASD or comparison group. In this stage of screening, 64 individuals who identified as having ASD were removed from analyses because they scored below the clinical cutoff on the AQ-10; of these, 27 reported having a formal diagnosis and 37 reported that they did not. Seventeen individuals were removed from analyses because they did not identify as having ASD

and did not have a formal diagnosis, but scored above the clinical cutoff on the AQ-10. Finally, three participants were removed from analyses because while they reported having a formal diagnosis of ASD, they indicated that they did not self-identify as being on the autism spectrum. After these screening steps, no additional participant was removed from analyses on the basis of their performance on the informed consent “quiz” or the five attentional items contained in the battery. These steps yielded a final sample of 427 participants, with 248 individuals in the ASD group and 179 in the comparison group.

These participant screening steps are different from the data screening steps that were subsequently taken to ensure high quality statistical data. These data screening steps are discussed in detail in the beginning of the next chapter.

## **Measures**

Constructs were assessed in the following order for all participants: demographics, ASD symptoms, sensory symptoms, sexual history, sexual orientation, sexual desire, sexual education exposure, sexual behavior, sexual satisfaction, sexual victimization, sexual awareness (including sexual consciousness and sexual monitoring), depressive symptoms, anxiety symptoms, and social anxiety symptoms. One open-ended item about the impact of ASD on experiences of sexuality followed the social anxiety items. A second open-ended item about rationale for participating in the study was added to the battery prior to the recruitment of comparison participants. The methods used to assess each construct are discussed in detail below, and the complete online battery is provided in Appendix D.

### **Sexuality-related variables.**

***Sexual history.*** Ten items were adapted from the *Sexual History Questionnaire* (SHQ; Cupitt, 1998) to collect information about participants' sexual histories, including number of sexual partners, age of first sexual experience, and risk and protective behaviors around engaging in sexual activity. Although this questionnaire was developed for use with a non-ASD population, the questions were intentionally written in a direct, face-valid manner so that they were very likely clear and interpretable for participants with ASD. The questionnaire demonstrated good test-retest reliability when piloted among a group of typical undergraduate students (Cronbach's  $\alpha = .80$ ). In the current study, individual items on this questionnaire were considered separately and a summary score was not calculated.

***Sexual orientation.*** Due to time and space constraints in the current battery, sexual orientation was assessed using one open-ended item: "In your own words, how would you describe your sexual orientation? Examples might include 'straight,' 'lesbian,' 'bisexual,' 'queer,' etc." Participants' responses to the open-ended item were coded by the PI into 36 distinct categories.

***Sexual desire.*** Consistent with previous research with adult ASD samples (e.g., Byers, Nichols, & Voyer, 2013), Spector, Carey, and Steinberg's (1998) *Sexual Desire Inventory* was used to assess participants' levels of sexual desire and interest. The *Sexual Desire Inventory* is a multi-dimensional measure, which captures participants' levels of partner-oriented sexual desire, as well as self-oriented sexual desire. Five of the original 14 multiple-choice items were included in the current battery, which captured desire both

for partnered sexual activity and for solo sexual activity. Participants responded to items on either an 8- or 9-point scale; a sample item included, “During the last month, how often would you have liked to engage in sexual activity with a partner (for example, touching each other's genitals, giving or receiving oral stimulation, intercourse, etc.)?” (0 = not at all, to 7 = more than once a day). Items were standardized (i.e., converted to z scores) before being summed to create a composite score. In Byers, Nichols, and Voyer’s (2013) adult ASD sample, strong internal consistencies were found for both the dyadic and solitary sexual desire dimensions. In the current sample, internal consistency for all items was very good for both the ASD (Cronbach’s  $\alpha = .88$ ) and comparison groups (Cronbach’s  $\alpha = .85$ ).

***Sex education exposure.*** Ten items were adapted from Bennett and Dickinson’s (1983) *Sex Education Inventory* to assess participants’ sources of sexuality information, and their level of satisfaction with these sources. In addition, several items were added to assess participants’ involvement in school-based and other formal sexuality education programs, as well as the extent to which they receive sexuality information in an informal manner from friends. Bennet and Dickinson (1983) demonstrated the scale’s internal validity, as well as its construct validity through correlations with established measures of sexual knowledge and attitudes toward sexuality. Like the measure of sexuality history, this questionnaire was not scored; its purpose was to yield descriptive data only.

***Sexual behavior.*** An adapted 19-item version of Trotter and Alderson’s (2007) *Sexual Experience Questionnaire* was used to measure the sexual activities in which participants engage, and the frequency with which they do so. Participants were asked to

report on a 4-point scale (never, once, a few times, many times) the lifetime frequency in which they engaged in different sexual activities. The PI added several items to this questionnaire to capture lower base-rate sexual activities (e.g., having sex with more than one person at the same time) and to increase the variability within the sample. Although not designed specifically for use with individuals with on the autism spectrum, versions of this questionnaire have been used successfully in recent studies with adults with ASD (e.g., Gilmour et al., 2012).

In the current sample, internal consistency on the full 19-item measure was excellent for both the ASD (Cronbach's  $\alpha = .94$ ) and comparison groups (Cronbach's  $\alpha = .94$ ). However, subsequent analyses revealed a non-normal, multimodal distribution when all 19 items were dichotomized (0 = never, 1 = once, a few times, or many times) and summed to create a composite score. An exploratory factor analysis indicated the presence of four factors within sexual behavior: partnered sexual activity (deep kissing, someone else touching one's breasts or nipples, touching another's breasts or nipples, someone else touching one's genitals, touching another's genitals, performing oral sex, receiving oral sex, mutual masturbation, experiencing orgasm with a partner, vaginal intercourse), individual sexual activity (masturbating alone, experiencing orgasm alone, looking at erotica or pornography), low base rate partnered sexual activity (anal intercourse, having sex on a "one night stand," group sex, bondage/S&M activity), and sexual activity with technology ("sexting," having phone or Internet sex with someone else). In the current study, the decision was made to explore items on the individual level in Specific Aims 1 and 2, as well as to dichotomize the four scales listed above, and then

add those dichotomized scores to create an index score (range = 0-4). The latter variable was used in tests of Specific Aims 3 and 4.

***Sexual satisfaction.*** The 6-item contentment scale of Meston and Trapnell's (2005) *Sexual Satisfaction Scale for Women* was used to assess participants' sexual satisfaction. Participants were asked to respond to a series of statements such as, "I feel content with the way my present sex life is," and, "I often feel I don't have enough emotional closeness in my sex life," on a 5-point Likert scale ("strongly disagree" to "strongly agree"). Validation studies on the full measure with non-spectrum female samples have demonstrated strong construct validity and discriminant validity between clinical and non-clinical population, and good internal reliability and test-retest reliability. In the current study, the full contentment scale was used; for this, internal consistency was very good for both the ASD (Cronbach's  $\alpha = .87$ ) and comparison groups (Cronbach's  $\alpha = .87$ ).

***Sexual victimization.*** An adapted version of the *Childhood Sexual Abuse Scale* (CSAS; Aalsma, Zimet, Fortenberry, Blythe, & Orr, 2002) was used to assess lifetime experiences of sexual victimization. The questionnaire was originally worded to assess for sexual victimization prior to age 12 among typical individuals; however, it was adapted to assess for lifetime exposure in the current study. Participants were asked to respond with "yes" or "no" to the following 4 items: "Someone tried to touch me in a sexual way against my will," "Someone tried to make me touch them in a sexual way against my will," "I believe that I have been sexually abused by someone," and, "Someone threatened to tell lies about me or hurt me unless I did something sexual with

them.” Among typical young women between 14 and 24 years old, the scale has shown very strong internal and test-retest reliabilities; it also has demonstrated consistency with other, more detailed measures of sexual victimization (Aalsma et al., 2002). In the current sample, internal consistency was good for both the ASD (Cronbach’s  $\alpha = .83$ ) and comparison groups (Cronbach’s  $\alpha = .79$ ).

***Sexual awareness.*** Participants were asked to complete 15 selected items of the *Sexual Awareness Questionnaire* (SAQ; Snell et al., 1991). This measure captures the domains of sexual consciousness (knowledge and awareness of one’s own sexuality) and sexual monitoring tendencies (concern about one’s own sexuality and how one presents sexually to others). Participants will rate a series of statements (e.g., “I am very aware of my sexual feelings,” “I never seem to know when I’m turning others on”) on a 5-point Likert scale, ranging from, “not at all characteristic of me,” to, “very characteristic of me”. The SAQ has shown good internal reliability across all of its subscales, including two that were not included in the current study due to time and space constraints. Scores on the SAQ have been shown to be correlated, in expected directions, with reports of sexual attitudes, dispositions, and behaviors (Snell et al., 1991). In both the ASD and comparison groups, internal consistency was very good for the sexual consciousness subscale (Cronbach’s  $\alpha = .87$  and  $.89$ , respectively), the sexual monitoring subscale (Cronbach’s  $\alpha = .88$  and  $.87$ , respectively), and the overall measure (Cronbach’s  $\alpha = .89$  and  $.88$ , respectively).

**Non-sexuality-related variables.**



***Demographics.*** A 28-item questionnaire was administered first, to gather demographic information. Items included inquiries about ASD diagnostic status, family history of ASD, age, gender identity, racial identity, ethnic identity, income, immigration status, languages spoken, education level, employment status, housing situation, relationship status, parent status, and how the participant learned about the current study.

***Autism symptoms.*** As quantitative data collection was conducted online, it was necessary not only to inquire about participants' diagnostic status, but also to assess their level of ASD-related symptomatology. To this end, all participants completed the 10-item *Autism Spectrum Quotient* (AQ-10; Allison et al., 2012). This is an abbreviated version of the 50-item *Autism-Spectrum Quotient* (AQ; Baron-Cohen et al., 2001), which has been used successfully in recent online studies with adult participants with ASD (e.g., Byers, Nichols, & Voyer, 2013; Gilmour et al., 2012). The items on the AQ-10 cover the areas of attention to detail, attention switching, communication, social skills, and imagination. Participants were asked to report their level of agreement with each item on a 4-point Likert scale (definitely agree, slightly agree, slightly disagree, definitely disagree); some items were reverse-coded (i.e., items reflect the experiences of individuals with and without ASD). Examples of items include, "When I'm reading a story, I find it difficult to work out the characters' intentions," and, "I find it easy to work out what someone is thinking and feeling just by looking at their face." While the AQ-10 is based on a 4-point scale, item responses were dichotomized and then summed to obtain a total scale; a score above 6 has been associated with significant ASD symptomatology (Allison et al., 2012).

The AQ-10 appears to be as face valid and as sensitive to detecting the presence of ASD as the original 50-item questionnaire (Booth et al., 2013); the original version on which the AQ-10 is based has shown excellent test-retest reliability, reasonable construct validity, and good discriminative validity (Baron-Cohen et al., 2001). In the current sample, however, internal consistency on the dichotomized measure was found to be unacceptably low for both the ASD (Cronbach's  $\alpha = .18$ ) and comparison groups (Cronbach's  $\alpha = .22$ ); similarly low internal reliability also was observed by Nishiyama and colleagues (2014). Internal reliability was somewhat improved for both groups when the items remained on a 4-point scale (Cronbach's  $\alpha = .40$  for the ASD group,  $.53$  for the comparison group). The low internal reliability may reflect a high degree of variability in ASD symptoms within the current sample; it also may suggest that ASD symptoms may present differently for young women on the autism spectrum, with average intelligence or higher (Allison et al., 2012). Scores from the dichotomized version of the AQ-10 were used exclusively for determining inclusion in the ASD or comparison groups; scores on the 4-point version of the AQ-10 also were used, with caution, to test ASD symptomatology as a continuous variable.

***Sensory symptoms.*** Sensory symptoms, including hypersensitivity and hyposensitivity to sensory stimuli, were assessed using Minshew and Hobson's (2008) *Sensory Sensitivity Questionnaire*. In this questionnaire, participants were asked to respond with "yes" or "no" to 13 items, which fell under the following four categories: low temperature/pain tolerance (e.g., "Are you unusually sensitive to heat or cold?"), high temperature/pain tolerance (e.g., "Are you unusually insensitive to heat or cold?"),

tactile (e.g., “Are you made uncomfortable by touch or texture of clothing?”), and overall sensory sensitivities (e.g., “Do you become easily upset or overwhelmed in loud or crowded places?”) This self-report questionnaire has been used in samples of individuals with ASD and without ASD of many ages. It has revealed significant differences in sensory symptoms between individuals with and without ASD, and it has also revealed significant variation in sensory symptoms among individuals with ASD. As such, lower internal consistency on the SSI was anticipated, as it functioned more like a checklist than a cohesive measure of the overall experience of having sensory issues. In the current sample, internal consistency for the total measure was poor for both the ASD (Cronbach’s  $\alpha = .30$ ) and comparison groups (Cronbach’s  $\alpha = .55$ ), and similarly low for the temperature/pain tolerance, high temperature/pain tolerance, and tactile scales. Internal consistency for the overall sensory sensitivity scales was somewhat improved but still low for the ASD (Cronbach’s  $\alpha = .46$ ) and comparison groups (Cronbach’s  $\alpha = .62$ ).

***Depressive symptoms.*** To assess participants’ levels of depressive symptomatology, the *Personal Health Questionnaire Depression Scale* (PHQ-8; Kroenke et al., 2009) was administered. The PHQ-8 consists of eight items (e.g., “Feeling down, depressed, or hopeless”) that describe different depressive symptoms that are consistent with DSM-IV criteria for Major Depressive Disorder. Participants were asked to consider their feelings and experiences over the past two weeks and to rate each item from 0 (not at all) to 3 (nearly every day); total scores range from 0 to 24. While the PHQ-8 is designed for use with the general population in both clinical and research settings, it was selected for the current study because to date, no self-report measure has been developed

to measure depressive symptomatology specifically among adults with ASD. The PHQ-8 correlates highly with other measures of depression and has demonstrated very good internal consistency (Kroenke et al., 2009). In the current study, internal consistency was very good for both the ASD sample (Cronbach's  $\alpha = .89$ ) and the comparison sample (Cronbach's  $\alpha = .88$ ).

**Anxiety symptoms.** To assess generalized anxiety symptoms, participants completed the 7-item version of the *Generalized Anxiety Disorder Scale* (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006). This measure assesses symptoms of Generalized Anxiety Disorder, consistent with the criteria put forth in the DSM-IV. Participants were presented with seven statements (e.g., “Feeling nervous, anxious, or on edge,”) and asked to rank each one on a 4-point Likert scale, ranging from 0 (“not at all”) to 3 (“nearly every day”); possible scores range from 0 to 21. The GAD-7 has been observed to have adequate internal consistency, moderate correlations with other longer, well-established measures of anxiety symptoms, and good sensitivity in a sample of non-ASD adults diagnosed with Generalized Anxiety Disorder (Dear et al., 2011); these findings are relevant for the current study because participants with ASD are likely to experience heightened levels of anxiety symptoms. While the GAD-7 does not appear to have been used in any studies of adults with ASD to date, it was believed to be a good match for participants in the current study due to its sensitivity, content validity, and brevity (Spitzer et al., 2006). In the current study, internal consistency was excellent for both the ASD and comparison samples (Cronbach's  $\alpha = .90$  for both).

***Social anxiety symptoms.*** To assess social anxiety symptoms, participants were asked to complete the *Mini-Social Phobia Inventory* (MINI-SPIN; Connor, Kobak, Churchill, Katzelnick, & Davidson, 2001). The MINI-SPIN is an abbreviated, 3-item version of the *Social Phobia Inventory* (SPIN; Connor, Davidson, et al., 2000). To complete the MINI-SPIN, participants were asked to answer items regarding social anxiety symptoms (e.g., “Does fear of embarrassment cause you to avoid doing things or speaking to people?”) on a 5-point Likert scale, ranging from “not at all” to “extremely”. Answers were scored on a scale from 0 to 4, respectively; an index score of 6 or higher has been found to be predictive of a clinically significant social anxiety symptoms in the non-spectrum standardization sample (Connor, Kobak, et al., 2001). Additionally, among typical adults seeking treatment for social anxiety, generalized anxiety, or worry, the MINI-SPIN was observed to have strong internal reliability, convergent validity, discriminant validity, sensitivity, and diagnostic efficiency (Weeks, Spokas, & Heimberg, 2007). Although the MINI-SPIN has not been used widely with individuals with ASD, it was selected for the current study because of its brevity and demonstrated psychometric properties; further, there is no existing social anxiety screening measure specifically for individuals with ASD. In the current study, internal consistency was good for both the ASD sample (Cronbach’s  $\alpha = .83$ ) and the comparison sample (Cronbach’s  $\alpha = .83$ ).

**Qualitative items and analysis.** Two qualitative items appeared at the end of the current battery. The first item was, “If you identify as being on the autism spectrum, are there central ways that being on the spectrum has influenced your sexuality? If so, please describe.” Although this item was specifically for participants with ASD, comparison

participants were able to view it, as the same battery was used for both groups. The vast majority of participants with ASD (84%) provided a response to this question.

A second open-ended item was added prior to the large-scale recruitment of comparison participants. This item was, “We are interested in your decision to participate in the Women’s Sexuality Study. In the text box below, could you please describe your reason(s) for participating in this study?” While this was included, in part, as a data quality measure for comparison participants, individuals with ASD who completed the survey following the recruitment of comparison participants were able to view it and provide a response too. Overall, 88% of comparison participants and 56% of participants with ASD provided a response to this item (keeping in mind that it was not presented to participants with ASD who completed the survey prior to October, 2014).

Thematic analysis was used to analyze the qualitative data in an exploratory manner; this method was selected for its accessibility, flexibility, and capacity to yield a rich overall description of the entire data set (Braun & Clarke, 2006). An inductive, semantic, data-driven approach was taken to analyzing the qualitative data. Before commencing coding, the PI read each response carefully, to familiarize herself with the data. Then, the PI began the coding by reading the first response in full, and then identifying the key points contained within it (“codes”). Then, the PI read the second response in full, and determined whether it contained any of the same codes as the first response, and whether it contained any new codes. This was an iterative process, and for each following written response, the PI determined whether it contained existing and/or new codes. Once this procedure was complete, the PI determined how the codes might fit

together to form coherent themes. Following this step, the PI reread the complete data set, to determine if the identified themes accurately reflected it, and refined the names of the themes. These methods were repeated twice, once for each open-ended item. Given the exploratory nature of this thematic analysis, responses were coded solely by the PI and not by a coding team.

## CHAPTER 4

### RESULTS

#### **Data Processing Procedure**

Following participant screening, multiple data cleaning steps were taken to ensure high data quality. First, data were assessed for missingness, which was reconciled in several ways. In instances where participants completed 66% or more (but fewer than 100%) of the items in a given questionnaire, excluding demographics and other categorical variables, the missing items were replaced with the mean of the other, completed items and then the total scores were computed. For questionnaires with dichotomous items, a more conservative approach was taken: if the participant left an item blank, then it was coded as the absence of the particular symptom or experience, and then the scaled score was computed. For questionnaires with ordinal-level items, the missing values were replaced with the average of the completed items, and then the scaled score was computed.<sup>1</sup> These steps accounted for the vast majority of data missingness for both the ASD and comparison samples. However, after completing these

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<sup>1</sup> There was one exception to this approach: missing items on the *Sexual Experience Questionnaire* were reconciled in the same manner as missing dichotomous items (i.e., they were treated as the absence of the given behavior).



steps, 1% of sexual desire and sexual awareness data remained missing in the ASD group, and 1% of sexual awareness data remained missing in the comparison group. In these rare cases, listwise deletions were used to account for the missingness. Table 2 presents a breakdown of data missingness and the methods used to reconcile it in analyses for Specific Aims 1, 2, and 3.

Table 2

*Breakdown of Continuous Missing Data for ASD and Comparison Groups*

<u>Questionnaire</u>	<u>ASD Group</u>			<u>Comparison Group</u>		
	<u>% complete</u>	<u>% manual</u>	<u>% listwise</u>	<u>% complete</u>	<u>% manual</u>	<u>% listwise</u>
<i>Sexual Desire Inventory</i>	97	2	1	97	3	0
<i>Sexual Experience Questionnaire</i>	94	6	0	96	4	0
<i>Sexual Satisfaction Survey for Women</i>	98	2	0	97	3	0
<i>Childhood Sexual Abuse Scale</i>	98	2	0	99	1	0
<i>Sexual Awareness Questionnaire</i>	92	7	1	90	9	1
<i>Autism Quotient-10</i>	96	4	0	95	5	0
<i>Sensory Symptom Inventory</i>	98	2	0	96	4	0
<i>Patient Health Questionnaire-8</i>	96	4	0	97	3	0
<i>Generalized Anxiety Disorder-7</i>	99	1	0	94	6	0

In tests of Specific Aim 4, which used structural equation models to test the potential moderating effects of internalizing symptoms and sensory symptoms on the relation between ASD symptoms and sexuality outcomes, missing data were treated somewhat differently. Instead of manual substitutions and subsequent listwise deletions, missing data were treated with full information maximum likelihood (FIML). This method, which is the default feature of the Mplus software used to perform analyses of Specific Aim 4, uses observed, exogenous (independent) variable data to approximate values for missing endogenous (dependent) variables.

**Normality analyses.** All continuous sexuality- and non-sexuality-related variables were assessed for normality, skewness, and kurtosis. The vast majority of variables had statistically significant Kolmogorov-Smirnov and Shapiro-Wilk statistics, indicating deviation from normal distribution. However, skewness and kurtosis for each variable fell between -1.50 and +1.50, the currently accepted levels (Tabachnick & Fidell, 2013). Further, visual inspection of frequency distributions suggested good symmetry and approximate normality. It was reasoned that the statistically significant Kolmogorov-Smirnov and Shapiro-Wilk statistics likely were due to the powerful nature of the sample, and did not reflect fatal deviations from normality. The decision was made to proceed, with appropriate caution, with the planned parametric tests, instead of transforming variables (and losing interpretability) or performing less powerful non-parametric tests.

In addition to tests of normality, skewness, and kurtosis, continuous data also were screened for univariate outliers. No significant outliers were detected for the vast majority of sexuality- and non-sexuality-related variables included in analyses of Specific Aims 2, 3, and 4. However, several participants in both the ASD and comparison groups reported having sex for the first time in their late 20s, which were statistically significant outliers. However, to capture the wide range of sexual experience within the current sample, these outliers were not transformed and were retained for analyses involving the age of first sex variable. One participant in the ASD group identified as a sex worker and reported a high number of lifetime sexual partners (>1,000); given the unique nature of this participant's work, this value was excluded when calculating the average number of lifetime sexual partners for the ASD sample.

**Analyses for potential covariates.** Analyses for potential covariates took place in two phases. In the first phase, differences in demographic variables were tested between the ASD and comparison groups. As reported previously, attempts were made during recruitment to maximize similarities between groups in regard to age, racial identity, nationality, student status, and housing status. In addition, employment status, education level, household income were compared between groups. In the second phase, relations between demographic variables, and sexuality- and non-sexuality-related variables, were tested. The results of these analyses informed the inclusion of covariates when testing Specific Aim 4.

***Between-group comparisons on demographic variables.*** Participants with ASD were older, on average, than the comparison sample participants [ $t(425) = 4.03, p < .001$ ];

while statistically significant, the effect size for this difference was found to be somewhat small (Cohen's  $d = .40$ ). Racial identities were comparable between the ASD and comparison groups [ $\chi^2(7, N = 427) = 10.21, p = .18$ ; Cramer's  $\phi = .15$ ]. Comparison sample participants were significantly more likely than participants with ASD to live in the U.S. or Canada [84% versus 71%;  $\chi^2(1, N = 427) = 10.95, p = .001$ ; Cramer's  $\phi = -.16$ ]. Comparison group participants also were significantly more likely to be either part-time or full-time students, compared to participants in the ASD group [65% versus 55%;  $\chi^2(1, N = 427) = 4.77, p = .03$ ; Cramer's  $\phi = -.11$ ]; however, no significant differences were observed between groups in terms of educational attainment (Mann–Whitney  $U = 21467, n_1 = 248, n_2 = 179, p = .55$ ). Comparison group participants also were more likely to be employed either part-time or full-time, compared to participants in the ASD group [54% versus 39%;  $\chi^2(1, N = 427) = 9.35, p = .002$ ; Cramer's  $\phi = -.15$ ]. In terms of housing status, participants in the ASD and comparison groups were equally likely to live by themselves, with a romantic partner, with siblings, with other relatives, or with their own children; however, participants with ASD were significantly more likely to live with their parents [41% versus 31%;  $\chi^2(1, N = 427) = 4.48, p = .03$ ; Cramer's  $\phi = -.10$ ], and not to live with roommates [18% versus 29%;  $\chi^2(1, N = 427) = 7.04, p = .01$ ; Cramer's  $\phi = .13$ ]. No significant difference in household income was observed between groups (Mann–Whitney  $U = 19431, n_1 = 239, n_2 = 175, p = .21$ ).

In the absence of conducting an experiment, in which participants are assigned to different levels of the independent variable, the risk of having non-equivalent groups is always present. In the current study, a causal-comparative design, random assignment to

the ASD and comparison groups was not feasible. In addition to their ASD status, differences were observed between groups in terms of age, nationality, student status, employment status, and housing situation; these posed potential threats to internal validity. However, the associated effect sizes indicated that these differences were indeed small, and that they were likely due to the powerful nature of the sample and not indicative of dramatic, real-world differences between the groups. Guided by Martella, Nelson, Morgan, and Marchand-Martella (2013), the decision was made to use statistical methods to control for these small yet statistically significant differences, as age, student status, employment status, and housing situations each were associated with some aspects of sexuality (see next section for results). This course of action was preferred to removing participants selectively from either the ASD or comparison groups in order to yield more comparable samples.

*Comparisons between demographic variables and continuous variables.* Seeing that differences in terms of age, nationality, student status, employment status, and housing situation emerged between the ASD and comparison groups (i.e., independent variable), these demographic variables were tested for relations with each of the major, continuous sexuality- and non-sexuality-related variables (sexual desire, sexual behavior, sexual satisfaction, sexual victimization, sexual awareness including consciousness and monitoring, ASD symptoms, sensory symptoms, depression, anxiety, and social anxiety), which would serve as dependent variables and moderators in the planned analyses.

Age was significantly correlated with sexual desire [ $r(244) = .17, p < .01$ ], sexual behavior [ $r(246) = .21, p = .001$ ], sexual satisfaction [ $r(242) = -.18, p < .01$ ], and sexual

consciousness [ $r(245) = .13, p = .05$ ] for participants with ASD. However, for comparison sample participants, age was correlated with sexual behavior [ $r(177) = .21, p < .01$ ], sexual consciousness [ $r(177) = .17, p = .02$ ] and depressive symptoms [ $r(177) = -.19, p < .01$ ].

Participants' nationality (U.S. or Canada, versus other countries) was not significantly associated with any of the sexuality- or non-sexuality-related variables. Among comparison sample participants, those living outside the U.S. or Canada were marginally more likely to report instances of sexual victimization than those living in the U.S. or Canada [ $t(49) = 1.92, p = .06$ , Cohen's  $d = .35$ ].

Student status (full- or part-time student, versus not a student) was significantly associated with sexual behavior [ $t(246) = -2.52, p = .01$ , Cohen's  $d = .32$ ] and sexual victimization among participants with ASD [ $t(246) = -2.91, p < .01$ , Cohen's  $d = .37$ ]. Specifically, participants with ASD who were not students reported more sexual behavior and more sexual victimization than participants with ASD who were students. For comparison sample participants, student status was associated significantly with sexual consciousness [ $t(156) = -2.22, p = .03$ , Cohen's  $d = .33$ ] and depressive symptoms [ $t(177) = 2.20, p = .03$ , Cohen's  $d = .35$ ], with students reported less sexual consciousness and more depressive symptoms than non-students.

Employment status (full- or part-time employee, versus unemployed) was significantly associated with sexual desire [ $t(244) = 3.86, p < .001$ , Cohen's  $d = .49$ ], sexual behavior [ $t(219) = 2.86, p < .01$ , Cohen's  $d = .39$ ], sexual victimization [ $t(246) = 1.97, p = .05$ , Cohen's  $d = .25$ ], sexual monitoring [ $t(181) = 2.29, p = .02$ , Cohen's  $d =$

.34], and marginally with depressive symptoms [ $t(246) = -1.69, p = .09$ , Cohen's  $d = .22$ ] for participants with ASD; participants who were employed reported more desire, behavior, victimization, and monitoring, and fewer depressive symptoms. For comparison sample participants, employment status was significantly associated with sexual behavior [ $t(151) = 2.68, p = .01$ , Cohen's  $d = .39$ ], sexual consciousness [ $t(177) = 2.16, p = .03$ , Cohen's  $d = .32$ ], and sexual monitoring [ $t(177) = 2.39, p = .02$ , Cohen's  $d = .36$ ], and marginally with social anxiety symptoms [ $t(177) = -1.92, p = .06$ , Cohen's  $d = .29$ ]. Employed participants reported more behavior, sexual consciousness, and sexual monitoring, and fewer social anxiety symptoms.

In terms of living situation, significant differences in sexual desire [ $t(244) = -4.89, p < .001$ , Cohen's  $d = .63$ ], sexual behavior [ $t(246) = -6.36, p < .001$ , Cohen's  $d = .81$ ], sexual satisfaction [ $t(242) = 3.91, p < .001$ , Cohen's  $d = .50$ ], sexual consciousness [ $t(244) = -2.78, p < .01$ , Cohen's  $d = .36$ ], sexual monitoring [ $t(246) = -4.38, p < .001$ , Cohen's  $d = .56$ ], and autism symptoms [ $t(246) = 2.25, p = .03$ , Cohen's  $d = .29$ ], and a marginal difference in sexual victimization [ $t(246) = -1.89, p = .06$ , Cohen's  $d = .24$ ], were observed between participants with ASD who did and did not live with their parents. Specifically, participants with ASD who lived with their parents reported greater desire, more behaviors, greater awareness (including consciousness and monitoring), and less satisfaction; they also reported more ASD symptoms. Interestingly, none of these differences was observed for comparison sample participants who did and did not live with their parents, although comparison sample participants who lived with their parents reported marginally higher depressive symptoms [ $t(177) = -1.78, p = .08$ , Cohen's  $d =$

.28]. Further, no significant differences were observed between participants with ASD who lived with roommates and those who did not, although comparison sample participants who lived with roommates reported significantly more sexual behavior [ $t(75) = -2.20, p = .03$ , Cohen's  $d = .39$ ] and sexual victimization [ $t(111) = -2.82, p < .01$ , Cohen's  $d = .45$ ] compared to those who did not. It was observed that very few participants (two in the ASD group, and three in the comparison group) reported living both with their parents and with roommates. Given the significant, inverse overlap in these variables, only the living with parents variable was retained as a covariate.

Since age, student status, employment status, and living situation were significantly correlated with both independent and dependent variables, they were covaried in relevant tests of Specific Aims 3 and 4.

### **Tests of Specific Aims**

**Specific Aim 1: To describe the experiences of women with ASD across multiple aspects of sexuality.** The preeminent goal of the current study was to describe, for the first time, the sexualities and sexual experiences specifically of young women and gender-fluid individuals on the autism spectrum. Experiences along the dimensions of relationship and family status, gender identity, sexual history, sexual orientation, sexual desire, sexual education exposure, sexual behavior, sexual satisfaction, sexual victimization, and sexual awareness (including sexual consciousness and sexual monitoring) were explored. To maintain the focus on the experiences of individuals with ASD, comparisons between individuals with and without ASD were explored separately in Specific Aim 2, and relations across sexuality-related and non-sexuality related



variables for both the ASD and comparison groups were explored separately in Specific Aims 3 and 4.

***Relationship and family status.*** Slightly more than half of participants with ASD (52%) identified as being single. Twenty-two percent of participants reported being in a relationship, 9% reported being married (either legally or non-legally recognized), 7% reported being polyamorous and being in more than one romantic relationship, 5% reported other relationship statuses, and 4% reported being engaged. Of those reporting other relationship statuses, three did not provide a status but reinforced their aromantic and/or asexual identity. Four reported being in open relationships, including one open marriage. Two individuals reported being in a “half-relationship” or an undefined relationship; one individual reported being in an unstable relationship. Three individuals reported being in a queer platonic partnership or partnerships.

Among those participants who reported being in a partnership (i.e., not single), the average relationship length was 3.80 years ( $SD = 3.19$  years, range = 2 weeks through 14 years, median = 3 years). In cases where participants reported having more than one partner, their longest relationship was used to calculate the statistics above. Participants reported the gender identities of their partners: 58% were cisgender men, and 11% were cisgender women. A considerable minority (21%) of partners had a genderfluid identity; these included biological men with a genderfluid identity (5%), biological women with a genderfluid identity (4%), and individuals with a genderfluid identity for whom biological sex was not reported (12%). Further, 4% of participants reported that their partners were transgender; one participant reported that the partner was a queer male.

About 3% of participants reported having multiple partners, including cisgender men and women; another 3% of participants reported having multiple partners, all of whom had genderfluid identities. The majority of partners (74%) did not identify as being on the autism spectrum; 15% of partners were reported to be on the autism spectrum but without a formal diagnosis, and 8% of partners were reported to be on the autism spectrum with a formal diagnosis. A small minority (3%) of participants reported having multiple partners, some of whom were on the autism spectrum and some of whom were not.

In terms of family status, 6% of participants with ASD reported being parents, and one participant reported being pregnant with her first child.

***Gender identity.*** As anticipated, great diversity was observed in how participants described their gender, when given the opportunity to do so in an open-ended format. The overwhelming majority (more than 99%) of participants responded to this item. Half of the participants with ASD reported identifying as a female, a woman, or a cisgender woman (i.e., their gender identities aligned with their biological sex and/or the gender ascribed to them at birth). The other half of the sample reported a more fluid gender identity; descriptions of gender were varied, and some participants wrote at length and used multiple terms to describe their identities. Among those reporting a more fluid gender identity, the most frequently reported genders were agender (28%) and genderqueer (28%). Fourteen percent described themselves as a “demigirl,” or identified somewhat, but not fully, as a woman. Six percent identified as transgender. Other identities included genderfluid, non-binary, pangender, neutrois, bigender, butch, and questioning.

***Sexual history.*** Participants were asked, “Who do you engage in sexual activity with?” A substantial minority (40%) reported that they do not engage in sexual activity with others. Others reported that they have sexual contact with only men (19%); people of all sexes and genders (13%); both men and women (11%); women, men, and transgender people (7%); only women (5%); women and transgender people (2%); women, transgender, and intersex people (2%); men and transgender people (2%); and only transgender people (<1%). Responses to this item should be interpreted with caution, as some participants reported with whom they would like to have sexual contact (e.g., some participants reported that they had not engaged in sexual activity with someone else yet, but would be open to doing so with people of all genders), and others reported with whom they had had sex to date. Within the “other” box associated with this item, 6% of participants spontaneously indicated that they would be open to, if not enthusiastic about having sexual partners or experiences that they have not had yet.

Next, participants were asked whether they had ever had sex with someone else. In an attempt to reduce heteronormative bias in the battery, “have sex” was not defined further, or as vaginal intercourse. The majority of participants (58%) reported having had sex with someone else; an additional 1% reported engaging in some kind of sexual contact (e.g., oral sex) but felt unsure as to whether they considered it sex. Two percent of participants indicated the only sex that they had experienced with another person was non-consensual, and that they had been victimized. Finally, a substantial minority (39%) of participants reported that they had never had sex with someone else. Among those who identified as having had sex with another person, the average age of first sex was 17.12

years ( $SD = 3.23$  years, range = 5<sup>2</sup>-27 years, median = 17 years). Among those who had had sex with another person, the average number of lifetime sexual partners was 7.8 ( $SD = 14.3$ , range = 1-120, median = 3)<sup>3</sup>. Participants who had had sex reported most recently having contact less than a week ago (37%), between one week and one month ago (19%), one to three months ago (10%), three to six months ago (9%), six months to a year ago (6%), and more than one year ago (19%).

Regarding sexual health, about half (53%) of the participants with ASD reported not using birth control devices, as they do not engage in sexual activities that they believe carry the risk of pregnancy or STI transmission. Among those who reported using birth control devices, the methods most frequently cited were the male condom (79%), contraceptive pill (39%), intrauterine device (22%), and withdrawal before ejaculation (20%). The methods least frequently endorsed were spermicidal cream or foam (5%), female condom (3%), surgical procedure (3%), Nuvaring (3%), Depo Provera injections (2%), Implanon or other implanted device (3%), and calendar/rhythm method (3%); virtually no participant endorsed using a diaphragm or cervical cap. Among those using birth control devices, 55% reported using more than one method. Also among participants using birth control devices, the vast majority reported using them all of the time (72%) or most of the time (10%).

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<sup>2</sup> The current battery did not assess whether participants' first sexual experiences were coercive, although the very low values suggest that some were.

<sup>3</sup> One participant, who identified as a sex worker and reported a high number of lifetime sexual partners (>1,000), was excluded from this calculation.

Fifteen participants (6%) made use of the text box in which they could provide additional information about their use of birth control devices; these responses were very informative and clarifying. For instance, one participant clarified that she and her partner were trying to conceive, and thus did not use birth control. Several other participants indicated that they had undergone STI testing with their partners, and that this had influenced their choices around birth control. One participant reported that she did not yet engage in sexual activity with other people, but indicated which birth control methods she planned to use in the future.

Half of the participants with ASD reported that they had received at least one lifetime gynecological exam; 37% indicated that they had been tested for Human Immunodeficiency Virus (HIV) and/or other STIs.

***Sexual orientation.*** Similar to how participants described their gender, there was a great deal of diversity in how participants described their sexual orientation when given the opportunity to do so in an open-ended format. The vast majority of participants with ASD (99%) provided a response to this item, and most participants with ASD identified as a sexual minority (92%). Participants with ASD identified sexually as the following: asexual (13%), bisexual (12%), pansexual or polysexual (12%), queer (10%), heterosexual (8%), predominately straight with some sexual experiences and/or fantasies about women (7%), gay or lesbian (6%), asexual and panromantic (4%), asexual and aromantic (3%), “other” or without label (3%), questioning (2%), asexual and queer (2%), demisexual and pansexual (2%), asexual and demi-romantic (2%), asexual and bisexual (2%), predominately straight and asexual (2%), gay or lesbian and queer (2%),

and bisexual and aromantic (2%). Less than one percent of the sample identified as each of the following: asexual and heteroromantic, pansexual and homoromantic, asexual and bisexual, asexual and homoromantic, pansexual and asexual, androsexual and aromantic, demisexual and aromantic, bisexual and heteroromantic, pansexual and panromantic, demisexual and demiromantic, asexual and panromantic, bisexual and biromantic, demisexual and homoromantic, and gynosexual. A substantial minority of participants (22%) described their romantic orientation alongside their sexual orientation, particularly when these differed (e.g., some participants identified as asexual and reported not wanting any sexual contact with others, but also identified as panromantic and sought emotional relationships with individuals of any or all genders.)

***Sexual desire.*** Participants were asked to reflect on the past month and indicate how frequently they desired sexual activity with a partner and by themselves, and their level of desire of sexual activity with a partner and by themselves on a scale from 0 (very low) to 8 (very high). They also were asked how comfortably they could go without engaging in sexual activity of any kind. For participants in the ASD group, the median response was once a week to once every two weeks for partnered sexual activity, with an average desire level of 3.61 ( $SD = 2.76$ , range = 0-8). Interestingly, a significant minority of participants (34%) reported not desiring partnered sexual at all in the past month; about 9% of participants reported desiring partnered sexual activity once a day or more than once a day. Participants' desire for solitary sexual activity was somewhat greater, with a median response of twice a week, with an average desire level of 4.22 ( $SD = 2.67$ , range = 0-8). A similar percentage of participants reported no desire to engage in solitary

sexual activity (13%) as those who reported desiring it at least once a day (14%).

Participants on the autism spectrum reported that they could forego any sexual activity comfortable for the following amounts of time: forever (16%), a year or two (8%), several months (22%), one month (14%), a few weeks (23%), a week (9%), a few days (6%), one day (1%), and less than one day (1%).

***Sex education exposure.*** Participants with ASD reported having multiple sources of sex education, including media sources, such as Internet, television, and radio (86%), books about sexuality (70%), female friends (50%), teachers at school (28%), male friends (23%), mothers (22%), medical professionals (16%), professional sex educators (16%), fathers (5%), family members other than parents (4%), and religious leaders (2%). One percent of participants reported having no sources of sex education, and 11% reported having sources not included in the battery. These alternate sources of sex education included friends who have gender identities other than female or male, current and former sexual partners, Facebook groups, YouTube videos, Tumblr, health websites, academic texts and articles, academic coursework, sex workers, fanfiction, pornography, sex stores, and personal experiences. On average, participants reported having 3.4 sources (median = 3) of sex education.

While the majority of participants with ASD counted friends as sources of sex education, even more reported discussing sexuality with friends. The majority (68%) reported that they discuss sexuality with their friends of different genders; 19% of participants reported that they discuss sexuality with their female friends only. Only 13% of participants reported that they do not discuss sexuality with any friends.

The majority of participants (81%) reported receiving some type of school-based education, although many fewer (10%) reported participating in an organized sex education program outside of school, including programs held at religious establishments, community health/outpatient settings, therapeutic support groups, inpatient settings, and online. Only six participants (less than 2% of the overall sample) reported participating in a sex education program specifically for individuals on the autism spectrum.

Overall, participants reported a high level of satisfaction with their level of knowledge about sexuality. While asked to rate their level of satisfaction with their knowledge on a scale from 1 (low) to 10 (high), the average score was 8.12 ( $SD = 1.83$ , range = 2-10), with more than a quarter of participants (27%) reporting the highest level of satisfaction with their level of sexuality knowledge.

***Sexual behavior.*** Table 3 presents a breakdown of different sexual behaviors, and the lifetime frequency with which participants with ASD engaged in them.

Table 3

*Frequencies of Sexual Behaviors Among Participants with ASD*

<u>Activity</u>	<u>% Never</u>	<u>% Once</u>	<u>% Few</u>	<u>% Many Times</u>
			<u>Times</u>	
<b>Partnered Sexual Activity</b>				
Deep kissing	31	8	15	47
Touching another's nipples	41	6	18	35
Someone touching your nipples	35	7	15	43
Touching another's genitals	38	6	12	44



Someone touching your genitals	36	5	12	45
Performing oral sex	44	6	10	39
Receiving oral sex	44	6	17	33
Masturbating with a partner	59	10	12	19
Orgasm with a partner	50	6	9	34
Vaginal intercourse	49	5	8	37
<b>Solo Sexual Activity</b>				
Masturbating alone	8	2	12	77
Orgasm alone	22	3	10	65
Looking at pornography	11	6	27	57
<b>Sexual Activity with Technology</b>				
Phone/Internet sex	55	11	21	12
“Sexting”	59	8	18	15
<b>Low Base Rate Activity</b>				
Anal intercourse	71	9	9	11
Sex on a “one night stand”	78	8	8	5
Group sex	81	7	8	4
Bondage/S&M activity	58	7	20	15

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As shown above, the most frequently endorsed activities by participants with ASD included masturbating alone (92%), looking at pornography or erotica (89%), achieving orgasm alone (78%), and deep kissing (69%). The activities reported least frequently were having sex with more than one person at the same time (19%), having

sex on a “one night stand” (22%), and anal intercourse (29%). A very small percentage of participants reported engaging in none of the activities listed above (3%); a similarly small percentage reported engaged in all of the activities (5%). The median number of sexual activities in which participants had engaged at least once was 11.

As discussed in the previous chapter, a factor analysis yielded 4 factors within sexual behavior: partnered sexual activity (high base rate), solo sexual activity, sexual activity with technology, and partnered sexual activity (low base rate). The vast majority of participants (96%) reported at least one lifetime solo sexual activity, followed by at least one high base rate partnered sexual activity (77%), at least one low base rate partnered sexual activity (50%), and at least one sexual activity with technology (49%).

***Sexual satisfaction.*** The majority of participants (54%) reported some degree of contentment with their sex lives; however, 12% expressed a very strong degree of dissatisfaction. A significant minority of participants (44%) reported feeling as though something were missing from their sex lives, and 30% reported that they did not have enough emotional closeness in their sex lives. A significant minority of participants (39%) expressed dissatisfaction with the amount of physical closeness they currently had; however, the questionnaire did not ask whether they felt that they had too much or too little. A substantial minority indicated that they had some degree of concern regarding sex (e.g., arousal, orgasm). Participants described the overall quality of their current sex lives in the following ways: completely satisfactory (20%), very satisfactory (17%), reasonably satisfactory (36%), not very satisfactory (21%), and not at all satisfactory (6%).

***Sexual victimization.*** Four questions, to which participants responded on a “yes” or “no” basis, were used to assess lifetime exposure to sexual victimization. Responses to these items revealed an unexpectedly high rate of sexual victimization among participants with ASD: 59% endorsed that they had been touched sexually against their will, 35% reported that they were forced to touch someone else sexually against their will, 44% reported that they believed that they had been sexually abused, and 19% reported that someone else had threatened to hurt them or spread lies about them unless they did something sexual with that person. About two-thirds of participants (62%) responded affirmatively to at least one of these four items.

***Sexual awareness.*** Fifteen items were used to assess participants’ sexual awareness; their responses yielded a sexual consciousness score (awareness of one’s own sexual feelings and behaviors), a sexual monitoring score (awareness of one’s sexuality in relation to others), and an overall sexual awareness score (a combination of the sexual consciousness and sexual monitoring scores). Participants’ average score on the sexual consciousness scale was 13.34 ( $SD = 6.33$ , range = 0-24, median = 13); the average score on the sexual monitoring scale was 15.16 ( $SD = 8.88$ , range = 0-36, median = 15). These subscales were moderately, positively correlated [ $r(244) = .41, p < .001$ ] suggesting some association between one’s awareness of one’s own sexuality and one’s awareness of one’s sexuality as it relates to other people, but also distinction between these constructs. The average overall sexual awareness score was 28.54 ( $SD = 12.82$ , range = 1-59, median = 28).

## Specific Aim 2: To identify potential differences in aspects of sexuality

**between women with and without ASD.** While the first and foremost goal was to understand better the sexualities of young women with ASD, the inclusion of a non-spectrum community sample was a deliberate decision in the current study. The comparison sample provided a helpful context for understanding the experiences of individuals with ASD, and identifying unique ways in which individuals on the spectrum may perceive and experience their sexuality. See Table 4 for descriptive statistics and between-group comparisons for all major continuous variables.

Table 4

### *Descriptive Statistics and Between-Group Differences for Major Continuous Variables*

<u>Variable (Questionnaire)</u>	<u>Mean</u>	<u>SD</u>	<u>Range</u>	<u>Between-Group Difference</u>
Sexual Desire (SDI)				
ASD group	-.44	4.18	-7.21-9.05	$t(404) = -2.79^{**}$
Comparison group	.65	3.77	-7.21-9.05	Cohen's $d = -.27$
Sexual Behavior (SEQ)				
ASD group	2.74	1.22	0-4	$t(396) = -3.09^{***}$
Comparison group	3.10	1.16	0-4	Cohen's $d = -.30$
Sexual Satisfaction (SSSW)				
ASD group	19.58	6.65	6-30	$n.s.$
Comparison group	20.09	6.68	6-30	
Sexual Victimization (CSAS)				
ASD group	1.54	1.51	0-4	$t(401) = 2.55^{*}$
Comparison group	1.19	1.38	0-4	Cohen's $d = .24$
Sexual Consciousness (SAQ)				
ASD group	13.34	6.33	0-24	$t(423) = -5.47^{***}$
Comparison group	16.66	5.96	0-24	Cohen's $d = -.54$
Sexual Monitoring (SAQ)				
ASD group	15.16	8.88	0-36	$t(425) = -5.40^{***}$
Comparison group	19.83	8.75	0-36	Cohen's $d = -.53$
ASD symptoms (AQ-10)				
ASD group	32.78	2.95	25-40	$t(326) = 35.88^{***}$
Comparison group	20.70	3.74	11-32.22	Cohen's $d = 3.59$
Sensory symptoms (SSQ)				
ASD group	9.19	1.69	3-13	$t(317) = 23.73^{***}$
Comparison group	4.50	2.22	0-12	Cohen's $d = 2.38$

Depression (PHQ8)				
ASD group	11.45	6.27	0-24	$t(425) = 3.46^{**}$
Comparison group	9.36	6.00	0-24	Cohen's $d = .34$
Anxiety (GAD7)				
ASD group	10.28	5.92	0-21	$t(425) = 3.32^{***}$
Comparison group	8.36	5.90	0-21	Cohen's $d = .32$
Social Anxiety (MINI-SPIN)				
ASD group	7.83	3.41	0-12	$t(425) = 4.58^{***}$
Comparison group	6.32	3.29	0-12	Cohen's $d = .45$

*Note.* AQ-10 = *Autism-Spectrum Quotient* (Allison et al., 2012). SSI = *Sensory Sensitivity Questionnaire* (Minshew & Hobson, 2008). PHQ8 = *Personal Health Questionnaire Depression Scale* (Kroenke et al., 2009). GAD7 = *Generalized Anxiety Disorder Scale* (Spitzer et al., 2006). MINI-SPIN = *Mini-Social Phobia Inventory* (Connor, Kobak, et al., 2001). SDI = *Sexual Desire Inventory* (Spector et al., 1998). SEQ = *Sexual Experience Questionnaire* (Trotter & Alderson, 2007). SSSW = *Sexual Satisfaction Scale for Women* (Maston & Trapnell, 2005). CSAS = *Childhood Sexual Abuse Scale* (Aalsma et al., 2002). SAQ = *Sexual Awareness Questionnaire* (Snell et al., 1991).

\*\*  $p < .01$  \*\*\*  $p < .001$

***Relationship and family status.*** Significant differences emerged between the ASD and comparison groups in terms of relationship status [ $\chi^2(1, N = 427) = 18.21, p < .01$ , Cramer's  $\phi = .21$ ]. While participants in both groups reported comparable rates of being single (52% versus 50%, respectively), being engaged (4% in each group), and being married (9% versus 8%, respectively), comparison sample participants were more likely to report being in a relationship (35%, versus 23% of participants with ASD), and less likely to report being polyamorous (1%, versus 7% of participants with ASD) or having a different kind of relationship status (1%, versus 5% of participants with ASD).

While comparison sample participants were more likely than individuals with ASD to report having a romantic partner, participants on the spectrum reported having significantly longer relationships with their primary partner [ $t(199) = 2.41, p = .02$ , Cohen's  $d = .34$ ]. Overall significant differences were observed in partners' gender identities between the ASD and comparison groups [ $\chi^2(1, N = 200) = 18.88, p = .02$ ,

Cramer's  $\phi = .31$ ]. Among those in partnerships, participants in the comparison group were more likely to report being in a relationship with a cisgender man (80%, versus 58% of participants with ASD), and less likely to report being in a relationship with a genderfluid or transgender individual (6%, versus 29% of participants with ASD). Participants with and without ASD had comparable rates of being in a relationship with one cisgender woman (11% versus 10%, respectively), and with having multiple cisgender male and female partners (3% versus 5%, respectively).

Significant differences, too, were observed in ASD status among partners of the ASD and comparison group participants [ $\chi^2(1, N = 205) = 14.88, p < .01$ , Cramer's  $\phi = .27$ ]. While the majority of participants in both groups had partners not on the autism spectrum, participants in the ASD group were more likely to have a partner also on the autism spectrum (26%), as compared to comparison group participants (7%).

In terms of family status, similar percentages of participants with and without ASD reported having children (6% versus 5%, respectively), or being pregnant with their first child (1% versus 2%, respectively).

***Gender identity.*** No hypothesis was associated with gender identity; an exploratory approach was taken in light of limited existing research. Individuals with ASD were significantly more likely than comparison sample participants to report a more fluid gender identity [50% versus 22%,  $\chi^2(1, N = 427) = 34.55, p < .001$ , Cramer's  $\phi = .29$ ]. In addition to cisgender, comparison sample participants reported identifying as the following genders: agender, non-binary, genderfluid, genderqueer, "demigirl" or somewhat female, bigender, and questioning. Each of these genders was also reported by

participants in the ASD group. The high rate of gender fluidity among comparison sample participants was an unexpected finding; however, the increased likelihood of participants with ASD to have a non-binary or genderfluid identity still was pronounced.

***Sexual history.*** No hypothesis was associated with sexual history, given the conceptual overlap with sexual behavior, and the mixed findings on differences in sexual behavior between individuals with and without ASD. Participants with ASD were about as likely as comparison participants to report having sex with women [40% versus 36%,  $\chi^2(1, N = 427) = .76, p = .38$ , Cramer's  $\phi = -.04$ ] and with intersex people [16% versus 11%,  $\chi^2(1, N = 427) = 2.11, p = .15$ , Cramer's  $\phi = -.07$ ]. However, relative to individuals without ASD, individuals with ASD were significantly less likely to report having sex with men [48% versus 70%,  $\chi^2(1, N = 427) = 20.27, p < .001$ , Cramer's  $\phi = .22$ ], and significantly more likely to report having sex with transgender people [26% versus 13%,  $\chi^2(1, N = 427) = 10.76, p = .001$ , Cramer's  $\phi = -.16$ ] or not having sex with anyone [37% versus 22%,  $\chi^2(1, N = 427) = 10.59, p = .001$ , Cramer's  $\phi = -.16$ ].

The median age of first sex was 17 years old for both the ASD and comparison groups. Among those who had sex with other people, the median number of lifetime sexual partners for participants with ASD was 3, and for comparison sample participants it was 3.5.

Participants with ASD were significantly more likely than comparison sample participants to report not engaging in sexual activities that carry a risk of pregnancy or STIs [53% versus 32%,  $\chi^2(1, N = 427) = 19.27, p < .001$ , Cramer's  $\phi = -.21$ ]. Among those who endorsed using birth control, participants with and without ASD reported

generally comparable rates of using different devices. For both groups, the most frequently endorsed methods were the male condom (79% versus 76%), contraceptive pill (39% versus 47%), intrauterine device (22% versus 13%), and withdrawal before ejaculation (20% versus 25%). A similar percentage of participants in both groups reported using more than one method of birth control (56% in the ASD group, and 63% in the comparison group). Overall, participants with and without ASD reported similar rates of using birth control all or most of the time (81% versus 85%, respectively); however, participants with ASD were more likely to report using them all of the time (72%, versus 64% of participants with ASD), and participants without ASD were more likely to report using them most of the time (21%, versus 9% of participants with ASD).

Participants with ASD were about as likely as comparison sample participants to have received at least one gynecological exam [51% versus 53%,  $\chi^2(1, N = 426) = .25, p = .61$ , Cramer's  $\phi = -.02$ ]; however, they were significantly less likely to have undergone screening for HIV or other STIs [38% versus 48%,  $\chi^2(1, N = 427) = 4.75, p = .03$ , Cramer's  $\phi = -.11$ ]. However, the effect size of the difference was small, as the difference itself is likely attributable to the differences in partnered sexual activity between groups.

***Sexual orientation.*** As anticipated, participants with ASD were significantly more likely than comparison group participants to have a sexual minority identity [92% versus 72%,  $\chi^2(1, N = 425) = 29.53, p < .001$ , Cramer's  $\phi = -.26$ ]. Participants in both the ASD and comparison groups were equally likely to discuss their romantic orientations in response to the open-ended item about sexual orientation [22% versus 19%,  $\chi^2(1, N = 425) = .97, p = .33$ , Cramer's  $\phi = -.05$ ]. It is important to note that the rates of sexual



minority identity among comparison sample participants were unexpectedly high – much higher than what would be expected based on previous studies of sexual orientation among young women. However, the differences in sexual orientation between individuals with and without ASD still were pronounced.

***Sexual desire.*** The hypothesis that women with ASD would report comparable rates of sexual desire as women without ASD was partially supported. When asked to report their level of desire on a scale from 0 (low) to 8 (high), participants with ASD reported significantly lower levels of desire for partnered sexual activity [ $t(423) = -5.49$ ,  $p < .001$ , Cohen's  $d = .54$ ]. However, level of desire for solo sexual activity, reported on the same scale, was comparable between the groups [ $t(406) = -.28$ ,  $p = .78$ , Cohen's  $d = .03$ ]. Participants with ASD indicated that they would be comfortable foregoing sexual activity for a longer period of time than participants without ASD [Mann–Whitney  $U = 19142.5$ ,  $n_1 = 247$ ,  $n_2 = 179$ ,  $p = .02$ ]; the median response for participants with ASD was several months, and for comparison sample participants, it was one month. On the overall 5-item scale of sexual desire, participants with ASD scored significantly lower than those in the comparison group [ $t(404) = -2.79$ ,  $p < .01$ , Cohen's  $d = .27$ ].

***Sex education exposure.*** The hypothesis that individuals with ASD would report less exposure to sexual education, and less satisfaction with sexual education received, relative to those without ASD was partially supported. Participants with and without ASD endorsed a number of sources of sexual education; both groups were equally likely to learn from their media sources including Internet, television, and radio [86% versus 80%,  $\chi^2(1, N = 427) = 2.25$ ,  $p = .14$ , Cramer's  $\phi = -.08$ ], teachers in school [28% versus

25%,  $\chi^2(1, N = 427) = .71, p = .40$ , Cramer's  $\phi = -.04$ ], mothers [22% versus 26%,  $\chi^2(1, N = 427) = .71, p = .40$ , Cramer's  $\phi = .04$ ], professional sex educators [16% versus 22%,  $\chi^2(1, N = 427) = 3.02, p = .08$ , Cramer's  $\phi = .08$ ], fathers [5% versus 8%,  $\chi^2(1, N = 427) = 1.62, p = .20$ , Cramer's  $\phi = .06$ ], religious leaders [2% for both groups,  $\chi^2(1, N = 427) = .22, p = .64$ , Cramer's  $\phi = .02$ ], and alternate methods [11% versus 10%,  $\chi^2(1, N = 427) = .22, p = .64$ , Cramer's  $\phi = -.02$ ]. Participants with ASD were less likely than comparison sample participants to endorse learning about sex from female friends [50% versus 73%,  $\chi^2(1, N = 427) = 22.08, p < .001$ , Cramer's  $\phi = .23$ ], male friends [23% versus 36%,  $\chi^2(1, N = 427) = 9.65, p = .002$ , Cramer's  $\phi = .15$ ], medical professionals [16% versus 27%,  $\chi^2(1, N = 427) = 7.97, p = .01$ , Cramer's  $\phi = .14$ ], and family members other than parents [4% versus 11%,  $\chi^2(1, N = 427) = 7.01, p = .01$ , Cramer's  $\phi = .13$ ]. However, participants with ASD were significantly more likely than comparison sample participants to gather information by reading sexuality books independently [70% versus 60%,  $\chi^2(1, N = 427) = 4.98, p = .03$ , Cramer's  $\phi = -.11$ ]. While some differences were observed between groups in their use of individual sources of sexual education, participants with and without ASD reported, on the whole, similar total numbers of sources (3.4 and 3.8, respectively). While this difference was found to be statistically significant [ $t(425) = -2.63, p = .01$ ], the effect size was indeed small (Cohen's  $d = .26$ ).

Differences were observed between the ASD and comparison groups in terms of how participants communicated about sexuality with friends [ $\chi^2(3, N = 426) = 26.01, p < .001$ , Cramer's  $\phi = .25$ ]. Participants with and without ASD were similarly likely to discuss sexuality with female friends only (19% in both groups) or with male friends only

(<1% in both groups). However, comparison sample participants were more likely to discuss sexuality with friends of all genders (77%, versus 61% of participants with ASD), and participants with ASD were more likely not to discuss sexuality with any friend (20%, versus 3% of comparison sample participants).

Participants with ASD were marginally more likely than comparison sample participants to have received school-based sexual education [81% versus 74%,  $\chi^2(1, N = 424) = 3.38, p = .07$ , Cramer's  $\phi = .09$ ]. Participants in both groups were about as likely to have participated in an organized sex education program outside of school [11% for ASD versus 10% for comparison,  $\chi^2(1, N = 427) = .22, p = .64$ , Cramer's  $\phi = .02$ ]. When asked to rate their level of satisfaction with their sexuality knowledge on a scale from 1 (low) to 10 (high), participants with and without ASD reported comparably high levels of satisfaction [ $t(424) = -1.21, p = .23$ ].

***Sexual behavior.*** As hypothesized, participants with ASD reported fewer sexual behaviors and overall less sexual experience relative to comparison sample participants. Table 5 presents a breakdown of each sexual activity included in the questionnaire, the percentage of ASD and comparison sample participants who had engaged in it at least once, and the results of a chi-squared test to determine whether the groups differed significantly, based on the activity.

Table 5

*Differences in Sexual Behaviors Between ASD and Comparison Groups*

<u>Activity</u>	<u>% ASD</u>	<u>% Comparison</u>	<u>Difference?</u>
<b>Partnered Sexual Activity</b>			
Deep kissing	70	82	$\chi^2(1, N = 427) = 8.46^{**}$ Cramer's $\phi = .14$
Touching another's nipples	59	67	<i>n.s.</i>
Someone touching your nipples	65	79	$\chi^2(1, N = 427) = 9.95^{**}$ Cramer's $\phi = .15$
Touching another's genitals	62	77	$\chi^2(1, N = 427) = 9.99^{**}$ Cramer's $\phi = .15$
Someone touching your genitals	63	78	$\chi^2(1, N = 427) = 10.06^{**}$ Cramer's $\phi = .15$
Performing oral sex	56	70	$\chi^2(1, N = 427) = 9.08^{**}$ Cramer's $\phi = .15$
Receiving oral sex	56	69	$\chi^2(1, N = 427) = 7.69^{**}$ Cramer's $\phi = .13$
Masturbating with a partner	41	44	<i>n.s.</i>
Orgasm with a partner	49	63	$\chi^2(1, N = 427) = 7.96^{**}$ Cramer's $\phi = .14$
Vaginal intercourse	50	62	$\chi^2(1, N = 427) = 5.67^*$ Cramer's $\phi = .12$
<b>Solo Sexual Activity</b>			
Masturbating alone	91	92	<i>n.s.</i>
Orgasm alone	78	82	<i>n.s.</i>
Looking at pornography	89	92	<i>n.s.</i>
<b>Sexual Activity with Technology</b>			
Phone/Internet sex	44	50	<i>n.s.</i>

“Sexting”	41	64	$\chi^2(1, N = 427) = 22.93^{***}$ Cramer’s $\phi = .23$
<b>Low Base Rate Activity</b>			
Anal intercourse	29	32	<i>n.s.</i>
Sex on a “one night stand”	22	36	$\chi^2(1, N = 427) = 10.16^{**}$ Cramer’s $\phi = .15$
Group sex	19	19	<i>n.s.</i>
Bondage/S&M activity	42	42	<i>n.s.</i>

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*Note.* \*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

As shown above, there were some activities in which participants with and without ASD engaged in similar rates. These included touching another’s nipples, masturbating alone and with a partner, phone or Internet sex, achieving orgasm alone, anal sex, looking at pornography, group sex, and bondage/S&M activity. However, there were a number of activities for which the ASD and comparison groups differed; these included deep kissing, someone else touching one’s nipples, touching another’s genitals, someone one touching one’s genitals, performing and receiving oral sex, achieving orgasm with a partner, vaginal intercourse, sending sexual text messages or pictures, and having sex on a one night stand. For each of these activities, it was always the case that participants without ASD were significantly more likely than participants with ASD to engage in them; there was no sexual activity in which participants with ASD were significantly more likely to engage than participants not on the autism spectrum. Overall, the median number of sexual activities in which participants without ASD had engaged at least once was 14; this was significantly more than the 11 reported by participants with ASD (Mann–Whitney  $U = 18870$ ,  $n_1 = 248$ ,  $n_2 = 179$ ,  $p = 0.01$ ).

**Sexual satisfaction.** The hypothesis that individuals with ASD would report lower rates of sexual satisfaction than individuals without ASD was not supported: both groups reported comparable rates of sexual satisfaction [ $t(425) = -.78, p = .43$ , Cohen's  $d = .07$ ].

**Sexual victimization.** The hypothesis that women with ASD would report higher rates of sexual victimization, relative to women without ASD was supported. Table 6 presents a breakdown of sexual victimization events, the frequency with which participants with and without ASD were exposed, and significant differences observed between groups.

Table 6

*Differences in Sexual Victimization Between ASD and Comparison Groups*

<u>Event</u>	<u>% ASD</u>	<u>% Comparison</u>	<u>Difference?</u>
Sexually touched against will	59	49	$\chi^2(1, N = 425) = 4.12^*$ Cramer's $\phi = .10$
Forced to touch someone else	35	27	$\chi^2(1, N = 424) = 2.85^\dagger$ Cramer's $\phi = .08$
Believe sexual abuse occurred	44	31	$\chi^2(1, N = 424) = 6.94^{**}$ Cramer's $\phi = .13$
Threatened with violence to behave sexually	19	11	$\chi^2(1, N = 424) = 4.55^*$ Cramer's $\phi = .10$

Note.  $^\dagger p < .10$  \*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

Overall, 53% of participants in the comparison sample endorsed at least one of the events listed above, compared to 62% of participants with ASD; this was observed to be a marginally significant difference between groups [ $\chi^2(1, N = 426) = 2.95, p = .09$ , Cramer's  $\phi = .09$ ]. When sexual victimization was measured continuously, not dichotomously,

participants with ASD were found to report, on average, significantly more lifetime events than participants without ASD [ $t(401) = 2.55, p = .01$ , Cohen's  $d = .26$ ].

***Sexual awareness.*** As expected, participants with ASD, relative to comparison sample participants, reported lower rates of sexual consciousness [ $t(423) = -5.47, p < .001$ , Cohen's  $d = -.55$ ], sexual monitoring [ $t(425) = -5.40, p < .001$ , Cohen's  $d = -.53$ ], and overall sexual awareness [ $t(423) = -6.45, p < .001$ , Cohen's  $d = -.63$ ]. Medium effect sizes were observed for each of these group differences along the domain of sexual awareness.

**Specific Aim 3: To understand how sexuality-related variables are associated with each other, and with key demographic variables, ASD symptoms, internalizing symptoms, and sensory symptoms.** Partial correlational analyses were performed between each of the major continuous sexuality- and non-sexuality-related variables; these analyses were performed separately for the ASD and comparison groups. In these analyses, participants' age, student status, employment status, and housing situation were held constant. Table 7 shows the results for the ASD group and Table 8 shows the results for the comparison group.

Table 7

*Partial Correlations Between Sexuality and Non-Sexuality Related Variables for ASD**Group*

Variable (Questionnaire)	1	2	3	4	5	6	7	8	9	10	11
1. ASD symptoms (AQ-10)	--										
2. Sensory symptoms (SSQ)	.15*	--									
3. Depression (PHQ8)	.12†	.23**	--								
4. Anxiety (GAD7)	.22**	.26***	.72***	--							
5. Social Anxiety (MINI-SPIN)	.10	.00	.30***	.38***	--						
6. Sexual Desire (SDI)	.10	.10	.05	.19**	.12†	--					
7. Sexual Behavior (SEQ)	.07	.14*	.17**	.21**	.07	.36***	--				
8. Sexual Satisfaction (SSSW)	.05	-.10	-.25***	-.22**	-.10	-.33***	-.13*	--			
9. Sexual Victimization (CSAS)	.15*	.22**	.21**	.27***	-.01	.16*	.32***	-.08	--		
10. Sexual Consciousness (SAQ)	-.08	.03	-.05	.03	.12†	.51***	.20**	-.05	.09	--	
11. Sexual Monitoring (SAQ)	-.07	.10	.16*	.32***	.19**	.50***	.31***	-.40***	.20**	.38***	--

*Note.* AQ-10 = *Autism-Spectrum Quotient* (Allison et al., 2012). SSI = *Sensory Sensitivity Questionnaire* (Minshew & Hobson, 2008). PHQ8 = *Personal Health Questionnaire Depression Scale* (Kroenke et al., 2009). GAD7 = *Generalized Anxiety Disorder Scale* (Spitzer et al., 2006). MINI-SPIN = *Mini-Social Phobia Inventory* (Connor, Kobak, et al., 2001). SDI = *Sexual Desire Inventory* (Spector et al., 1998). SEQ = *Sexual Experience Questionnaire* (Trotter & Alderson, 2007). SSSW = *Sexual Satisfaction Scale for Women* (Maston & Trapnell, 2005). CSAS = *Childhood Sexual Abuse Scale* (Aalsma et al., 2002). SAQ = *Sexual Awareness Questionnaire* (Snell et al., 1991). Participant age, student status, employment status, and housing situation were covaried.

†  $p < .10$  \*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$



Table 8

*Partial Correlations Between Sexuality and Non-Sexuality Related Variables for Comparison Group*

Variable (Questionnaire)	1	2	3	4	5	6	7	8	9	10	11
1. ASD symptoms (AQ-10)	--										
2. Sensory symptoms (SSQ)	.24**	--									
3. Depression (PHQ8)	.21**	.27**	--								
4. Anxiety (GAD7)	.15*	.39***	.70***	--							
5. Social Anxiety (MINI-SPIN)	.31***	.16*	.32***	.30***	--						
6. Sexual Desire (SDI)	-.15†	.16*	.07	.02	-.00	--					
7. Sexual Behavior (SEQ)	-.11	.13†	.09	.16*	-.10	.45***	--				
8. Sexual Satisfaction (SSSW)	-.05	-.01	-.30***	-.24**	-.19**	-.27***	-.08	--			
9. Sexual Victimization (CSAS)	-.05	.23**	.31***	.32***	.06	.11	.34***	-.04	--		
10. Sexual Consciousness (SAQ)	-.26**	.11	-.06	.02	-.09	.50***	.46***	-.03	.22**	--	
11. Sexual Monitoring (SAQ)	-.11	-.02	.21**	.13†	.17*	.43***	.37***	-.30**	.21**	.33***	--

*Note.* AQ-10 = *Autism-Spectrum Quotient* (Allison et al., 2012). SSI = *Sensory Sensitivity Questionnaire* (Minshew & Hobson, 2008). PHQ8 = *Personal Health Questionnaire Depression Scale* (Kroenke et al., 2009). GAD7 = *Generalized Anxiety Disorder Scale* (Spitzer et al., 2006). MINI-SPIN = *Mini-Social Phobia Inventory* (Connor, Kobak, et al., 2001). SDI = *Sexual Desire Inventory* (Spector et al., 1998). SEQ = *Sexual Experience Questionnaire* (Trotter & Alderson, 2007). SSSW = *Sexual Satisfaction Scale for Women* (Maston & Trapnell, 2005). CSAS = *Childhood Sexual Abuse Scale* (Aalsma et al., 2002). SAQ = *Sexual Awareness Questionnaire* (Snell et al., 1991). Participant age, student status, employment status, and housing situation were covaried.

†  $p < .10$  \*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

As shown in Tables 7 and 8, many significant correlations were observed within and across the non-sexuality- and sexuality-related variables, even after controlling for the effects of age, student status, employment status, and housing situation. Of note, among individuals in the ASD group, autism, sensory, depressive, and anxiety symptoms were positively correlated with one another; social anxiety symptoms were correlated with depressive and anxiety symptoms but not with autism or sensory symptoms. The strongest correlations between sexuality- and non-sexuality-related variables were observed for depressive and anxiety symptoms, which both were correlated positively with sexual behavior, sexual victimization, and sexual monitoring, and negatively with sexual satisfaction. Similar, though not identical patterns between sexuality- and non-sexuality-related variables were observed for the comparison group.

Next, exploratory factor analyses were performed to determine whether the sexuality-related variables could be condensed into meaningful factors. If so, these factors would inform the inclusion of dependent variables in analyses of Specific Aim 4.

Decisions around performing exploratory factor analyses in the current study were informed by the work of Costello and Osborne (2005). Given the similar correlation patterns observed within the ASD and comparison groups, comparable factor structures were anticipated. Also in light of the numerous correlations observed across the sexuality-related variables, from which the items for the exploratory factor analyses were drawn, the analyses were performed with oblique (oblimin) rotation. Principal components analysis was selected as the extraction method, as the goals of these analyses were to reduce data and to identify meaningful dependent variables for tests of Specific

Aim 4 (Fabrigar, Wegener, MacCallum, & Strahan, 1999). The exploratory factor analyses were performed in two ways: first, all 45 items contained in the sexual desire, sexual behavior, sexual satisfaction, sexual consciousness, and sexual monitoring scales were included, and second, only the total scores for the sexual desire, sexual behavior, sexual satisfaction, sexual consciousness, and sexual monitoring scales were included. These analyses were performed separately for the ASD and comparison samples.

*Exploratory factor analyses on the item level.* When the exploratory factor analysis with 45 items was run for the ASD group, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .90 (greater than the generally recommended value of .60), and Bartlett's Test of Sphericity was significant [ $\chi^2(990) = 7979, p < .001$ ]; this indicated that the sample was sufficiently powerful to perform this type of analysis. The diagonals of the anti-image correlation matrix all were over .50, and the communalities all were above .30, indicating that each of the 45 items shared some common variance with each of the other items. In light of these indicators, exploratory factor analysis was determined to be an appropriate statistical method for these data.

This first exploratory factor analysis yielded 8 factors with Eigenvalues greater than 1; together, these factors accounted for 71.39% of the total variance. The first factor, with an Eigenvalue of 14.75, was significantly greater than the others (which had Eigenvalues that ranged from 1.22 to 5.47) and accounted for 32.77% of the total variance. Of the 45 items included in the analysis, 4 failed to have a primary loading

greater than .50 or had cross-loading values of approximately .40 or greater<sup>4</sup>; these included two items related to desire for solo sexual activity, one item related to anal sex, and one item related to thinking about one's sex appeal. The decision was made to perform a second exploratory factor analysis, excluding the 4 problematic items from the first analysis.

The second exploratory factor analysis, performed with the same extraction and rotations methods, again yielded 8 factors with Eigenvalues greater than 1; together, these factors accounted for 72.43% of the total variance. As in the previous analysis, the first factor, with an Eigenvalue of 13.82, was significantly greater than the others and accounted for 33.72% of the total variance. Two items, involving mutual masturbation and bondage/S&M activity, failed to have a primary loading greater than .50 or had cross-loading values of .40 or greater; these items were removed and a third exploratory factor analysis was performed with the remaining 39 items.

The third exploratory factor analysis, with the same extraction and rotation methods, again yielded 8 factors with Eigenvalues greater than 1; together, these factors accounted for 72.99% of the total variance. As in the previous analysis, the first factor, with an Eigenvalue of 12.83, was significantly greater than the others and accounted for 32.89% of the total variance. In this iteration, all items had primary loading greater than .50 and cross-loading values, when present, of less than .40. While some of the factors had only a couple of primary factor loadings and therefore should be interpreted with

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<sup>4</sup> Several items had cross-loadings slightly above .40, but loaded very clearly onto one factor (i.e., > .70). These items were retained for analysis.

caution, the following eight factors emerged: higher base rate partnered sexual activity (9 items), sexual satisfaction (6 items), sexual consciousness (6 items), sexual monitoring (2 items), solo sexual activity (3 items), sexual monitoring and lower base rate partnered sexual activity (6 items), sexual activity involving technology (2 items), and sexual desire and monitoring (5 items). Table 9 presents a breakdown of factor loadings and communalities.

Table 9

*Factor Loadings and Communalities Based on a Factor Analysis with Oblimin Rotation**for 39 Sexuality-Related Items (ASD Group)*

<u>Item</u>	<u>Factor 1</u>	<u>Factor 2</u>	<u>Factor 3</u>	<u>Factor 4</u>	<u>Factor 5</u>	<u>Factor 6</u>	<u>Factor 7</u>	<u>Factor 8</u>	<u>Communality</u>
Preferred frequency for sexual activity with partner								-.61	.76
Strength of desire to engage in partnered sexual activity								-.60	.78
Comfortable length of time without any sexual activity					.41			-.65	.71
Deep kissing	.89								.83
Touching another's nipples	.80								.79
Someone touching your nipples	.94								.90
Touching another's genitals	.97								.95
Someone touching your genitals	.97								.92
Performing oral sex	.92								.92
Receiving oral sex	.93								.89
Masturbating alone					.83				.75
Phone/Internet sex							-.75		.82
Orgasm alone					-.76				.75
Orgasm with a partner	-.80								.79
Vaginal intercourse	-.86								.75
Looking at pornography					-.63		-.35		.58
"Sexting"							-.82		.86
Sex on a "one night stand"						-.59			.55
Group sex						-.62			.61
Contentment with present sex life		.88							.79
Feeling something is missing from present sex life		.73							.71
Lacking emotional closeness in present sex life		.61							.49
Contentment with frequency of sexual intimacy		.79							.68
Lack of problems or concerns about sex		.69							.52
How satisfactory/unsatisfactory is present sex life?		.91							.83
Very aware of own sexual feelings			.76						.71
Very aware of own sexual motivations			.77						.69
Very alert to changes in own sexual desires			.70						.61
Very aware of own sexual tendencies			.86						.71
Very aware of how own mind works when aroused			.73						.60
Knows own sexual turn-ons			.56						.57
Wonder if others think I am sexy						-.41			.56
Concerned about sexual appearance of own body						-.55			.70
Worry about making good sexual impression on others						-.63			.75
Concerned what others think about my sex appeal				.36		-.64			.76
Do not care what others think of my sexuality				.88					.76
Rarely think about sexual aspects of own life								-.70	.76
Do not think about own sexuality that much								-.69	.65
Others' opinions on my sexuality do not matter that much to me				.86					.75

*Note.* Table contains abbreviated item descriptions. See Appendix D for complete text of all items. Factor loadings below .32 are not reported.

The series of exploratory factor analyses described above was replicated for the comparison sample, and very similar patterns emerged. The first exploratory factor analysis yielded 10 factors (as opposed to 8 factors in the ASD group) with Eigenvalues greater than 1; together, these factors accounted for 75.83% of the total variance. The first factor, with an Eigenvalue of 14.41, was significantly greater than the others and accounted for 32.02% of the total variance. Of the 45 items included in the analysis, 4 failed to have a primary loading greater than .50 or had cross-loading values of approximately .40 or greater. These included one item about desire for partnered sexual activity, one item about masturbating alone, one item about having phone/Internet sex, and one item about bondage/S&M activity; the last item was the only one of the four that was problematic in the ASD sample too. The decision was made to perform a second exploratory factor analysis, excluding the four problematic items from the first analysis.

The second exploratory factor analysis, performed with the same extraction and rotations methods, yielded 8 factors with Eigenvalues greater than 1; together, these factors accounted for 72.43% of the total variance. Again, the first factor, with an Eigenvalue of 12.84, was significantly greater than the others and accounted for 31.32% of the total variance. Four items, involving mutual masturbation, experiencing orgasm alone, lacking any problems in one's present sex life, and rarely thinking about the sexual aspects of one's life, failed to have a primary loading greater than .50 or had cross-loading values of .40 or greater. These items were removed and a third exploratory factor analysis was performed with the remaining 37 items.



The third exploratory factor analysis, with the same extraction and rotation methods, yielded seven factors with Eigenvalues greater than 1; together, these factors accounted for 71.99% of the total variance. Again, the first factor, with an Eigenvalue of 11.87, was significantly greater than the others and accounted for 32.08% of the total variance. Two items, involving “sexting” and not thinking about one’s sexuality that much, failed to have a primary loading greater than .50 or had cross-loading values of .40 or greater. These two items were removed and a fourth exploratory factor analysis was performed with the remaining 35 items.

The fourth exploratory factor analysis, with the same extraction and rotation methods, again yielded seven factors with Eigenvalues greater than 1; together, these factors accounted for 73.72% of the total variance. As in the previous analysis, the first factor, with an Eigenvalue of 11.29, was significantly greater than the others and accounted for 32.25% of the total variance. In this iteration, all items had primary loading greater than .50 and cross-loading values, when present, of less than .40. While a couple of factors contained fewer than 5 primary loading items and therefore should be interpreted with caution, the following domains emerged: higher base rate partnered sexual activity (9 items), sexual satisfaction (5 items), sexual consciousness (6 items), sexual monitoring (5 items), sexual desire and looking at pornography (5 items), lower base rate partnered sexual activity (3 items), and lack of sexual monitoring (2 items). Overall, these factors were highly consistent with those that emerged from the ASD sample. Table 10 presents a breakdown of factor loadings and commonalities.

Table 10

*Factor Loadings and Communalities Based on a Factor Analysis with Oblimin Rotation**for 35 Sexuality-Related Items (Comparison Group)*

<u>Item</u>	<u>Factor 1</u>	<u>Factor 2</u>	<u>Factor 3</u>	<u>Factor 4</u>	<u>Factor 5</u>	<u>Factor 6</u>	<u>Factor 7</u>	<u>Communality</u>
Preferred frequency for sexual activity with partner					.45			.58
Preferred frequency for solo sexual activity					.91			.81
Strength of desire to engage in solo sexual activity					.91			.82
Comfortable length of time without any sexual activity					.75			.64
Deep kissing	.93							.84
Touching another's nipples	.82							.63
Someone touching your nipples	.96							.90
Touching another's genitals	.92							.94
Someone touching your genitals	.92							.93
Performing oral sex	.86							.89
Receiving oral sex	.86							.86
Orgasm with a partner	.78							.71
Vaginal intercourse	.75							.80
Anal sex						.64		.59
Looking at pornography					.49			.42
Sex on a "one night stand"						.68		.64
Group sex						.73		.57
Contentment with present sex life		.88						.82
Feeling something is missing from present sex life		.83						.74
Lacking emotional closeness in present sex life		.75						.56
Contentment with frequency of sexual intimacy		.76						.67
How satisfactory/unsatisfactory is present sex life?		.91						.85
Very aware of own sexual feelings			.85					.73
Very aware of own sexual motivations			.79					.70
Very alert to changes in own sexual desires			.78					.68
Very aware of own sexual tendencies			.87					.75
Very aware of how own mind works when aroused			.69					.63
Knows own sexual turn-ons			.75					.66
Wonder if others think I am sexy				.89				.77
Concerned about sexual appearance of own body				.68				.74
Worry about making good sexual impression on others				.67				.76
Concerned what others think about my sex appeal				.73				.80
Rarely think about own sex appeal				.85				.71
Do not care what others think of me sexually							.87	.84
Others' opinions on my sexuality do not matter that much to me							.90	.83

*Note.* Table contains abbreviated item descriptions. See Appendix D for complete text of all items. Factor loadings below .32 are not reported.

*Exploratory factor analyses on the total score level.* The above section reported on the factor analysis results at the individual item level. Next, exploratory factor analyses were conducted on the total score level. When the exploratory factor analysis with total scores on the sexual desire, sexual behavior, sexual satisfaction, sexual consciousness, and sexual monitoring measures was run for the ASD group, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .73 (greater than the generally recommended value of .60), and Bartlett's Test of Sphericity was significant [ $\chi^2(10) = 298$ ,  $p < .001$ ]. These values indicated that the sample was sufficiently powerful to perform this type of analysis. The diagonals of the anti-image correlation matrix all were over .50, and the communalities all were above .30, indicating that each of the six total scores shared some common variance with each of the others. In light of these indicators, exploratory factor analysis was determined to be an appropriate statistical method for these data.

Within the ASD group, the six total scores all loaded significantly onto the same factor, although sexual satisfaction was the only item that loaded negatively, suggesting that a single-factor approach was best supported by the data. This factor had an Eigenvalue of 2.51 and accounted for 50.23% of the total variance. See Table 11 for a breakdown of factor loadings and communalities.

Table 11

*Factor Loadings and Communalities Based on a Factor Analysis with 6 Total Scores on Sexuality-Related Constructs (ASD Group)*

<u>Item</u>	<u>Factor 1</u>	<u>Commonality</u>
Sexual desire	<b>.84</b>	.71
Sexual behavior	<b>.63</b>	.40
Sexual satisfaction	<b>-.57</b>	.32
Sexual consciousness	<b>.65</b>	.42
Sexual monitoring	<b>.81</b>	.65

The results of this exploratory factor analysis suggests that strong relations exist across the dimensions of sexual desire, behavior, satisfaction, consciousness, and monitoring for young women with ASD. Although not statistically significant, there was some indication that sexual satisfaction might be functioning somewhat separately and differently from the other aspects of sexuality for individuals in the current sample. Specifically, sexual satisfaction was the only item to load negatively onto the factor, and it had the lowest commonality of all the items. Overall, these results were consistent with the moderate to strong correlations observed among sexuality-related variables in other tests of Specific Aim 3.

The exploratory factor analysis with total scores on the sexual desire, sexual behavior, sexual satisfaction, sexual consciousness, and sexual monitoring measures was replicated with the comparison sample. Here, the Kaiser-Meyer-Olkin Measure of

Sampling Adequacy was .74 (greater than the generally recommended value of .60), and Bartlett's Test of Sphericity was significant [ $\chi^2(10) = 187.77, p < .001$ ]. These values indicated that the sample was sufficiently powerful to perform this type of analysis. The diagonals of the anti-image correlation matrix all were over .50, and the communalities all were above .30, indicating that each of the six total scores shared some common variance with each of the others. In light of these indicators, exploratory factor analysis was determined to be an appropriate statistical method for these data.

Within the comparison group, two factors with Eigenvalues greater than 1 emerged. The first factor had an Eigenvalue of 2.40 and accounted for 47.92% of the total variance; the second factor had an Eigenvalue of 1.05 and accounted for 20.93% of the total variance; together, the two factors accounted for 68.85% of the total variance. See Table 12 for a breakdown of factor loadings and communalities.

Table 12

*Factor Loadings and Communalities Based on a Factor Analysis with 6 Total Scores on Sexuality-Related Constructs (Comparison Group)*

<u>Item</u>	<u>Factor 1</u>	<u>Factor 2</u>	<u>Commonality</u>
Sexual desire	<b>.80</b>		.65
Sexual behavior	<b>.74</b>		.64
Sexual satisfaction	-.37	<b>-.86</b>	.88
Sexual consciousness	<b>.74</b>	.38	.69
Sexual monitoring	<b>.72</b>		.59

These results are highly consistent with, and more pronounced than the findings with the ASD group. These findings suggest that strong relations exist across the dimensions of sexual desire, behavior, consciousness, and monitoring for young women without ASD, and also that sexual satisfaction appears to function somewhat differently.

Based on the results of the exploratory factor analyses on the total score level, it was determined that “global sexuality,” a latent variable driven by participants’ sexual desire, behavior, consciousness, and monitoring, would be one dependent variable, and that participants’ sexual satisfaction, an observed variable, would be a second dependent variable.

**Specific Aim 4: To explore whether internalizing symptoms and sensory symptoms moderate the relation between ASD symptoms and aspects of sexuality for women with ASD.** Structural equation models and path analyses, executed with the

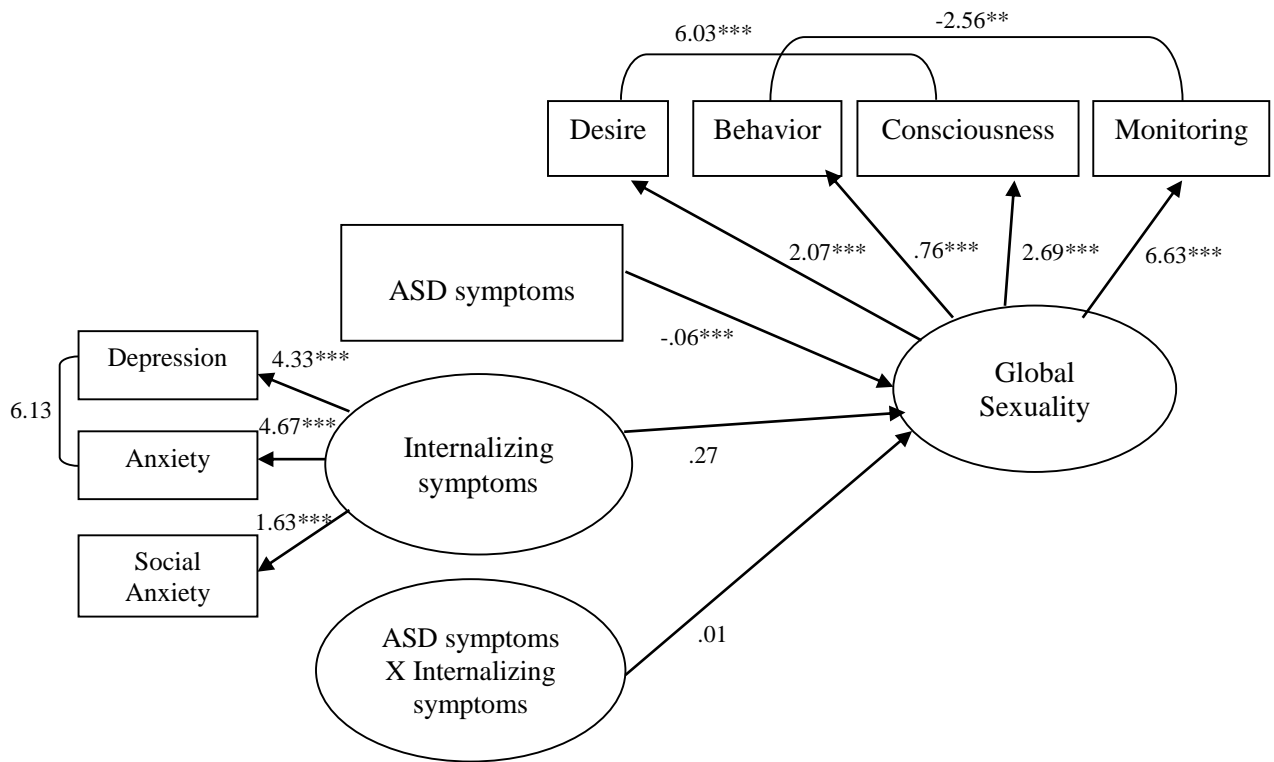
Mplus Version 7.3 software package, were used to test the hypotheses that internalizing symptoms would moderate the relation between ASD symptoms and sexuality outcomes (Hypothesis 8), and that sensory symptoms would moderate the relation between ASD symptoms and sexuality outcomes (Hypothesis 9).

In these analyses, the independent variable was ASD symptoms, measured continuously using the 4-point version of the AQ-10. Internalizing symptoms, a moderator, were measured as a latent variable; the observed predictors were total scores on the *Personal Health Questionnaire Depression Scale* (Kroenke et al., 2009), the *Generalized Anxiety Disorder Scale* (Spitzer et al., 2006), and the *Mini-Social Phobia Inventory* (Connor, Kobak, et al., 2001). Sensory symptoms, another moderator, were measured as the total score on the *Sensory Sensitivity Questionnaire* (Minshew & Hobson, 2008). The two dependent variables were two sexuality outcomes, identified in analyses of Specific Aim 3. The first sexuality outcome, “global sexuality,” captured participants’ thoughts, feelings, and actions in regard to their sexuality; this was measured as a latent variable, and its observed predictors were total scores on the *Sexual Desire Inventory* (Spector et al., 1998), *Sexual Experience Questionnaire* (Trotter & Alderson, 2007), and the sexual consciousness and sexual monitoring subscales of the *Sexual Awareness Questionnaire* (Snell et al., 1991). The second sexuality outcome captured participants’ sexual satisfaction; this observed variable was the total score on the *Sexual Satisfaction Scale for Women* (Maston & Trapnell, 2005). Each model test also included the covariates of age, student status, employment status, and housing situation (i.e., whether or not participants lived with their parents).



***Moderating effects of internalizing symptoms.*** In the first model, potential interaction effects between ASD symptoms and internalizing symptoms in predicting global sexuality were measured. See Figure 1.

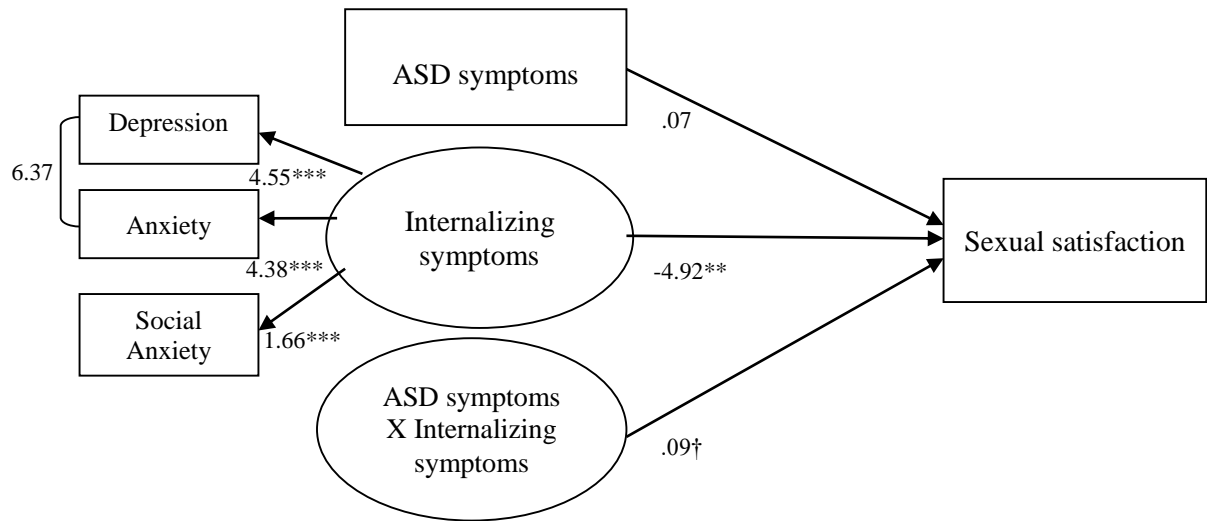
Figure 1. Structural Equation Model to Test Potential Moderating Effects of Internalizing Symptoms on the Relation Between ASD Symptoms and Global Sexuality



Due to the inclusion of a latent interaction variable in the model above, standardized estimates and the traditional model fit indices were not calculated here, or for any of the other models in which internalizing symptoms were the moderator. Instead, the unstandardized estimates are provided in Figure 1, and these were the basis for interpreting several relations across the variables in the model. First, the internalizing symptoms and global sexuality latent variables each had good factor loadings. Second, a main, negative effect of ASD symptoms on global sexuality was observed [unstandardized estimate =  $-.06$ , standard error =  $.01$ ,  $p < .001$ ]; additionally, the age [unstandardized estimate =  $.04$ , standard error =  $.02$ ,  $p = .02$ ], employment status [unstandardized estimate =  $-.41$ , standard error =  $.12$ ,  $p = .001$ ], and housing situation [unstandardized estimate =  $-.36$ , standard error =  $.12$ ,  $p < .01$ ] covariates each significantly predicted global sexuality. Third, neither internalizing symptoms nor an interaction between internalizing and ASD symptoms appeared to predict participants' global sexuality.

In the second model, potential interaction effects between ASD symptoms and internalizing symptoms in predicting sexual satisfaction were measured. See Figure 2.

*Figure 2. Structural Equation Model to Test Potential Moderating Effects of Internalizing Symptoms on the Relation Between ASD Symptoms and Sexual Satisfaction*

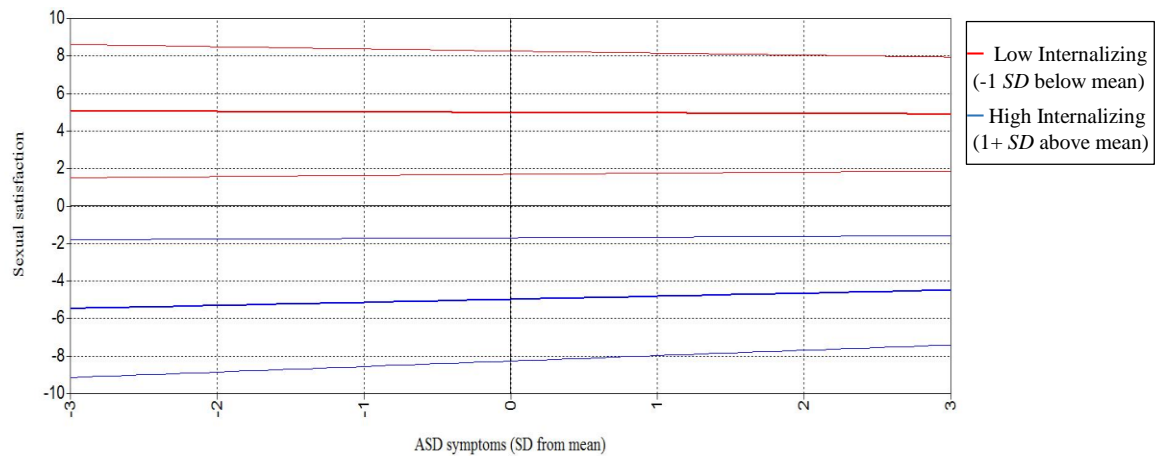


The unstandardized estimates yielded for the second model demonstrate a main, negative effect of internalizing symptoms on sexual satisfaction [unstandardized estimate = -4.92, standard error = 1.68,  $p < .01$ ]; the age covariate (not shown above) also significantly predicted sexual satisfaction [unstandardized estimate = -.26, standard error = .10,  $p = .01$ ]. A marginal interaction effect was observed between internalizing symptoms and ASD symptoms in predicting sexual satisfaction [unstandardized estimate = .09, standard error = .06,  $p = .096$ ]. This marginal interaction effect was explored further using the loop plot function within Mplus (see Figure 3). These results clearly demonstrate the significant main effect of internalizing symptoms on sexual satisfaction, and the lack of a significant main effect of ASD symptoms on sexual satisfaction. The slightly positive slope of the line representing high levels of internalizing symptoms (i.e., more than one standard deviation above the mean) also shows that participants with high levels of both ASD and internalizing symptoms reported slightly greater sexual satisfaction than those with high levels of internalizing symptoms but lower levels of ASD symptoms. This marginal, unanticipated finding should be interpreted with caution.

Figure 3

*Decomposition of Interaction Effect Between Autism Symptoms and Internalizing*

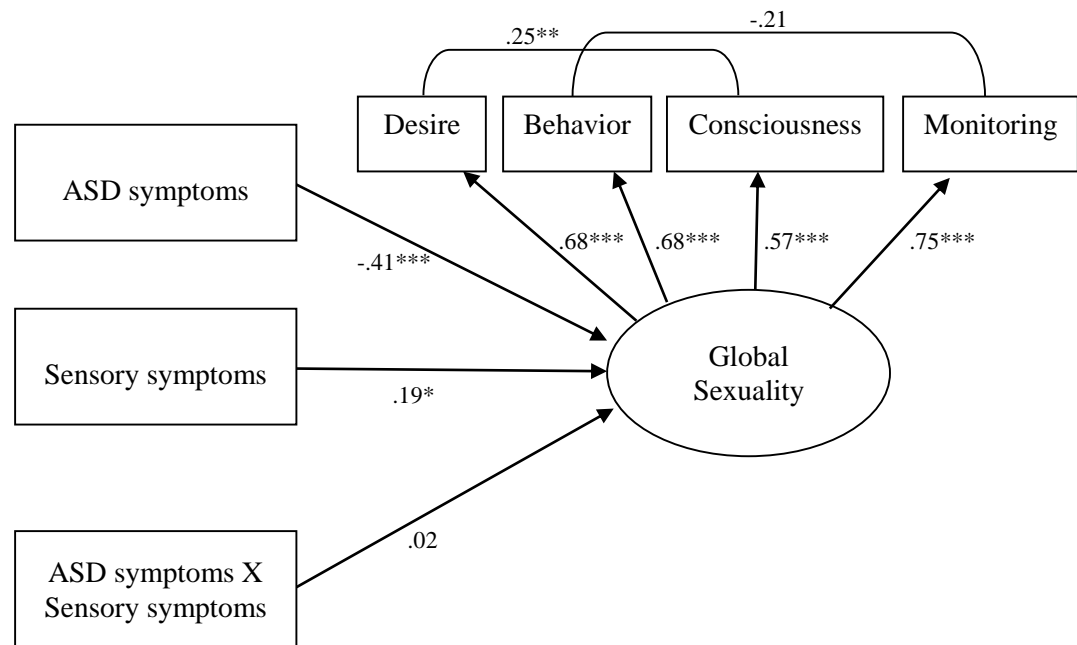
*Symptoms in Predicting Sexual Satisfaction*



*Note.* Confidence bands (95%) are shown above and below the lines for low internalizing symptoms and high internalizing symptoms.

***Moderating effects of sensory symptoms.*** Seeing that sensory symptoms were an observed variable (not a latent variable, as opposed to internalizing symptoms), standardized estimates were calculated for the next series of models, and are reported in Figures 4 and 5. In the third model, potential interaction effects between ASD symptoms and sensory symptoms in predicting global sexuality were measured. See Figure 4.

Figure 4. Structural Equation Model to Test Potential Moderating Effects of Sensory Symptoms on the Relation Between ASD Symptoms and Global Sexuality

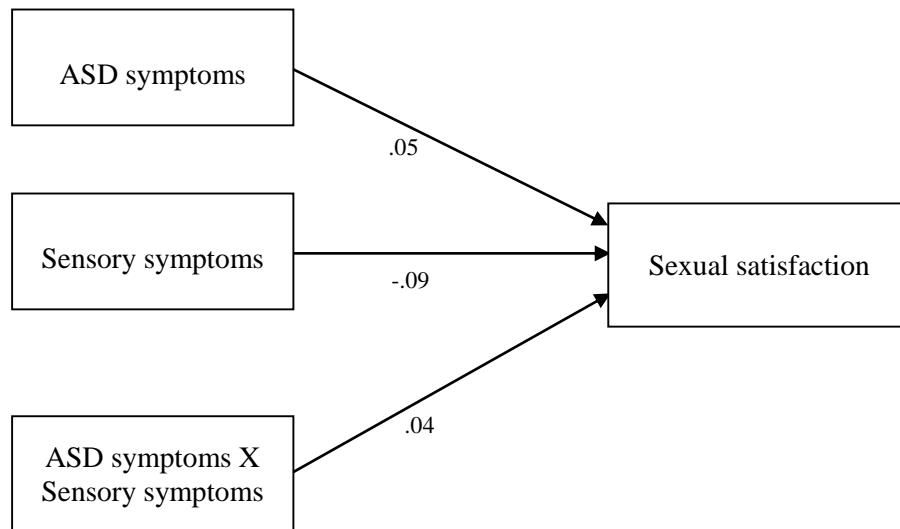




As shown in Figure 4, a main, negative effect of ASD symptoms on global sexuality was observed [standardized estimate =  $-.41$ , standard error =  $.08$ ,  $p < .001$ ], and a main, positive effect of sensory symptoms on global sexuality was observed [standardized estimate =  $.19$ , standard error =  $.08$ ,  $p = .01$ ]. Additionally, the employment status [standardized estimate =  $-.19$ , standard error =  $.05$ ,  $p < .001$ ], and housing situation [standardized estimate =  $-.17$ , standard error =  $.05$ ,  $p = .001$ ] covariates, not shown, each significantly predicted global sexuality. However, ASD symptoms and sensory symptoms did not interact significantly to predict global sexuality [standardized estimate =  $.02$ , standard error =  $.05$ ,  $p = .70$ ].

In the fourth and final model, potential interaction effects between ASD symptoms and sensory symptoms in predicting sexual satisfaction were measured. See Figure 5.

*Figure 5.* Structural Equation Model to Test Potential Moderating Effects of Sensory Symptoms on the Relation Between ASD Symptoms and Sexual Satisfaction



As shown in Figure 5, no significant main effects on sexual satisfaction were observed for either ASD symptoms [standardized estimate = .05, standard error = .07,  $p = .48$ ] or sensory symptoms [standardized estimate = -.09, standard error = .07,  $p = .23$ ]. Further, ASD symptoms and sensory symptoms were not found to interact significantly to predict sexual satisfaction [standardized estimate = .04, standard error = .05,  $p = .44$ ]. In this model, the age covariate [standardized estimate = -.11, standard error = .06,  $p = .05$ ] was a marginal predictor of global sexuality.

### **Exploratory Qualitative Analyses**

***Impact of ASD on sexuality.*** All participants with ASD were asked to answer the following open-ended item: “If you identify as being on the autism spectrum, are there central ways that being on the spectrum has influenced your sexuality? If so, please describe.” While a full qualitative analysis of participants’ responses was beyond the specific aims of the current project, the PI used a thematic analysis approach to analyze the responses preliminarily and identified a number of compelling themes.

Of the 84% of participants who responded, relatively few reported that their ASD had had no impact on their sexuality (13%), or that they were unsure as to whether their ASD had impacted their sexuality (6%). Some participants indicated that having ASD was central to their personhood and in the absence of never *not* being on the autism spectrum, they could not say whether it had impacted their sexuality.

Having sensory issues associated with their ASD was identified as a theme in participants’ responses. A significant portion of the sample (37%) reported experiencing sensory sensitivities; while many individuals reported that these interfered with their

engagement in, and enjoyment of sexual activities, several indicated that their sensory sensitivities were a positive influence that heightened their sexual experiences. Related to sensory sensitivities, some participants indicated that they disliked and felt uncomfortable with physical closeness and touching, in both platonic and romantic contexts. Also related to sensory sensitivities, some participants (8%) reported being sensory seeking, including participating in BDSM activities. In addition to enjoying the sensory aspect of these sexual activities, some participants reported enjoying BDSM due to their more defined and less ambiguous social roles.

Interpersonal difficulties as a barrier to relationships and sexuality was another identified theme. A significant portion (20%) of participants cited having difficulty forming relationships with other people, and experienced these as impediments to having the kinds of sexual lives that they desired. Some participants discussed having difficulty interpreting others' verbal cues and body signals, to determine platonic, romantic, and/or sexual interest (7%); some participants discussed having difficulty interpreting their own emotions and feelings of attraction (5%). Many participants discussed having communication difficulties (10%) although interestingly, some participants (4%) reported having strengthened communication abilities, as a result of having devoted so much time and attention to improving these skills. Some participants discussed the challenges of "coming out" as having ASD in both friendships and romantic relationships, and coping with negative perceptions and stereotypes about people on the autism spectrum. Some participants reported that these misconceptions made it difficult to access the queer community and the types of social spaces (e.g., bars, parties) in which new relationships

could form. Additionally, some participants believed that negative perceptions of ASD had resulted in compromised sexual education. In light of these challenging stereotypes and misconceptions, some participants discussed desiring partners with previous disability experience, if not a disability or ASD identity themselves. A small number of participants reported appreciating and benefiting from their current partners who provided support around every day routines and tasks made challenging by their ASD.

Having non-mainstream levels of desire for relationships and sexual contact with others was another identified theme. Consistent with participants' open-ended responses around sexual orientation, a number of participants discussed being on the asexual spectrum (13%), and believed that this was associated with being on the autism spectrum. In fact, some participants reported that they had identified as asexual for much longer than they had identified as being on the autism spectrum; thus, some individuals discussed their sexuality shaping their autistic identity, instead of the other way around (as the open-ended item had presumed). Separate from asexuality, several participants discussed experiencing a very low sex drive, and experiencing sexual attraction very rarely, and only in very specific situations. On the other hand, a few participants discussed having very high sex drives. Similar to how a significant portion of participants discussed their romantic and sexual orientations separately in response to the open-ended sexual orientation item, a number of participants discussed how they teased apart sexual behaviors from emotional relationships, and their belief that ASD might be associated with their desire to do so. A number of participants reported having a lower interest in romantic relationships and/or sexual things, relative to peers without ASD.

Another theme identified involved feeling different from mainstream society and having feelings and experiences different from those of their non-ASD peers. A considerable percentage of participants (11%) reported feeling less wedded to societal norms, including gender roles and heterosexism, relative to individuals without ASD. Further, some participants reported having a delayed interest in dating, masturbation, and other romantic and sexual activities, and others believed, to varying degrees, that their romantic and/or sexual patterns differed from the non-ASD norm. Participants discussed different reactions and experiences in relation to these perceived differences: some discussed abstaining from romantic and sexual activities, because they felt anxious about not understanding the norms surrounding these behaviors, while others reported that their divergent experiences led them to be more comfortable and flexible in their personal identities, thus increasing their feelings of self-acceptance.

There were additional ways in which participants reported that the symptoms and features associated with ASD had impacted their sexualities. Consistent with the high rate of sexual victimization reported by participants with ASD, some individuals (5%) explicitly stated that they believed that their ASD was associated with their experiences of childhood and adulthood victimization. Several participants reported being interested in sexuality on an intellectual level, but not on an emotional or physical level, and others reported that it was an area of particular, focused interest. A small number of participants reported having ritualized sexual routines, including fetishes, and others reported experiencing a very high level of anxiety around sexuality. Finally, given that the average

age of ASD diagnosis within the current sample was 17 years old, some participants (4%) discussed the unique challenges of being diagnosed later in life.

***Rationale for participating.*** About 56% of participants with ASD, and 88% of comparison sample participants, provided a brief explanation as to why they participated in the current study. Table 13 presents a breakdown of the different codes that were identified in these responses.

Table 13

*Codes Identified in Participants' Responses Regarding Study Participation*

<u>Theme</u>	<u>% ASD Group</u>	<u>% Comparison</u>
		<u>Group</u>
Contribute to scientific research	32	41
Interest in ASD and/or disability broadly	29	10
Interest in sexuality issues	24	31
Interest in women's and/or gender issues	21	20
Desire to have identities/experiences represented	19	10
Appreciated approach to ASD/inclusion criteria	15	0
Increase public and professional awareness of ASD	13	0
Enjoyment of surveys and quizzes	12	13
Trusted source shared study information	12	6
Finding study topics interesting	11	21
Having free time to participate	9	9
Met inclusion criteria	9	0
Curiosity about survey content	6	8

Desire to learn about oneself	5	9
Increase resources for sex education	5	4
Interest in psychology/mental health	4	6
Feeling bored	4	4
Unsure/did not think too much about it	3	3
Sympathy for dissertation/research process	2	3
Procrastination	<1	4
Increase awareness and empathy for others	<1	1
Knowing someone with ASD	0	4
Knowing someone who is a sexual minority	0	<1

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*Note.* Percentages do not add up to 100% because a number of participants in both the ASD and comparison groups provided multiple reasons for completing the current study.

### **Subgroup Analyses**

A couple of unanticipated findings emerged among participants in the current sample. First, a significant minority of participants in both the ASD and comparison groups reported living outside the U.S. or Canada (29% and 16%, respectively), and a significant minority of participants (36%) included in the ASD group reported not having a formal diagnosis. Nationality, in terms of living in the U.S. or Canada versus another country, was tested as a potential covariate but ultimately was not included as such, as it was not significantly associated with any of the major sexuality- or non-sexuality-related variables. How nationality, cultural identity, and ASD identity may interact to predict one's experience of sexuality is a much larger question to be explored in a future study.



Second, a significant minority of participants (36%) in the ASD group scored above the clinical cutoff on the AQ-10 (Allison et al., 2012) and self-identified as being on the autism spectrum, but did not have a formal diagnosis. A series of independent samples t tests were performed to determine whether participants with and without a formal diagnosis of ASD significantly differed on any major continuous sexuality- or non-sexuality-related variable (see Table 14). These analyses showed that the ASD group participants with and without a formal diagnosis shared many similarities across the major sexuality- and non-sexuality-related variables. The only significant difference observed between the groups was in regard to social anxiety: participants without a formal diagnosis reported a higher rate of symptoms than participants with a formal diagnosis. However, the effect size for this difference was somewhat small. Given the vast similarities between those with and without a formal diagnosis, analyses of Specific Aims 3 and 4 were not replicated to compare subgroups.

Table 14

*Descriptive Statistics and Between-Group Differences on Major Continuous Variables**for Participants in ASD Group With and Without a Formal Diagnosis*

<u>Variable (Questionnaire)</u>	<u>Mean</u>	<u>SD</u>	<u>Range</u>	<u>Between-Group Difference</u>
ASD symptoms (AQ-10)				
Formal diagnosis of ASD	32.78	2.92	25-40	<i>n.s.</i>
No formal diagnosis	32.77	3.02	26-40	
Sensory symptoms (SSQ)				
Formal diagnosis of ASD	9.23	1.76	3-13	<i>n.s.</i>
No formal diagnosis	9.12	1.55	3-12	
Depression (PHQ8)				
Formal diagnosis of ASD	11.16	6.56	0-24	<i>n.s.</i>
No formal diagnosis	11.95	5.71	2-24	
Anxiety (GAD7)				
Formal diagnosis of ASD	10.15	6.01	0-21	<i>n.s.</i>
No formal diagnosis	10.51	5.77	0-21	
Social Anxiety (MINI-SPIN)				
Formal diagnosis of ASD	7.36	3.47	0-12	<i>t</i> (246) = -2.92*** Cohen's <i>d</i> = .37
No formal diagnosis	8.66	3.16	0-12	
Sexual Desire (SDI)				
Formal diagnosis of ASD	-.11	4.33	-7.21-9.05	<i>n.s.</i>
No formal diagnosis	-1.01	3.85	-7.21-8.06	
Sexual Behavior (SEQ)				
Formal diagnosis of ASD	2.66	1.25	0-4	<i>n.s.</i>
No formal diagnosis	2.89	1.17	0-4	
Sexual Satisfaction (SSSW)				
Formal diagnosis of ASD	19.36	6.71	6-30	<i>n.s.</i>
No formal diagnosis	19.98	6.55	6-30	
Sexual Victimization (CSAS)				
Formal diagnosis of ASD	1.63	1.52	0-4	<i>n.s.</i>
No formal diagnosis	1.39	1.50	0-4	
Sexual Consciousness (SAQ)				
Formal diagnosis of ASD	13.39	6.56	0-24	<i>n.s.</i>
No formal diagnosis	13.24	5.92	0-24	
Sexual Monitoring (SAQ)				
Formal diagnosis of ASD	16.27	5.98	1.29-30	<i>n.s.</i>
No formal diagnosis	16.11	6.37	7-30	

*Note.* AQ-10 = *Autism-Spectrum Quotient* (Allison et al., 2012). SSI = *Sensory Sensitivity Questionnaire* (Minshew & Hobson, 2008). PHQ8 = *Personal Health Questionnaire Depression Scale* (Kroenke et al., 2009). GAD7 = *Generalized Anxiety Disorder Scale* (Spitzer et al., 2006). MINI-SPIN = *Mini-Social Phobia Inventory* (Connor, Kobak, et al., 2001). SDI = *Sexual Desire Inventory* (Spector et al., 1998). SEQ = *Sexual Experience Questionnaire* (Trotter & Alderson, 2007). SSSW = *Sexual Satisfaction Scale for Women* (Maston & Trapnell, 2005). CSAS = *Childhood Sexual Abuse Scale* (Aalsma et al., 2002). SAQ = *Sexual Awareness Questionnaire* (Snell et al., 1991).

\*\* *p* < .01 \*\*\* *p* < .001

## CHAPTER 5

### DISCUSSION

The current study was successful in recruiting a large sample of women, including transfeminine women and female-bodied individuals with more fluid gender identities, between 18 and 30 years old to participate. With a total sample size of 248 individuals with ASD and 179 individuals without ASD, the sample is unprecedentedly large among self-report ASD and sexuality studies. The online nature of recruitment and data collection undoubtedly contributed to the large sample size, which allowed for a powerful analysis of relations across sexuality-related and non-sexuality-related variables.

#### **ASD Sample Characteristics**

At 17.9 years old, one of the most surprising characteristics of the current ASD sample was the average age of first diagnosis. According to the latest CDC (2014) statistics, the average age of diagnosis for autism and ASD is about four years old and for Asperger's Syndrome – the most frequently reported diagnosis in the current sample – it is about six years old. It is also the case that the rate of ASD diagnosis is increasing, as are tools for validly and reliably detecting ASD in younger and younger children

(Kleinman et al., 2008). Autistic self-advocate and author Rudy Simone (2010) posited that increasing autism awareness, as well as communities and resources for individuals on the spectrum, are leading individuals to question whether they are on the autism spectrum and to undergo diagnostic testing later in life. Simone argued that this particularly may be the case for women with ASD, without concurrent ID, who may have functioned well academically, professionally, or in other areas, and have “flown under the radar” of diagnosis earlier in life. While diagnostic status, average age of first diagnosis, and who made the first diagnosis were examined in the current study, few other details are known as to how participants came to be diagnosed, and in turn, why the average age of first diagnosis was so high. While this finding requires replication in comparable samples, it does speak to the unique profiles and experiences of some young women with ASD, and to the need for focused research within this age and gender group.

### **Sexuality and Well-Being Among Young People With and Without ASD**

In terms of relationship and family status, about half of the participants in both the ASD and comparison groups reported being single; further, low percentages of participants in each group reported being engaged or married. Where the groups differed significantly was in terms of being in a relationship: participants with ASD were significantly less likely than participants without ASD to report having a boyfriend or girlfriend. This discrepancy between groups resonated with many participants’ responses to the open-ended item about how being on the autism spectrum may have impacted their sexuality: some participants discussed barriers to finding partners, including difficulties with communication, forging new connections with others, understanding and following

social conventions, and integrating into social spaces; other participants discussed having little interest in romantic or sexual relationships with others.

Participants with ASD were also significantly more likely to report being polyamorous, or having more than one concurrent romantic relationship. These experiences were also consistent with the open-ended responses: a number of individuals with ASD reported feeling more open-minded than non-spectrum peers, including feeling less wedded to societal norms and expectations (e.g., heterosexism, traditional gender roles, monogamy). Among those participants who reported having a romantic partner, individuals with ASD reported significantly longer relationships, on average, than participants without ASD. While unexplored in the current study, relationship satisfaction in relationships in which one or more partners has ASD would be an important construct to examine in future studies; doing so would build upon the mixed-methods work of Sarah Hendrickx (2008). Future work may also follow the example of Byers, Nichols, and Voyer (2013), and Byers, Nichols, Voyer, and Reilly (2013) and examine sexuality within those with more or less experience in relationships.

Among those individuals with ASD who had romantic partners, about one-quarter of partners were on the autism spectrum, while seven percent of participants in the comparison group reported having a partner on the autism spectrum. Consistent with emerging research on romantic relationship preferences among people on the autism spectrum (e.g., Goldsworthy, 2010), these findings suggest that relationships in which one partner has ASD and one partner does not are more common than relationships in which both partners have ASD. It is recommended that future sexuality resources for

individuals with ASD and their partners explore the benefits and challenges of, and provide helpful recommendations for navigating both types of relationships.

The current study expanded upon the existing research of Bejerot and Eriksson (2014) and Ingudomnukul and colleagues (2007) to explore gender identity in an open-ended format. To our knowledge, this was the first time that gender identity was assessed in this manner within a self-report ASD and sexuality study. Individuals with ASD were more likely than those without ASD to report a genderfluid identity, including but not limited to genderfluid, genderqueer, agender (absence of gender), bigender (both male and female), non-binary, and transgender. The extent to which participants with ASD identified as genderqueer – 50% of the current sample – was unanticipated, and might be related to the study explicitly being open to individuals with genderfluid identities, or to the sampling methods used (e.g., a number of individuals publicized the study on social media, potentially within communities of genderqueer individuals on the autism spectrum). Such factors suggest that these gender identity findings require further investigation and replication.

In the domain of sexual history and health, some notable similarities were observed between sexually active participants with and without ASD. For instance, the average age of first sex for both groups was 17 years old, the average number of sexual partners was 3 for the ASD group and 3.5 for the comparison group, and both groups reported using similar methods of preventing pregnancy and STI transmission (most frequently, the male condom), when applicable. Further, participants with and without ASD were equally likely to have had at least one gynecological exam, which can be

considered a proxy for sexual health. However, participants with ASD were significantly less likely than comparison sample participants to have had sex, or otherwise to have engaged in partnered sexual activity.

Regarding sexual orientation, the majority of participants in both the ASD and comparison groups identified as sexual minorities. This finding was particularly pronounced for participants on the autism spectrum. A unique contribution of the current study involved asking participants about their sexual orientation in an open-ended format, which afforded participants great flexibility and freedom to describe themselves and their identities. Unanticipated findings included the number of participants with ASD who discussed their romantic orientation (i.e., their gender identity in relation to the gender identity of individuals with whom they desired close, emotional bonds) in addition to their sexual orientations, and the frequency with which sexual orientation and romantic orientation diverged. Like other constructs explored in the current study, romantic orientation and sexual orientation deserve continued exploration, particularly using open-ended methods.

Contrary to the findings of Gilmour and colleagues (2012), who observed comparable levels of sexual desire between adults with and without ASD, participants with ASD reported significantly lower levels of sexual desire than comparison sample participants in the current study. However, a wide range of sexual desire was observed within the ASD sample, which was supported by participants' open-ended responses about how being on the autism spectrum may have influenced their sexuality. Some participants reported feeling hypersexual and endorsed a high level of sexual sensation-

seeking behavior, which they attributed to being on the spectrum. However, other participants reported having a very low sex drive, and minimal desire for either relationships or sexual activity. The diversity around sexual desire observed within the current sample was more consistent with the mixed-methods work of Sarah Hendrickx (2008), then with the peer-reviewed, self-report studies. However, the current study's focus on women may partially explain the discrepancy between the current findings and previous findings with mixed-gender samples, seeing that women with ASD, relative to men with ASD, may experience lower levels of sexual desire (Byers, Nichols, Voyer, & Reilly, 2013).

Participants with and without ASD reported comparable numbers of sex education sources. However, these sources differed between groups: women with ASD were significantly more likely to read books independently to gain sexuality information, and were less likely to glean this information from more social sources, including female friends, male friends, relatives other than parents, and health professionals. Relatedly, participants with ASD were less likely to discuss sexual matters with both their male and female friends, and were more likely not to discuss sexual matters with any friends, thus providing support for Nichols and colleagues' (2008) hypothesis that girls and women on the autism spectrum are less likely to learn sexual information socially, relative to their non-spectrum peers. In spite of these differences that emerged between the ASD and comparison groups in terms of sex education sources, both groups reported comparably high levels of satisfaction with their level of knowledge. Of note, despite the emergence of new sex education programs designed specifically for individuals on the autism



spectrum, less than two percent of the ASD sample reported that they had participated in such a program.

As hypothesized, participants with ASD were found to engage in fewer sexual activities, with less frequency, than comparison sample participants; this finding was particularly pronounced in regard to partnered sexual activities (e.g., deep kissing, performing and receiving oral sex, vaginal intercourse). Individuals with and without ASD were more similar in their engagement in lower base rate partnered sexual activities (e.g., anal intercourse, group sex), and in solo sexual activities. A large majority of participants in both groups reported masturbating alone, experiencing orgasm alone, and looking at pornography. There was no sexual activity in which participants with ASD were significantly more likely to engage than comparison sample participants. In spite of the differences observed between the ASD and comparison groups, particularly in terms of partnered sexual activities, a wide range of sexual behaviors and experiences were reported by participants with ASD, and expanded upon in their responses to the open-ended sexuality item.

Contrary to expectations, the rates of sexual satisfaction were comparable between participants with and without ASD. In fact, this was the only aspect of sexuality in which significant differences did not emerge between the groups. The lack of significant findings between groups could reflect true similarity in the experiences of young women with and without ASD; however, caution should be taken when interpreting these findings, given that sexual contentment was used as a proxy for sexual satisfaction, and sexual satisfaction has been conceptualized by other researchers as

having additional components. For example, Byers and Nichols (2014) tested and found support for the well-established, multi-faceted Interpersonal Exchange Model of Sexual Satisfaction (IEMSS; Lawrance & Byers, 1995) in their sample of adults with ASD. While few differences were observed between men and women with ASD in Byers and Nichol's (2014) study, the research design did not include a sample of non-spectrum controls. Further research is necessary in order to understand how young people on the autism spectrum may experience the different dimensions of sexual satisfaction differently.

Consistent with previous findings, rates of sexual victimization were high in both groups: 62% of participants with ASD and 53% of participants without ASD reported at least one lifetime occurrence. While high, these rates were congruent with Brown-Lavoie and colleagues' (2014) findings in a slightly older sample, in which 78% of participants with ASD had experienced at least one instance of sexual victimization, compared to 47.4% of participants without ASD. In the current study, participants with ASD reported more types of sexual victimization, on average, and the difference between the groups grew when sexual victimization was measured continuously instead of dichotomously. In their open-ended responses, a number of participants with ASD expressed the belief that their ASD symptoms, including difficulty reading others' intentions and recognizing "red flags" in relationships, contributed to their victimization and mistreatment. Considering that rates of sexual victimization are frequently underreported in research contexts, the high rates of victimization reported in the current study may not even capture the full range of victimization among young women with and without ASD. The current findings

speak to the vulnerability of young people, particularly those with ASD, and carry important implications for researchers and clinicians alike.

Consistent with the expectation that the symptoms and features of ASD might interfere with individuals' sexual awareness, individuals with ASD reported lower levels of both sexual consciousness, including awareness of their own sexual thoughts, feelings, and sensations, and sexual monitoring, including awareness and concern about how they present sexually to other people, than participants without ASD. In their open-ended responses about how being on the autism spectrum may have impacted their sexuality, a number of participants identified as having alexithymia (Sifneos, 1973), a personality trait characterized by inabilities to identify and describe one's own emotional experiences. These qualitative responses were largely consistent with participants' quantitative responses around sexuality awareness; the current findings speak to the importance of awareness, of both self and others, in experiences of sexuality.

In addition to the difference observed between the ASD and comparison groups along many of the sexuality-related variables, differences were also observed along the non-sexuality-related variables included in the current study, including symptoms of ASD, sensory sensitivity, depression, anxiety, and social anxiety. Consistent with the findings of Byers, Nichols, and Voyer (2013), Lai and colleagues (2011), and others, participants with ASD reported greater symptomatology across each of these domains, relative to participants without ASD. In this regard, the experiences of the current sample of young women with ASD were consistent with the experiences reported by a wider age range of adults in mixed-gender ASD samples.

## **Relations Between and Across Sexuality-Related and Non-Sexuality-Related Constructs**

Tests for potential covariates shed light on the contextual factors that impact the sexualities of young women with ASD. Age, student status, employment status, and housing situation were found to be correlated with sexuality-related variables, while nationality, education level, and household income were not. Arguably, the most compelling findings regarding contextual factors and sexuality outcomes centered on age. Age was found to be significantly correlated with multiple aspects of sexuality, particularly for the ASD sample: older individuals on the autism spectrum reported greater sexual desire, behavior, and consciousness. Although the current study was cross-sectional, not longitudinal, these findings still speak to the developmental nature of sexuality. Other researchers, including Byers, Nichols, and Voyer (2013), have noted that romantic and sexuality development may unfold slower or otherwise differently for individuals with ASD, relative to those without ASD. In fact, these findings were supported by some participants' responses to the open-ended item about how being on the autism spectrum may have impacted their sexuality. In the comparison sample, age was positively correlated with sexual behavior and consciousness, but not with sexual desire or monitoring. Interestingly, age was negatively correlated with sexual satisfaction in the ASD group, but no significant correlation was observed in the comparison group. One potential explanation for this finding may be that women with ASD experience sexual desire later than women without ASD, which increases as they grow older. However, as they experience greater desire, a discrepancy may emerge between their

relatively higher levels of sexual desire and their relatively lower levels of sexual behavior, which may result in greater sexual dissatisfaction. Other potential explanations for this unanticipated finding include the possibility that women, with and without ASD, may feel increasingly more pressure to have had a sexual relationship as they age. As found in the current study, participants with ASD were less likely to be in a relationship than comparison sample participants; in turn, the dissatisfaction of not being in a sexual relationship may be felt more acutely by older women. Another possibility is that the negative relation between age and sexual satisfaction reflects a cross-sectional issue, in that younger sexual minority individuals, who comprised the majority of both the ASD and comparison groups, might experience more openness and affirmation around their sexuality relative to older individuals.

Correlational analyses and exploratory factor analyses helped illuminate the relations across different sexuality-related variables, and how these patterns may differ between young women with and without ASD. To our knowledge, no previous self-report study on ASD and sexuality has attempted an exploratory factor analysis to identify meaningful, multi-faceted sexuality outcomes. Thus, performing exploratory factor analyses on the data collected from participants with and without ASD signals a significant contribution of this study to the current literature. Overall, sexual desire, behavior, consciousness, and monitoring were found to be correlated with one another, in both the ASD and comparison samples; these findings were further supported by the results of exploratory factor analyses on both the individual item and the total score level. Given their high degree of correlation within both groups – yet not so strong that

multicollinearity was a serious concern – these variables were later tested together as a “global sexuality” variable.

In the current study, sexual satisfaction functioned differently from sexual desire, behavior, consciousness, and monitoring, which were consistently positively correlated with one another. Interestingly, sexual satisfaction was the only sexuality construct that did not differ significantly between the ASD and comparison groups. The results of the EFA supported testing sexual satisfaction as a separate sexuality outcome. Still, some correlations were observed between sexual satisfaction and other sexuality-related variables, including a negative relation between sexual satisfaction and sexual desire in both groups. It may have been the case that asexual individuals experienced lower sexual desire but also felt greater contentment with their sexual lives as they did not desire something that they were failing to obtain or achieve.

Lifetime sexual victimization, which was widely reported both by individuals with and without ASD, was found to be significantly correlated with other aspects of sexuality. For individuals with ASD, sexual victimization was positively correlated with sexual desire, behavior, and monitoring, but uncorrelated with sexual satisfaction or consciousness. Somewhat similarly, for individuals without ASD, sexual victimization was positively correlated with sexual behavior, consciousness, and monitoring, but uncorrelated with sexual desire or satisfaction. These findings speak to the resilience of women with and without ASD who have been sexually victimized, and their capacity to experience sexual desire, engage in sexual activity, and demonstrate insight into their sexualities, in spite of their traumatic experiences. The lack of precise information around

sexual victimization (e.g., perpetrator, age at victimization, frequency of victimization) in the current sample limits the extent to which conclusions can be drawn about the relations between victimization and other sexuality-related variables. However, given the high rates of sexual victimization within a young sample of women with ASD – and recent findings that suggest that rates may be similar among men with ASD (Brown-Lavoie et al., 2014) – continued research is needed to understand how victimization impacts sexual development and identity among people on the autism spectrum.

In the current study, significant relations between sexuality-related and non-sexuality-related constructs were observed for participants with and without ASD. For instance, depression and anxiety were positively correlated with sexual victimization and sexual monitoring for both groups. However, directionality is unclear: it could be the case that being victimized, as well as exerting effort to assess others' reactions to one's sexuality – a particularly challenging task for many individuals with ASD – results in increased depression and anxiety symptoms. Alternatively, greater depression and anxiety symptoms could make participants more vulnerable to perpetrators, or hypervigilant of others' perceptions and reactions to their sexuality.

To our knowledge, the current study was the first to explore directly the relation between sensory symptoms, beyond the scope of items contained in an ASD screening measure, and sexuality outcomes among young people with ASD. Sensory symptoms were positively correlated with sexual victimization in both groups. Further, sensory symptoms were positively correlated with sexual behavior in the ASD sample, and with sexual desire in the comparison sample. In their open-ended responses, a significant

minority (37%) of participants with ASD reported having sensory symptoms that either interfered or did not interfere with their sexual lives. Fewer, but still a considerable number of participants discussed having hyposensitivities, and being sensory-seeking in their sexual lives. Current findings suggest that further investigation is warranted into the impact of sensory symptoms on dimensions of sexuality; additionally, sexuality resources for individuals with ASD and their partners ought to include information as to how individuals can accommodate and integrate their sensory profiles into their sexual lives.

A final goal of the current study was to examine whether the impact of having an ASD identity, and associated symptoms, on one's sexuality actually depended on one's level of internalizing symptoms or sensory symptoms. Participants' global sexuality scores were associated with lower levels of ASD symptoms and higher levels of sensory symptoms, but sexual satisfaction was associated with neither ASD symptoms nor sensory symptoms. These findings suggest that ASD-related symptoms, including interpersonal challenges, may pose a greater barrier to experiencing sexual thoughts, feelings, and behaviors than sensory symptoms. Consistent with some participants' open-ended responses, sensory symptoms may have the potential to heighten experiences around sexuality, particularly for those who are sensory-seeking or who have found ways to incorporate their sensory profiles into their sexual lives. With regard to internalizing symptoms, individuals with higher depression and anxiety symptoms were less sexually satisfied; further research could take a longitudinal approach in order to assess the directionality of this association. None of these types of symptoms (ASD, sensory, or



internalizing) interacted with one another to predict global sexuality or sexual satisfaction.

### **Strengths and Limitations**

A compelling strength of the current study is its large, community-based sample of young women, including transfeminine women and female-bodied individuals with more fluid gender identities, on the autism spectrum. The current study is one of few self-report ASD and sexuality studies to focus on women's experiences and young people's experiences; at this time, this is the only one to do so simultaneously. The study was strengthened further by the inclusion of a non-spectrum comparison sample, which provided a helpful context for understanding the identities and experiences of the ASD sample. Further, the online survey methodology, which eliminated face-to-face contact with the PI, likely reduced desirability bias, and stringent data cleaning methods likely reduced the risks associated with conducting online sexuality research (e.g., Mustanski, 2001).

Other methodological strengths of the current study include a concise battery with strong psychometric properties. Participants with and without ASD demonstrated engagement by completing the vast majority of all items, and providing rich responses and commentary in the open-ended response boxes. In addition, by assessing constructs such as sexual awareness, and social anxiety and sensory symptoms in relation to sexuality, the current study expanded upon the existing literature.

Seeing that half of the participants in the ASD group endorsed having a fluid gender identity, including agender, pangender, genderfluid, genderqueer, and non-binary

identities, it was important to assess gender in an open-ended format. To our knowledge, this is the first self-report ASD and sexuality study to do so, as opposed to using a checkbox approach to gender, and asking participants exclusively about identifying as feminine or masculine. The open-ended approach to assessing gender in the current study likely contributed to the high level of gender diversity observed within the current sample. Future ASD and sexuality researchers are encouraged to take a similar approach to assessing gender within their samples, both to demonstrate respect to participants whose gender identities may not fall neatly into a “checkbox,” and to replicate the unexpected findings of the current study. Using close-ended, binary-driven methods to assess the gender of young people with ASD appears to be ill-advised, as it may force individuals to choose a group (i.e., males, females) with which they do not identify and thus, yield inaccurate data.

In addition to the capacity to detect gender diversity, the current study was made rich by participants’ cultural diversity. Participants from over 20 countries participated in the current study, thus demonstrating that indeed, ASD cuts across all cultures, and reflecting the vibrant and international nature of many online communities for individuals with ASD, from which many participants were recruited. Within this cultural diversity lies a potential weakness, given the diversity in which different cultures approach both sexuality and disability. Participants’ country of origin was tested as a potential covariate in the current study; however, it was not observed to be significantly correlated with any of the sexuality-related or non-sexuality-related constructs. Much of the extant ASD and sexuality research has been conducted by researchers in the United States and Canada

(e.g., Brown-Lavoie et al., 2014; Byers, Nichols, & Voyer, 2013; Byers, Nichols, Voyer, & Reilly, 2013; Gilmour et al., 2012), with several studies conducted by researchers in Western Europe (e.g., Bejerot & Eriksson, 2014; Dewinter et al., 2014) and Australia (e.g., Mehzabin & Stokes, 2011). It is hopeful that in the near future, the ASD and sexuality literature will be as culturally and nationally diverse as the current ID and sexuality literature, that future ASD and sexuality researchers will continue to engage with culturally diverse ASD communities, and that they will be able to recruit samples large enough to conduct cross-cultural investigation.

In light of its multiple strengths and contributions to the current literature, the current study possesses several limitations, which are important to discuss here. For instance, the online nature of the current study, which allowed for the recruitment of an unprecedentedly large and diverse sample, made it impossible to test participants' intelligence or adaptive behavior. However, it is very likely that all participants possessed average intelligence or greater in order to access and complete the battery successfully. Thus, the findings of the current study may not generalize to individuals who have both ASD and ID.

Along with cognitive functioning and adaptive behavior, participants' ASD symptomatology was not clinically assessed in the current study. In fact, having a formal diagnosis of ASD was not an inclusion criterion for the ASD group. In the current ASD and sexuality literature, some researchers have required their participants with ASD to have formal diagnoses (e.g., Gilmour et al., 2012) and others have not (e.g., Byers, Nichols, & Voyer, 2013). There are drawbacks to both approaches, as individuals with a

formal diagnosis may have received that diagnosis in error, or at a very early age and no longer meet full diagnostic criteria. Further, individuals who believe that they are on the autism spectrum may not meet full criteria, and perhaps would not receive a formal diagnosis if they underwent formal testing. Aware that formal testing requires a degree of economic and social privilege, the decision was made in the current study to be inclusive around diagnostic status. As an added measure, individuals in the ASD group with and without a formal diagnosis were compared, and they reported vastly similar experiences in regard to the sexuality-related and non-sexuality-related constructs of interest; similar findings were observed by Byers, Nichols, and Voyer (2013). Ultimately, our inclusive approach is believed to be more of a strength as a weakness, as it reflects the fact that individuals who participate in and contribute to ASD communities may not have a formal diagnosis, or the means or desire to pursue one. Future researchers may strongly consider including individuals without a formal diagnosis in their ASD samples, and perhaps exploring reasons for not having one.

Every effort was made to create a battery that contained that would be straightforward, accessible, and completed easily by participants with and without ASD. While a number of the questionnaires used in the current study were previously used in other self-report ASD and sexuality studies, no questionnaire, with the exception of the AQ-10, was specifically designed for use with individuals with ASD. Although the battery was piloted carefully and the vast majority of questionnaires showed good internal consistency in both the ASD and comparison samples, it is possible that some items may have been confusing, unclear, or less relevant to participants with ASD.

While the open-ended items regarding the potential impact of ASD on sexuality and rationale for participating added depth and dimension to the current study, the thematic analysis methods used to analyze these qualitative data had some limitations. For instance, the analysis was performed solely by the PI. This approach was acceptable in the current study, as the goal of the analysis was more exploratory and thematic analysis was separate from the four specific aims. However, an important next step will involve replicating the current analyses with a multi-person coding team, a credibility check to verify the accuracy of the currently identified themes and to establish inter-rater reliability. Additionally, adding a coding team could allow for more nuanced thematic analysis of the existing data.

### **Future Research Directions**

Given the limited nature of the self-report ASD and sexuality literature, there are many directions for future work. For instance, immediate next steps to expand the current study may include replicating these methods with men and male-bodied individuals, with and without ASD. Another immediate next step may include following up with current participants and completing a second wave of quantitative data collection. To date, no self-report ASD and sexuality study has reported longitudinal data; this is a significant limitation of the overall literature, given that sexuality is widely accepted as a developmental and somewhat fluid construct. Longitudinal data would illuminate shifts in identities over time (e.g., gender, sexual orientation), and could empirically test the widely-held belief that individuals with ASD may have different sexual trajectories than those without ASD – and if they do, then how the trajectories differ. In such longitudinal

studies, currently measured constructs (e.g., sexual desire, behavior, satisfaction) could be reassessed and additional constructs could be explored (e.g., romantic orientation, romantic relationship experience, trauma-related symptomatology, sensory sensitivities in sexual contexts).

To date, Hatton and Tector (2010) have published the only peer-reviewed, self-report ASD and sexuality study to include qualitative data. Based on Hatton and Tector's (2010) success using this methodology, the richness of participants' open-ended responses in the current study, and the use of qualitative methods to explore other topics with adults with ASD, it is recommended that researchers use qualitative methods to gain a more nuanced understanding of sexuality among young women on the autism spectrum. These qualitative findings could increase public awareness, improve service delivery, and, as was the case for Hatton and Tector (2010), inform the development of sex education curricula and other interventions for young people with ASD.

It is hoped that the current study will inform the development of sex education programs, and sexuality resources more generally, for young people with ASD. In light of how many participants learned about the current study through online communities and networks, future sexuality resources should be made available electronically, as to increase visibility, accessibility, and distribution. The high rates of sexual victimization, gender fluidity, and sexual minority identity, including asexuality, were among the most striking findings in the current study; moreover, these were consistent with the findings of other recent ASD and sexuality studies. It is important that future sexuality materials for young people with ASD be sensitive to these unique experiences and identities.

## **Clinical Applications**

The findings of the current study carry important implications for clinicians, educators, and other professionals who provide supports to young people on the autism spectrum. As mentioned previously, the high rates of sexual victimization, gender fluidity, and sexual minority identity, including asexuality, were among the most surprising and striking findings in the current study. It is important for professionals to recognize the increased vulnerability of individuals with ASD, to be familiar with the signs and symptoms of sexual victimization, and to be aware of area and national resources for domestic violence and sexual abuse. It is also recommended that professionals do not make assumptions about the gender identities or sexual orientations of their clients with ASD. Instead, professionals should ask clients about their identities in an accepting, non-judgmental manner. As relevant to their field, professionals should be open to discussing sexuality topics with their clients on the autism spectrum; overlooking or avoiding these are likely to result in missed opportunities for sex education and empowerment, and may be construed as perpetuating harmful stereotypes and misconceptions (e.g., that people on the autism spectrum are uninterested in sex). In addition to sexuality-related topics, professionals are advised to ask clients about other aspects of their identity, including feelings and self-concept around being on the autism spectrum, and to understand how different identities may intersect. Whenever possible, clinicians should use the preferred language of their clients when discussing their identities and experiences.

In addition to health and educational professionals, the current findings also carry implications for family members, romantic partners, and friends of young people on the autism spectrum. It is hoped that the findings of the current study will help dispel the pervasive misconceptions that people with ASD are childlike, uninterested in sex, sexually inexperienced, or asexual (Dotson et al., 2003). While it is the case that some people with ASD identify as asexual and/or aromantic, many others are interested in sex and partnerships, yet face barriers to achieving the intimate lives they desire. It is the case that all people with ASD have sex education needs and deserve to have their sexualities respected. The notable diversity observed within every sexuality domain in the current study speaks to the importance of not making assumptions about individuals with ASD, and instead asking thoughtful questions, providing education, and offering support.



## APPENDIX A

### INFORMED CONSENT FORM

University of Massachusetts Boston  
Department of Psychology  
100 Morrissey Boulevard  
Boston, MA. 02125-3393

#### **Consent Form for the Women's Sexuality Study**

Principal Investigator: Hillary Hurst Bush, M.A.

#### **Introduction and Contact Information**

You are asked to take part in a research study that looks at sexuality (for example, sexual activity and sexual orientation), among young women (18-30 years old) with and without an autism spectrum identity. The researcher is Hillary Hurst Bush, M.A., a Doctoral Candidate in Clinical Psychology at the University of Massachusetts Boston. She is supervised by Dr. Abbey Eisenhower, Assistant Professor of Psychology at the University of Massachusetts Boston. Please read this form carefully. If you have any questions, please email Hillary at [umbwomensstudy@gmail.com](mailto:umbwomensstudy@gmail.com), or Dr. Eisenhower at [abbey.eisenhower@umb.edu](mailto:abbey.eisenhower@umb.edu). You also may call Dr. Eisenhower at 617-287-6334.

#### **Description of the Project**

This study is to understand better the sexualities of women on the autism spectrum, so that better education programs and other services may be created. This study is also to raise understanding for the people involved in the lives of women on the autism spectrum, like their romantic partners, family members, service providers, teachers, and therapists. Participation in this study will take about 20 minutes. If you choose to be a part of the study, then you will be asked to answer an online survey. You can do the survey from your own computer. Please note that this is a **volunteer** study; you will not receive monetary compensation for completing the survey.

#### **Risks or Discomforts**

There is a risk of feeling slight discomfort when answering the survey questions because they deal with sexual topics. Also, you will be asked about your thoughts and experiences with sexuality in a direct way. Please click [HERE](#) for a list of resources that provide support around autism and sexuality issues. You may contact Hillary, Dr. Eisenhower, or any of the groups on the list of resources if taking part in this study raises any concerns for you.

**Confidentiality and Anonymity**

Data gathered in this study will be confidential. That is, the data will not be published or presented in a way that would allow anyone to know who you are personally. In this study, Internet provider (IP) addresses will be collected, to make sure that people do not take the survey more than once, but these will be deleted after the data is screened. Any personal information you choose to give will be saved separately from your survey answers. The data files with personal information will be destroyed as soon as data collection ends. Code numbers, not names, will be used in our data files. Our data files will be saved on an encrypted, password-protected computer, and no one outside the small research team will have access to them.

**Voluntary Participation**

The decision to take part or not take part in the Women's Sexuality Study is voluntary. If you do decide to take part, then you may choose to stop participating at any time. Nothing bad will happen to you if you do not take part in the study, or if you do take part but then decide to stop before you are finished. If you begin the survey but decide that you want to stop it, then you should close your browser.

**Rights**

You have the right to ask questions about this study before you begin the survey, and at any time during the study. Hillary can be contacted at [umbwomensstudy@gmail.com](mailto:umbwomensstudy@gmail.com) and Dr. Eisenhower can be contacted at [abbey.eisenhower@umb.edu](mailto:abbey.eisenhower@umb.edu) or at 617-287-6334. If you have any questions or concerns about your rights as a research participant, please contact the UMass Boston Institutional Review Board (IRB), which oversees research involving human participants. The IRB may be reached at the following address: IRB, Quinn Administration Building-2-080, University of Massachusetts Boston, 100 Morrissey Boulevard, Boston, MA 02125-3393. You can also contact the IRB by calling (617) 287-5370 or by emailing [human.subjects@umb.edu](mailto:human.subjects@umb.edu).

**By clicking to continue, you are agreeing that you have read this consent form and want to participate in this study. You will be led to a brief, 5-item quiz that will check your understanding of the information in this consent form. You will need to answer these questions before you begin the actual survey.**

## APPENDIX B

### INFORMED CONSENT QUIZ

1. Your participation in this study is completely voluntary.  
TRUE  
FALSE
2. This survey contains direct questions about different aspects of sexuality.  
TRUE  
FALSE
3. Some participants may experience slight discomfort due to the survey questions.  
TRUE  
FALSE
4. Your contact information will NOT be linked to your survey answers in any way.  
TRUE  
FALSE
5. You may stop participating at any time, and nothing bad will happen.  
TRUE  
FALSE

## APPENDIX C

### LIST OF RESOURCES FOR PARTICIPANTS

Note: A comprehensive list of print and online resources for sexuality and disability, compiled by the Massachusetts Department of Public Health and the Massachusetts Department of Developmental Services, can be obtained at:

<http://www.mass.gov/eohhs/docs/dph/com-health/prevention/hrhs-sexuality-and-disability-resource-guide.pdf>

#### ***Autism Resources (national)***

##### **Autism Women's Network (AWN)**

The Autism Women's Network is an online community dedicated to building a supportive community for Autistic women of all ages, our families, friends and allies. AWN provides a safe space to share our experiences in an understanding, diverse and inclusive environment.

Website: <http://autismwomensnetwork.org/>

**Autism Support Network (ASN)** The Autism Support Network is an online resource with over a thousand members, including individuals on the spectrum and their family members. The site contains many message boards, information resources, and events to foster communication among people on the spectrum.

Website: <http://www.autismsupportnetwork.com/>

##### **Autistic Self-Advocacy Network (ASAN)**

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens. Autistic Self Advocacy Network is a 501(c)(3) nonprofit organization run by and for Autistic people. ASAN was created to serve as a national grassroots disability rights organization for the Autistic community, and does so by advocating for systems change and ensuring that the voices of Autistic people are heard in policy debates and the halls of power while working to educate communities and improve public perceptions of autism. ASAN's members and supporters include Autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators and friends.

Website: <http://autisticadvocacy.org/about-asan/>

**Autism After 16** Autism After 16 is dedicated to providing information and analysis of adult autism issues, with the emphasis on analysis. Anyone can Google "autism + adults" and discover a vast array of programs, documents, and products. The intention of Autism After 16 is to try to help adults on the spectrum and their families make sense of what's

out there. There is a specific focus on issues related to Transitions.

Website: <http://www.autismafter16.com/>

**Autism Now (The National Autism Resource and Information Center)** The Autism NOW Center provides high quality resources and information in core areas across the lifespan to individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities, their families, caregivers, and professional in the field. Focus areas include: Early detection, Early intervention, and Early education; Transition from high school into early adulthood; Community based employment; Advocacy for families and self-advocates; Community Inclusion; Aging Issues; Policy; Implementation of Health Care Reform, including Long Term Care Services and Supports; Family and Sibling Support; and Networking in local, state, and national arenas. These goals are accomplished in a variety of ways.

Website: <http://autismnow.org/>

### ***Autism Resources (Boston-area)***

#### **Asperger/Autism Network (AANE; formerly Asperger Association of New England)**

The Asperger/Autism Network (AANE) works with individuals, families, and professionals to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives. We do this by providing information, education, community, support, and advocacy, all in an atmosphere of validation and respect.

Location: 51 Water Street, Suite 206, Watertown, MA 02472

Phone: 617-393-3824

Website: [aane.org](http://aane.org)

#### **Aspire at Massachusetts General Hospital**

Aspire is dedicated to providing children, teens, and young adults with Asperger's Syndrome and related Autism Spectrum Disorders with the knowledge and skills necessary to make social connections and develop independence leading to successful and fulfilling lives. Aspire's approach is to teach social skills, life skills and other behavioral strategies within a small-group setting. Our programs offer a variety of recreational, social and educational activities within a group environment to help our participants learn from real-life group experiences. We focus on our participants' strengths and interests and emphasize using empirically validated interventions. Aspire also believes that the skills taught need to be consistently applied across all settings in the participant's life. For this reason, we take a collaborative approach and strive to work closely with parents, teachers, providers and others involved in the person's team. Aspire aims to meet the needs of underserved communities in the metro Boston area.

Location: 1 Maguire Road, Lexington, MA 02421

Phone: 781-860-1900

Website: <http://www2.massgeneral.org/youthcare/index.html>

**Lurie Center for Autism at Massachusetts General Hospital**

The Lurie Center for Autism is an integrated and multidisciplinary clinical, research, training and advocacy program dedicated to treating individuals with autism spectrum disorders and other developmental disorders. The Lurie Center is the primary clinical care and clinical research site implementing the broader goals of the Lurie Center for Autism. The Lurie Center is born out of a philosophy that people with developmental disabilities deserve to be viewed as individuals, each with personal patterns of talents and challenges. We strongly believe each individual deserves the opportunity for access to the quantity and quality of services needed to reach his or her full potential, regardless of economic, social or ethnic background. The Lurie Center is a multidisciplinary program designed to evaluate and treat children, adolescents and adults with a wide variety of neurodevelopmental conditions.

Location: 1 Maguire Road, Lexington, MA 02421

Phone: 781-860-1700

Website: <http://www.massgeneral.org/children/services/treatmentprograms.aspx?id=1614>

**Alan & Lorraine Bressler Clinical and Research Program for Autism Spectrum Disorders**

The Bressler Clinical and Research Program is dedicated to improving the clinical care of children and adults with autism spectrum disorders, to advance the education of patients, families and service providers about these conditions, and to expand the scientific understanding of these disorders. This program offers complete psychiatric evaluation, including psychopharmacological, neuropsychological, behavioral, and social service consultation.

Location: 55 Fruit Street, Warren 625, Boston, MA 02114

Phone: 617-726-7899

Website: [http://www.massgeneral.org/psychiatry/services/autism\\_home.aspx](http://www.massgeneral.org/psychiatry/services/autism_home.aspx)

***Sexuality Resources (national)*****Planned Parenthood**

Planned Parenthood is a highly regarded provider of reproductive health care. Health care professionals are dedicated to offering men, women, and teens high-quality, affordable medical care. Planned Parenthood has 68 unique, locally governed affiliates nationwide operate more than 700 health centers, which reflect the diverse needs of their communities. These health centers provide a wide range of safe, reliable health care — and more than 90 percent is preventive, primary care, which helps prevent unintended pregnancies through contraception, reduce the spread of sexually transmitted infections through testing and treatment, and screen for cervical and other cancers. Additionally, Planned Parenthood is a respected leader in educating Americans about reproductive and sexual health. It delivers comprehensive sex education that empowers women, men, teens, and families to make informed choices and lead healthy lives. Planned Parenthood

is proud of its vital role in providing young people with honest sexuality and relationship information in classrooms and online to help reduce high rates of teen pregnancies and sexually transmitted infections.

Website: <http://www.plannedparenthood.org/>

### **Go Ask Alice!**

Go Ask Alice! is a health question and answer Internet resource produced by Alice! Health Promotion at Columbia University — a division of Columbia Health. The website provides readers with reliable, accurate, accessible, culturally competent information and a range of thoughtful perspectives so that they can make responsible decisions concerning their health and well-being. Please note that information provided by Go Ask Alice! is not medical advice and not meant to replace consultation with a health care professional. This site has three frequently used features:

*New Go Ask Alice! Q&As of the Week* gives you the most recently published inquiries and responses — this section is updated every Friday.

*Search Go Ask Alice!* lets you find health information by subject via a search of the ever-growing Go Ask Alice! archives containing thousands of previously-posted questions and answers, and reader responses. The search box is located at the top of every page on the site.

*Ask Alice!* gives you the chance to ask and submit a question to Alice!

Website: <http://goaskalice.columbia.edu/>

### **Kinsey Confidential**

Kinsey Confidential is a sexuality information service designed by The Kinsey Institute for Research in Sex, Gender, and Reproduction to meet the sexual health information needs of college-age adults. The site contains articles on a variety of sex information topics as well as podcasts and questions and answers from the weekly newspaper column, Kinsey Confidential.

Website: <http://kinseyconfidential.org/>

### ***Sexuality Resources (Boston-area)***

#### **Boston Area Rape Crisis Center (BARCC)**

The Boston Area Rape Crisis Center (BARCC) is the only rape crisis center in the Greater Boston area and the oldest and largest center in Massachusetts. Its vision is to end sexual violence through healing and social change. BARCC was founded in 1973 by a group of people dedicated to building a hotline to answer calls from rape survivors.

Today, BARCC are national leaders in providing comprehensive, free services including a 24-hour hotline, 24-hour medical advocacy, individual and group counseling, and legal advocacy. BARCC also provides community awareness and prevention services through partnerships and training with organizations and communities.

Phone: 800-841-8371 (24-hour hotline)

Website: <http://www.barcc.org/>

## APPENDIX D

### ONLINE BATTERY

Do you have a formal diagnosis of autism spectrum disorder (ASD)?

- ☐ Yes
- ☐ No

What is your diagnosis?

- ☐ Autism
- ☐ Asperger's
- ☐ PDD-NOS
- ☐ Autism spectrum
- ☐ Other (please specify: \_\_\_\_\_)

At what age did you receive your diagnosis? \_\_\_\_\_

From whom did you receive this diagnosis? (e.g., primary care doctor, psychologist, psychiatrist) \_\_\_\_\_

Regardless of your diagnostic status, do you believe that you are on the autism spectrum?

- ☐ Yes
- ☐ No

Do you have a family member diagnosed with ASD?

- ☐ Yes
- ☐ No

If yes, which family members? Please check all that apply:

- ☐ Mother
- ☐ Father
- ☐ Brother
- ☐ Sister
- ☐ Grandmother
- ☐ Grandfather
- ☐ Aunt
- ☐ Uncle
- ☐ Cousin
- ☐ Your son or daughter
- ☐ Other (please specify: \_\_\_\_\_)

What is your age in years? \_\_\_\_\_



“Gender” refers to the socially constructed roles, behaviors, activities, and attributes that a given society considers appropriate for men and women. Examples of gender identity include “female,” “male,” “genderqueer,” etc. In your own words, what is your gender identity? \_\_\_\_\_

Race is based on how you look (often skin tone or facial features) and how you think of yourself (e.g., Black, Asian, White). In your own words, what is your race(s)? \_\_\_\_\_

Ethnicity commonly emphasizes the common history, nationality, geography, language, food, or dress of groups of people (e.g., Haitian, African-American, European-American, Dominican, Irish, Cantonese). In your own words, what is your ethnicity(ies)? \_\_\_\_\_

What is your household annual income, from all sources? If you live with your parents or other family members, please include their income. If you live with roommates, please do not.

- ☐ \$0 – \$5,000
- ☐ \$5,001 – \$10,000
- ☐ \$10,001 – \$20,000
- ☐ \$20,001 – \$30,000
- ☐ \$30,001 – \$40,000
- ☐ \$40,001 – \$50,000
- ☐ \$50,001 – \$60,000
- ☐ \$60,001 – \$70,000
- ☐ \$70,001 – \$80,000
- ☐ \$80,000+

Where was the location of your birth? (state/province, country) \_\_\_\_\_

What is your native language(s)? \_\_\_\_\_

What is the highest grade you have completed in school?

- ☐ 8<sup>th</sup> grade or less
- ☐ 1-3 years of high school
- ☐ High school diploma
- ☐ Vocational school/other non-college
- ☐ 1-3 years of college
- ☐ Associate’s degree (2-year degree)
- ☐ Bachelor’s degree (e.g., BA, BS)
- ☐ Master’s degree (e.g., MA, MBA, MSW)
- ☐ Professional degree (e.g., JD, MD, PhD)

Are you currently a student?

- ☐ Yes (full-time)
- ☐ Yes (part-time)
- ☐ No

Have you ever received special education in school?

- ☐ Yes
- ☐ No

If you have received special education in school, please describe: \_\_\_\_\_

Are you currently employed?

- ☐ Yes (full-time)
- ☐ Yes (part-time)
- ☐ No

What is your current housing situation? Please check all that apply:

- ☐ Live alone
- ☐ Live with romantic partner
- ☐ Live with roommate(s)
- ☐ Live with parent(s)
- ☐ Live with your child/children
- ☐ Live with sibling(s)
- ☐ Live with other relative(s)
- ☐ Other (please specify: \_\_\_\_\_)

What is your relationship status?

- ☐ Single
- ☐ In a relationship (boyfriend/girlfriend)
- ☐ Engaged
- ☐ Married (legally or non-legally recognized)
- ☐ Divorced
- ☐ Polyamorous
- ☐ Other (please specify: \_\_\_\_\_)

If you currently have a romantic partner (or partners), what is the gender identity of your partner(s)? \_\_\_\_\_

If you currently have a romantic partner (or partners), are they on the autism spectrum?

- ☐ Yes, and they have a diagnosis.
- ☐ Yes, but they do not have a formal diagnosis.
- ☐ I have more than one partner; some are on the spectrum and some are not.
- ☐ No

Do you have children?

- ☐ Yes
- ☐ No
- ☐ I am pregnant with my first child.

How did you learn about this study?

- ☐ Poster in a health clinic or non-profit organization
- ☐ Study website
- ☐ Poster at UMass Boston
- ☐ Facebook group
- ☐ Message board/list serve
- ☐ From a friend or personal contact
- ☐ Came across it while searching online
- ☐ Support group
- ☐ Other (please specify: \_\_\_\_\_)

Please select one option per question:

I often notice small sounds when others do not.

- ☐ Definitely agree
- ☐ Slightly agree
- ☐ Slightly disagree
- ☐ Definitely disagree

I usually concentrate more on the whole picture, rather than the small details.

- ☐ Definitely agree
- ☐ Slightly agree
- ☐ Slightly disagree
- ☐ Definitely disagree

I find it easy to do more than one thing at once.

- ☐ Definitely agree
- ☐ Slightly agree
- ☐ Slightly disagree
- ☐ Definitely disagree

If there is an interruption, I can switch back to what I was doing very quickly.

- Definitely agree
- Slightly agree
- Slightly disagree
- Definitely disagree

I find it easy to “read between the lines” when someone is talking to me.

- Definitely agree
- Slightly agree
- Slightly disagree
- Definitely disagree

I know how to tell if someone listening to me is getting bored.

- Definitely agree
- Slightly agree
- Slightly disagree
- Definitely disagree

When I’m reading a story I find it difficult to work out the characters’ intentions.

- Definitely agree
- Slightly agree
- Slightly disagree
- Definitely disagree

I like to collect information about categories of things (e.g., types of car, types of bird, types of train, types of plant, etc.)

- Definitely agree
- Slightly agree
- Slightly disagree
- Definitely disagree

I find it easy to work out what someone is thinking or feeling just by looking at their face.

- Definitely agree
- Slightly agree
- Slightly disagree
- Definitely disagree

I find it difficult to work out people’s intentions.

- Definitely agree
- Slightly agree
- Slightly disagree
- Definitely disagree

Please select “yes” or “no” for each question:

Are you unusually sensitive to heat or cold?

- ☐ Yes
- ☐ No

Are you more sensitive to pain than other people?

- ☐ Yes
- ☐ No

Are you unusually insensitive to heat or cold?

- ☐ Yes
- ☐ No

Do you have a high pain tolerance?

- ☐ Yes
- ☐ No

Are you made uncomfortable by touch or texture of clothing?

- ☐ Yes
- ☐ No

Do you enjoy light brushing or touch?

- ☐ Yes
- ☐ No

Do you like and seek out deep pressure or squeezing?

- ☐ Yes
- ☐ No

Are you unusually sensitive to light?

- ☐ Yes
- ☐ No

Are you bothered by sounds?

- ☐ Yes
- ☐ No

Are you unusually responsive to odor or taste?

- ☐ Yes
- ☐ No

Do you cover your ears in response to the sound of fire trucks, crying babies, or other loud noises?

- ☐ Yes

- ☐ No

Do you become easily upset or overwhelmed in loud or crowded places?

- ☐ Yes
- ☐ No

Do you have overall sensitivity to the environment (e.g., bright lights, strong smells, coarse fabrics, or sirens)?

- ☐ Yes
- ☐ No

Type the word BLUE in the box below. Please do not skip this item! This is to make sure that you are paying attention to our items. \_\_\_\_\_

The next questions have to do with your sexual history and your sexual health:

Who do you engage in sexual activity with? Please check all that apply:

- ☐ Women
- ☐ Men
- ☐ People who identify as transgender
- ☐ People who identify as intersex
- ☐ I do not engage in sexual activity with other people.
- ☐ Other (please specify: \_\_\_\_\_)

Have you ever “had sex” with someone else?

- ☐ Yes
- ☐ No
- ☐ Other (please specify: \_\_\_\_\_)

At what age did you first “have sex” with someone else? \_\_\_\_\_

In the last month, how many sexual partners have you had? \_\_\_\_\_

In the last year, how many sexual partners have you had? \_\_\_\_\_

In your lifetime, how many sexual partners have you had? \_\_\_\_\_

When was the last time you engaged in sexual activity with someone else?

- ☐ Less than a week ago
- ☐ Between one week and one month ago
- ☐ Between one month and three months ago
- ☐ Between three months and six months ago
- ☐ Between six months and one year ago
- ☐ More than one year ago
- ☐ I have never engaged in sexual activity with someone else.

Please indicate, if any, the methods you use to prevent pregnancy and/or STIs (sexually transmitted infections). Select all that apply:

- ☐ Male condom
- ☐ Female condom
- ☐ Contraceptive pill
- ☐ Nuvaring
- ☐ Intrauterine device (IUD)
- ☐ Depo Provera injections
- ☐ Implanon or other implanted device
- ☐ Diaphragm or cervical cap
- ☐ Spermicidal cream or foam
- ☐ Surgical procedure (e.g., tubal ligation)
- ☐ Rhythm/calendar method
- ☐ Withdrawal method (“pulling out”)
- ☐ None – I do not engage in sexual activities that carry a risk of pregnancy or STIs.
- ☐ Other (please specify: \_\_\_\_\_)

How often do you use a birth control device(s) to prevent pregnancy and/or STIs?

- ☐ All of the time
- ☐ Most of the time
- ☐ Sometimes
- ☐ Very little of the time
- ☐ Never
- ☐ Not applicable – I do not engage in sexual activities that carry a risk of pregnancy or STIs.

Have you ever had a gynecological exam?

- ☐ Yes
- ☐ No

Have you ever been tested for HIV and/or other STIs?

- ☐ Yes
- ☐ No

Type the word RED in the box below. Please do not skip this item! This is to make sure that you are paying attention to our items. \_\_\_\_\_

In your own words, how would you describe your sexual orientation? Examples might include “straight,” “lesbian,” “bisexual,” “queer,” etc. \_\_\_\_\_

The next questions ask about your level of sexual desire. By desire, we mean *interest in* or *wish for sexual activity*. For each item, please choose the option that best shows your thoughts and feelings:

During the last month, how often would you have liked to engage in sexual activity with a partner (for example, touching each other's genitals, giving or receiving oral stimulation, intercourse, etc.)?

- ☐ Not at all
- ☐ Once a month
- ☐ Once every 2 weeks
- ☐ Once a week
- ☐ Twice a week
- ☐ 3 to 4 times a week
- ☐ Once a day
- ☐ More than once a day

How strong is your desire to engage in sexual activity with a partner?

- ☐ 0 (no desire)
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8 (strong desire)



During the last month, how often would you have liked to behave sexually by yourself (for example, masturbating, touching your genitals, etc.)?

- ☐ Not at all
- ☐ Once a month
- ☐ Once every 2 weeks
- ☐ Once a week
- ☐ Twice a week
- ☐ 3 to 4 times a week
- ☐ Once a day
- ☐ More than once a day

How strong is your desire to engage in sexual activity by yourself?

- ☐ 0 (no desire)
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8 (strong desire)

How long could you comfortably go without having sexual activity of some kind?

- ☐ Forever
- ☐ A year or two
- ☐ Several months
- ☐ A month
- ☐ A few weeks
- ☐ A week
- ☐ A few days
- ☐ One day
- ☐ Less than one day

The statements and questions that follow ask you to indicate your attitudes and experiences regarding sex education.

What are your main source(s) of information about sex in general? Select all that apply:

- ☐ Female friends
- ☐ Male friends
- ☐ Father
- ☐ Mother
- ☐ Other family members
- ☐ Physician and/or nurse

- ☐ Professional sex educator or counselor (including personnel at family planning clinic)
- ☐ Minister, priest, or other religious leader
- ☐ Media (Internet, TV, radio)
- ☐ Reading books on my own
- ☐ Teachers at school
- ☐ I have no sources of sex education.
- ☐ Other (please specify: \_\_\_\_\_)

Have you ever participated in a school-based sexuality education program?

- ☐ Yes
- ☐ No

Have you participated in an organized sexuality education program that was not school-based?

- ☐ Yes
- ☐ No

If yes, in what setting(s) was/were the program(s) offered?

- ☐ Community health center or outpatient hospital clinic
- ☐ Inpatient hospital clinic
- ☐ Therapeutic support group
- ☐ Religious establishment
- ☐ Virtual/Internet-based
- ☐ Other (please specify: \_\_\_\_\_)

Have you ever participated in a sexuality education program specifically for individuals with autism spectrum disorders (ASD)?

- ☐ Yes
- ☐ No

Do you ever discuss issues related to dating, interpersonal relationships, and/or sexuality with friends?

- ☐ Yes, with female friends only
- ☐ Yes, with male friends only
- ☐ Yes, with both female and male friends
- ☐ No, I do not discuss these issues with my friends

How satisfied are you with your current level of knowledge about sex?

- ☐ 1 (very dissatisfied)
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 8
- ☐ 10 (very satisfied)

Type the number 10 in the box below. Please do not skip this item! This is to make sure that you are paying attention to our questions. \_\_\_\_\_

Have you ever engaged in the following sexual behaviors?

Deep kissing/tongue kissing

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Touching or having oral contact with someone else's breasts/nipples

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Someone touching or having oral contact with your breasts/nipples

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Touching someone else's genitals

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Someone touching your genitals

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Having oral contact with someone else's genitals

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Someone else having oral contact with your genitals

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Masturbating by yourself (including use of sex toys)

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Masturbating while in phone or computer contact with someone else (e.g., phone sex)

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Masturbating in the presence of another ("mutual masturbation")

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Having an orgasm by yourself

- ☐ Never
- ☐ Once
- ☐ A few times
- ☐ Many times

Having an orgasm with a partner

- Never
- Once
- A few times
- Many times

Vaginal intercourse (e.g., penile-vaginal intercourse)

- Never
- Once
- A few times
- Many times

Anal intercourse (e.g., penile-anal intercourse)

- Never
- Once
- A few times
- Many times

Looking at erotica or pornography

- Never
- Once
- A few times
- Many times

Sending sexual text messages or pictures to someone else (“sexting”)

- Never
- Once
- A few times
- Many times

Having sex on a “one night stand”

- Never
- Once
- A few times
- Many times

Having sex with more than one person at a time (e.g., “threesome”)

- Never
- Once
- A few times
- Many times

Any type of bondage/S&M activity

- Never

- Once
- A few times
- Many times

Please read each statement carefully and indicate your level of agreement:

I feel content with the way my present sex life is.

- Strongly disagree
- Disagree a little
- Neither agree nor disagree
- Agree a little
- Strongly agree

I often feel something is missing from my present sex life.

- Strongly disagree
- Disagree a little
- Neither agree nor disagree
- Agree a little
- Strongly agree

I often feel I don't have enough emotional closeness in my sex life.

- Strongly disagree
- Disagree a little
- Neither agree nor disagree
- Agree a little
- Strongly agree

I feel content with how often I presently have sexual intimacy (kissing, intercourse, etc.) in my life.

- Strongly disagree
- Disagree a little
- Neither agree nor disagree
- Agree a little
- Strongly agree

I don't have any important problems or concerns about sex (arousal, orgasm, frequency, compatibility, communication, etc.)

- ☐ Strongly disagree
- ☐ Disagree a little
- ☐ Neither agree nor disagree
- ☐ Agree a little
- ☐ Strongly agree

Overall, how satisfactory or unsatisfactory is your present sex life?

- ☐ Completely satisfactory
- ☐ Very satisfactory
- ☐ Reasonably satisfactory
- ☐ Not very satisfactory
- ☐ Not at all satisfactory

Type the number 8 in the box below. Please do not skip this item! This is to make sure that you are paying attention to our questions. \_\_\_\_\_

Please indicate whether any of the following has happened to you anytime in your lifetime:

Someone tried to touch me in a sexual way against my will.

- ☐ Yes
- ☐ No

Someone tried to make me touch them in a sexual way against my will.

- ☐ Yes
- ☐ No

I believe that I have been sexually abused by someone.

- ☐ Yes
- ☐ No

Someone threatened to tell lies about me or hurt me unless I did something sexual with them.

- ☐ Yes
- ☐ No

The statements below refer to sexual aspects of people's lives. Please read each item carefully and decide how characteristic it is of you.

I am very aware of my sexual feelings.

- ☐ Not at all characteristic of me
- ☐ Slightly characteristic of me
- ☐ Somewhat characteristic of me
- ☐ Moderately characteristic of me
- ☐ Very characteristic of me

I wonder whether others think I'm sexy.

- ☐ Not at all characteristic of me
- ☐ Slightly characteristic of me
- ☐ Somewhat characteristic of me
- ☐ Moderately characteristic of me
- ☐ Very characteristic of me

I'm very aware of my sexual motivations.

- ☐ Not at all characteristic of me
- ☐ Slightly characteristic of me
- ☐ Somewhat characteristic of me
- ☐ Moderately characteristic of me
- ☐ Very characteristic of me

I'm concerned about the sexual appearance of my body.

- ☐ Not at all characteristic of me
- ☐ Slightly characteristic of me
- ☐ Somewhat characteristic of me
- ☐ Moderately characteristic of me
- ☐ Very characteristic of me

I'm very alert to changes in my sexual desires.

- ☐ Not at all characteristic of me
- ☐ Slightly characteristic of me
- ☐ Somewhat characteristic of me
- ☐ Moderately characteristic of me
- ☐ Very characteristic of me



I am very aware of my sexual tendencies.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I usually worry about making a good sexual impression on others.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I'm concerned about what other people think of my sex appeal.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I'm very aware of the way my mind works when I'm sexually aroused.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I rarely think about my sex appeal.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I know what turns me on sexually.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I don't care what others think of my sexuality.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I rarely think about the sexual aspects of my life.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

I don't think about my sexuality that much.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

Other people's opinions of my sexuality don't matter very much to me.

- Not at all characteristic of me
- Slightly characteristic of me
- Somewhat characteristic of me
- Moderately characteristic of me
- Very characteristic of me

Over the last two weeks, how often have you been bothered by any of the following problems?

Little interest or pleasure in doing things

- Not at all
- Several days
- More than half the days
- Nearly every day

Feeling down, depressed, or hopeless

- Not at all
- Several days
- More than half the days
- Nearly every day

Trouble falling or staying asleep, or sleeping too much

- Not at all
- Several days
- More than half the days
- Nearly every day

Feeling tired or having little energy

- Not at all
- Several days
- More than half the days
- Nearly every day

Poor appetite or overeating

- Not at all
- Several days
- More than half the days
- Nearly every day

Feeling bad about yourself – or that you are a failure and have let yourself or your family down

- Not at all
- Several days
- More than half the days
- Nearly every day

Trouble concentrating on things, such as reading the newspaper or watching television

- Not at all
- Several days
- More than half the days
- Nearly every day

Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual

- Not at all
- Several days
- More than half the days
- Nearly every day

Feeling nervous, anxious, or on edge

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

Not being able to stop or control worrying

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

Worrying too much about different things

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

Trouble relaxing

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

Being so restless that it is hard to sit still

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

Becoming easily annoyed or irritable

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

Feeling afraid as if something awful might happen

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

Type the word YES in the box below. Please do not skip this item! This is to make sure that you are paying attention to our questions.

Please read each statement and indicate how much the statement applied to you over the past week.

Does fear of embarrassment cause you to avoid doing things or speaking to people?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Very much
- ☐ Extremely

Do you avoid activities in which you are the center of attention?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Very much
- ☐ Extremely

Is being embarrassed or looking stupid among your worst fears?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Very much
- ☐ Extremely

If you identify as being on the autism spectrum, please answer the following question:

If you identify as being on the autism spectrum, are there central ways that being on the spectrum has influenced your sexuality? If so, please describe: \_\_\_\_\_

The following question is for **all participants**:

We are interested in your decision to participate in the Women's Sexuality Study. In the text box below, could you please describe your reason(s) for participating in this study?

\_\_\_\_\_

Completion screen text:

Thank you for taking the time to participate in the Women's Sexuality Study! We believe that the information gathered in this study will help shed light on the experiences of women with and without an autism spectrum identity, support the sexualities of women on the spectrum, and increase public awareness around this important topic. If you have any questions about the Women's Sexuality Study, please contact Hillary Hurst Bush, M.A., the Principal Investigator ([umbwomensstudy@gmail.com](mailto:umbwomensstudy@gmail.com)) or Abbey Eisenhower, Ph.D., the faculty co-investigator ([abbey.eisenhower@umb.edu](mailto:abbey.eisenhower@umb.edu), 617-287-6334).

In case answering these questions caused discomfort for you, or raised some issues that you would like to discuss further, please contact Abbey Eisenhower, Ph.D. ([abbey.eisenhower@umb.edu](mailto:abbey.eisenhower@umb.edu), 617-287-6334). A list of resources related both to sexuality and the autism spectrum is available [HERE](#).

We are actively looking for more people to be a part of the Women's Sexuality Study! We are especially looking for young women who identify as being on the autism spectrum. If you know anyone who might be interested in this study, please share a link to the study website: <http://www.umbwomensstudy.com/home.html> or like us on Facebook: <https://www.facebook.com/umbwomensstudy>.

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