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ABSTRACT

The purpose of this study was to explore the development of gender identity in children with autism. This research asked “Do people on the autism spectrum acquire gender identity differently than those who are neurotypically developing?” It was hypothesized that those on the autism spectrum did acquire gender identity differently, and that this process may be more influenced by individual cognition than social learning.

This was a descriptive study that was cross-sectional in nature. Young adults were asked retrospective questions in a mixed-methods survey that was conducted on the internet. A sample of 29 participants comprised this study. No clear conclusion was reached regarding the research question; however, the sample provided ample descriptive data.

Key findings of this study included the following: (1) participants’ process of establishing their gender identity, (2) the interaction between autism and gender, (3) the incidence of gender variant identity in this sample, and (4) how participants received information and support.

Important implications for this study include increased attention to gender identity development for all children with autism, by both mental health professionals and teachers, as well as continued commitment to exploring this scholarship.

GENDER IDENTITY DEVELOPMENT
IN INDIVIDUALS WITH AUTISM

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

Emily Green Kalafarski

Smith College School for Social Work
Northampton, Massachusetts 01063

2010

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With thanks and love to my friends and family for supporting me in this endeavor.

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CHAPTER I

INTRODUCTION

Autism is a hot topic. As the incidence rises, it seems to be a regular fixture in the United States media. Autism is frequently conceptualized from a deficits-perspective within the medical model (Gilson & DePoy, 2002); yet the neurodiversity movement shows resistance to this perspective, characterizing it as overly pathologizing (Bumiller, 2008). This movement considers whether the social and behavioral symptoms of autism could be viewed as differences in relating to others, rather than inherently disordered (Broderick & Ne'eman, 2008). The internet has also recently emerged as a valuable tool in relation to autism. This virtual space represents a place where people can create community, distribute information, advocate in the political realm, and access research.

This study sought to answer the question, “Do people on the autism spectrum acquire gender identity differently than those who are neurotypically developing?” The initial plan was to (1) explore the prevalence and co-occurrence of autism and gender variant identity, (2) ask participants to reflect on how they were taught gender norms, and (3) question whether participants experienced external influence in a positive or negative manner. This investigation was conducted by asking adults to recall their childhood and fill out a short internet survey. The study primarily gathered quantitative data, with several additional qualitative questions.

When children are born in the United States, their birth certificate indicates one sex or the other. Today, autism spectrum disorders are more prevalent amongst boys than girls, ranging from more than three to more than six boys for every girl with an autism spectrum disorder. Concerns about development are typically documented before a child is two years old, but the average age of diagnosis is not until roughly four and a half (Center for Disease Control and Prevention, 2010).

It is generally assumed that sex, gender, gender expression, and sexuality are aligned with one another; that is to say, a baby deemed male will see himself as a boy, enact masculine norms of gender expression, and be heterosexual (Butler, 1999). Some of these expectations may be communicated to children directly, through others' words and actions. Other items on the sex-gender continuum are subtle and nuanced.

Many children with autism have difficulty with social perception. They may have restricted interests and miss others' cues that it is time to change the topic for example. Children with autism may have a reduced social network, and as a result, less cumulative experience with peers. They may benefit from therapies that bolster their underlying skill deficits (Keane, 2004).

Individuals with autism most frequently cite difficulty with sensory integration and social relationships (Keane, 2004). If social workers could better understand the needs of children with autism in relation to gender identity development, this could have a positive impact on their social relationships and facilitate an improved sense of mastery-competence (Ashby, 2009).

As gender is, at least in part, socially constructed, how is gender affected for those with a different quality of social interaction? Do children with autism have a different

path of gender identity development than their neurotypically developing peers? What might this course be lacking, in terms of needed external supports?

CHAPTER II

LITERATURE REVIEW

This study sought to better understand the development of gender identity in children with autism. It questioned “Do people on the autism spectrum acquire gender identity differently than those who are neurotypically developing?” This researcher hypothesized that this process may be more influenced by individual cognition than social learning and hypothesized that gender variance may be more present in individuals with a diagnosis of ASD than the rest of the population.

The literature pertinent to this research can be grouped into several categories: (1) overarching theories of gender identity development, (2) current conception of autism and criteria for diagnosis, (3) a theory of gender identity development in children with autism, and (4) case studies of cross-gender or gender variant identity in children with autism.

Gender identity, simply put, is a person’s concept of himself or herself as male or female (Ross-Gordon, 1999, p. 29).

It is important to note from the onset that sex and gender have been defined differently across researchers and throughout time. The above referenced quotation does not presume that gender identity must be congruent with sex assigned at birth.

Scholarship that follows this vantage point has been highlighted in this review; however, literature relevant to this study that contains varying conceptions of gender identity development is also referenced within this review.

Gender Identity Development

Researchers have long been interested in the psychosocial process of gender identity development. Cognitive, psychoanalytic, and social learning theories have been used to explore this topic (Bailey & Zucker, 1995; Martin, Ruble, & Szkrybalo, 2002; Ross-Gordon, 1999; Stoller, 1992). For historical perspective, psychoanalytic theory proposes that “the fear of retaliation from his father causes the boy to separate himself from the mother to whom he initially develops an infantile sexual attraction (the Oedipal complex) and develop a gender identity in affinity with the father” (Ross-Gordon, p. 30). Despite their distinct beginnings, cognitive and social learning theories have recently moved closer to one another towards the conceptualization of social cognitive theory (Bussey & Bandura, 1999). In the exploration of these perspectives that follows, they will be delineated separately with acknowledgment of emerging commonalities.

Cognitive theory

How do children become gendered beings? Those who ascribe to cognitive theory believe that children are active agents in deciphering their social world. The information about gender that they encounter is perceived to be organizing. These environmental cues are thought to coalesce and form gender cognitions, including gender self-conceptions (gender identity) and gender stereotypes (Martin & Ruble, 2004).

Lawrence Kohlberg was the first to apply cognitive theory to the development of gender in 1966. He believed that cognition came before behavior (e.g., “I am a boy and therefore like to do things that boys do”). Heavily influenced by developmental psychologist Jean Piaget, Kohlberg’s work attempted to relate changes in children’s cognitive structures to their social environment. This signified a strong departure from contemporaries’ prior adherence to psychoanalytic and learning theory. One of the most important tenets of Kohlberg’s theory was the belief that children ultimately achieve gender constancy, a term representing a developmental understanding of the permanence of gender (as cited in Martin et al., 2002, p. 904). Kohlberg further believed that children are internally motivated to learn about gender, independent of any external reinforcement or reprisal. As children come to view their sex as unchanging, mastery motivation compels them to adhere to gender norms and learn more about gender (as cited in Ruble et al., 2007).

Cognitive-developmental theory was followed by gender-schema theory in the 1970s. This perspective echoed many of Kohlberg’s thoughts of children as active agents in gender development. This theory imagines the formation of organized knowledge structures, or schemas, which are made up of groups of associated thoughts related to gender concerning oneself and others. These schemas influence successive thoughts and actions. Gender schema theorists believe that children only need a basic understanding of gender in order to stimulate subsequent thought and behavior (Martin & Ruble, 2004).

Social learning theory

(learning theory): positive and negative reinforcement of gender behavior, from infancy on, shape gender fortuitously, with the strength of these reinforcements and their timing being crucial (Stoller, 1992, p. 78).

Kohlberg's 1966 contemporary was Walter Mischel, a social learning theorist. He had the opposite opinion as to the origins of gendered behavior and self-knowledge. Mischel looked outward to the environment for factors that affect gender development. He believed that behaviors come before cognitions (e.g., "I have been rewarded for doing boy things, I must be a boy") (as cited in Martin et al, 2002, p. 904).

In social learning theory, gender identity is produced by imitation, reinforcement for sex-typed activities, and modeling peers and adults in conjunction with reinforcement. In a general sense, gender identity development is a result of socialization. Real-life models may also be accompanied by symbolic media models of behavior that inform gender cognitions (Ross-Gordon, 1999).

Autism: Classification, Prevalence, and Co-occurrence with Gender Dysphoria

Autistic disorder, Asperger's disorder, and pervasive developmental disorder, not otherwise specified all fall under the common umbrella of autism spectrum disorders (ASDs). The *Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR)* characterizes these three diagnoses as consisting of a triad of impairment in the realms of social interaction, communication, and behavior that is stereotyped or displays a restricted range of interests (American Psychiatric Association, 2000). In the United States, 1 in 110 children are estimated to have autism, on average (Centers for Disease Control and Prevention, 2010).

Clinical practice indicates that the co-occurrence of autism and gender dysphoria is not unusual (de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers, 2010). In a population of children and adolescents referred to the Amsterdam Gender Identity Clinic, 7.8% were found to have an ASD (deVries et al.). Chance alone does not seem to account for this figure, which may indicate that ASDs are more common in individuals who are gender dysphoric. Yet there appears to be a dearth of research regarding the general process of gender identity development in children with autism. To this researcher's knowledge, Abelson (1981) has conducted the only empirical research to date.

Gender Identity Development in Children with Autism

Abelson defined gender identity as “the developed ability of a child to categorize himself/herself as a boy or a girl and the ability to recognize other children as being boys or girls” (1981, p. 347). The sample in this study was comprised of thirty subjects between three and eleven years of age, all of whom had been diagnosed as autistic at an Iowa hospital. Children were asked to sort pictures, including some of themselves, into categories of boys and girls using the Michigan Gender Identity Test. Subjects were also asked to classify themselves as a little boy or little girl. This study concluded that gender identity development was reliant upon cognition and developed in concert with mental age.

Abelson ultimately believed that some children with autism might not be picking up on cues and qualities that would allow them to differentiate between boys and girls (1981). He described this subgroup of his sample as children “who do not develop gender identity” (p. 355). Abelson hypothesized that developing gender identity is important for

children with autism, as it gives them a sense of who they are in relation to others. By knowing with which group to affiliate (boys or girls), children would then be able to increase their ability to learn appropriate social skills.

Gender Variant Identity in Individuals with Autism

While Abelson (1981) was interested in the general development of gender identity in children with autism, recent scholarship has focused upon describing individuals with autism whose gender identity does not match their sex assigned at birth. Much of this modern literature has been in the form of case studies. In sum, this scholarship documents the experiences of two boys, ages three and five (Williams, Allard, & Sears, 1996), one five-year-old boy (Tateno, Tateno, & Saito, 2008), two boys, ages seven and ten (Mukaddes, 2002), a forty-one year old male (Gallucci, Hackerman, & Schmidt Jr., 2005), a nine year old girl (Perera, Gadambanathan, & Weerasiri, 2003), a fourteen year old girl (Landen & Rasmussen, 1997), and a thirty-five year old woman (Kraemer, Delsignore, Gundelfinger, Schnyder, & Hepp, 2005). A more detailed consideration of each of these studies follows.

The paucity of research regarding cross-gender behavior in individuals with autism may be due, in part, to “interpretation of cross-gender behavior as a ‘usual’ part of ‘unusual’ interests of autistic individuals by clinicians” (Mukaddes, 2002, p. 532). Williams et al. (1996) also ascribed to this theory, postulating that cross-gender behavior in children with autism should be considered a preoccupation. These preoccupations are generally described as a restricted range of interests with a repetitive quality or marked intensity. It has also been suggested that cross-gender preoccupations may serve the

primary function of seeking sensory input with objects that happen to be feminine, such as silky fabrics, a flared skirt, or shiny jewelry (Williams et al.; Tateno, Tateno, & Saito, 2008). Williams et al. acknowledged that most preoccupations in children with autism are ascribed to specific objects versus a broad range of traditionally feminine interests; however, these researchers believed that subjects' cross-dressing and cross-gender role-play could be best understood as an "inherent predisposition towards unusual interests," and not likely indicative of gender identity confusion (p. 641). Galucci et al. (2005) similarly described the quality of pervasive preoccupation and distress with gender role in an adult male with Asperger's syndrome. This study and another suggested a possible relationship between autism and obsessive compulsive disorder, as well as gender identity disorder and obsessive compulsive disorder (Galucci et al.; Landen & Rasmussen, 1997). It is important to note that both Galucci et al. and Landen and Rasmussen did not feel that cross-gender identification was merely a manifestation of a restricted interest.

There are varied theories as to the etiology of gender dysphoria in autism. Some researchers and clinicians feel that cross-gender identification is a maladaptive response to a psychosexual dilemma; in sum, it is seen as a manner to avoid conventional relationships (Galucci et al., 2005; Landen & Rasmussen, 1997). Other researchers point to gender stereotypes as the root of cross-gender identification in women on the autism spectrum. An adult woman with Asperger's syndrome displayed a high level of logical thinking and a low level of emotionality; therefore, researchers believed that her stereotypically masculine traits facilitated female-to-male gender identity disorder (Kraemer et al., 2005).

Summary

Social learning and cognitive theories are commonly referenced mechanisms of gender identity development; however, to this researcher's knowledge, these theories have not yet been considered in the development of gender identity in children with autism. Clinical practice indicates that the co-occurrence of autism and gender variance is not unusual (deVries et al., 2010); however, little is known about gender identity development in people with autism. This descriptive study will add to the research regarding gendered cognition, behaviors, and experiences of children on the autism spectrum and assist social workers in creating relevant interventions.

CHAPTER III

METHODOLOGY

Study Aims and Hypothesis

This study examined gender identity development in people diagnosed with autistic disorder, Asperger's disorder, or pervasive developmental disorder, not otherwise specified. It was hypothesized that this population acquires gender identity differently than neurotypically developing people.

The topics of autism and gender identity have mostly been considered independently, and rarely in concert with one another. In considering how individuals on the autism spectrum construct a system of internal beliefs regarding being a boy, girl, or something in-between and less easily defined, this study hoped to reveal potential patterns, identify areas for future investigation, and consider possible implications for the field of social work.

Research Design

This was a descriptive, cross-sectional, retrospective study that aimed to investigate gender identity in children with autism. The original plan was to conduct a study that was largely quantitative, along with a few open-ended questions. This decision was made in order to survey the greatest number of individuals possible.

The research instrument was an anonymous internet survey designed by this researcher. There were 33 questions, including sociodemographic questions regarding participants' age, race and ethnicity, religion, geographic location of childhood home, and childhood socioeconomic status (see Appendix D). Data were gathered from participants in order to explore (1) the prevalence and co-occurrence of autism and gender variant identity, (2) how participants acquired gender norms, and (3) whether participants experienced external influence of others in a positive or negative manner.

Sampling

A nonprobability, convenience sampling method was utilized in this investigation. The sample was recruited through the internet. This manner was chosen for many reasons: (1) the societal stigma attached to autism spectrum disorders, (2) the difficulty that many individuals on the spectrum face during interpersonal situations, (3) the potentially sensitive nature of the topic of gender identity development, and (4) concerns related to the safety of non-gender conforming individuals in public spaces. This researcher ultimately believed that participants might feel most comfortable if they were approached virtually about this study.

For practical considerations, it was also fitting that recruitment was conducted via the internet, as the study instrument itself was solely available online. Recruiting in this manner had a high likelihood of producing a sample of computer and internet-savvy individuals who would be able to navigate the survey with the lowest likelihood of technical difficulties that could affect the integrity of data gathered. The internet also

functioned as a highly efficient means of surveying adults on the autism spectrum from a wide geographic expanse across the United States.

Despite the many factors that motivated the recruitment of participants through the internet, there were also drawbacks to this method. The use of the internet in both recruitment and survey administration is a limitation to the findings of this study, which restricted the research to individuals who had knowledge of how to use computers, as well as access to the internet. This may have skewed the sample towards those of a higher socioeconomic status and education level. Furthermore, reasons that might motivate individuals to respond to electronic recruitment and participate in an internet study are also unknown. It is impossible to know all of the contributing factors that caused participants to be at a given virtual location at a given time. This potential bias is an important consideration to take into account in this research.

A goal was established to recruit between 30 and 60 participants, in order for this study to have adequate statistical power to support findings. Participants were recruited over the course of one month. Only 29 participants were able to be recruited, due to the time constraints of this researcher. It is hypothesized that the restricted age range eligible to participate in this study (those between 20 and 30 years old) may have adversely affected the number of respondents.

Attempts were made to minimize selection bias. Subjects were not offered compensation for their participation. This researcher was not aware of a personal connection to any respondent. There was no affiliation to either the national organization or the website that aided in recruitment.

Selection Criteria

The following characteristics were set as inclusion criteria for participants: (1) a prior diagnosis by a medical or mental health professional of autistic disorder, Asperger's disorder, or pervasive developmental disorder, not otherwise specified, (2) an age of between 20 and 30 years, (3) the experience of growing up and currently living in the United States, and (4) being able to read questions in English. An expanded rationale for establishing each of these standards follows.

A prior diagnosis was an essential condition for participation, as being on the autism spectrum was the dependent variable in this study. This survey question was worded in the following manner: "Have you been diagnosed with autistic disorder, Asperger's disorder, or pervasive developmental disorder, not otherwise specified?" Participants were directly asked if they had received a diagnosis in order to screen out those who may have self-diagnosed themselves as on the autism spectrum, without direct contact with medical or mental health professionals. This may have biased the sample towards those with frequent access to health care providers, as well as excluded those with moderate symptoms that may have gone undiagnosed. Participants were allowed to indicate previously receiving more than one of these three diagnoses, in order to allow for the possibility of diagnostic clarification over time.

Participants were required to be between 20 and 30 years old in order to partake in this study. As participants were also asked to reflect upon their childhood gender identity development, the decision was made that they should be out of their teenage years and into young adulthood, in order to have sufficient perspective upon their childhood. The lower limit of this group was established such that participants would all

be over the age of legal consent. In addition, this restricted age of the participants moderated cohort variability in relation to the historical conception of autism spectrum disorder diagnoses, as well as available forms of treatment.

Participants' current and past environment influenced whether they were eligible to participate. They had to have grown up in the United States and currently live in the United States. These eligibility criteria limited the participants to a defined cultural landscape with shared structures of education and health care. The cultural construction of gender was also considered to be of utmost importance in relation to this selection criteria. Participants were required to be both current and past residents of United States in order to be able to speak to gender norms that may be culturally bound.

Finally, participants must have been able to read questions in English. Due to the small scope of the study and limited financial means, it was not possible for the survey to be translated into different languages.

Recruitment

Individuals were recruited to join this research in three different ways:

(1) Recruitment material was emailed to state chapters of the Autism Society of America, with the request that it be further distributed to local chapters and their members. It was hoped that this outreach would generate general knowledge of and interest in this study. While some large states have more than one state chapter, this mechanism attempted to recruit participants from all over the United States in a fairly even manner.

(2) An internet domain name was registered with the project title, entitled “Gender Identity in Individuals with Autism.” This ensured that potential participants could potentially find the survey through internet search engines. This website contained the study recruitment material, as well as a link to the survey. This website was deleted once the survey was closed.

(3) Information about the study was also posted on one general website that reaches out to individuals with an autism diagnosis (<http://www.neurodiversity.com>). This researcher communicated with the site administrator of this website and requested that recruitment material be posted in the research section. A survey link was provided. While there are many websites concerning autism research, the vast majority do not allow unaffiliated individuals to post a call for participants.

Individuals also may have been recruited to join this research through snowball sampling. This researcher was contacted by a psychologist from Austin, Texas who works for an organization that does post-secondary work with individuals diagnosed with autistic spectrum disorders at four sites across the country. The psychologist stated that he was interested in the study and might consider redistributing it to students after reviewing the study synopsis and Human Subjects Review (HSR) approval letter. Communication with this individual was endorsed by the chair of the HSR Committee, which was assessed to not deviate excessively from this study’s previously approved recruitment methods.

It is important to note that while the methods outlined above were the means of recruitment initiated by or communicated to this researcher, it is possible that this study was publicized through other means. The nature of the internet makes it easy for users to

share content with one another, as well as repost links without the permission of the author. It is unknown to what extent this study may have been redistributed, and how that may have affected the composition of subjects and data that ensued.

Data Collection

Survey

This study utilized a measure developed by this researcher. The study instrument was piloted with one person. Subtle adjustments were made prior to implementation regarding the number of questions on each page of the website. The survey was open for the entire month of April 2010. Participants were asked to complete an online survey of 33 questions (see Appendix D), which was estimated to take no more than 15 minutes to complete. Some examples of demographic data collected were the subjects' age, race and ethnicity, state of childhood residence, current and childhood religion, and childhood socioeconomic status. Participants were also asked to classify their childhood home as rural, urban, or suburban.

Procedure

Upon arriving at the study instrument webpage, potential participants saw a welcome page that thanked them for their interest. They were then asked the five questions that determined eligibility, in a "yes" or "no" format. If the prospective participants did not meet the criteria to participate, they were subsequently informed that they were not eligible to take the study, thanked for their interest, and given the referral

sources. Others who were found eligible proceeded to the Informed Consent (see Appendix C).

The Informed Consent delineated the eligibility requirements, as well as functioned as an electronic agreement that indicated a willingness to participate in the study. Participants were explicitly invited to contact this researcher or the Chair of the Smith College School for Social Work Human Subjects Review Committee, should they have needed any further explanation of the Informed Consent. After the Statement of Agreement, participants had the option to check a “Continue” button at the end of the Informed Consent. If they chose to proceed, they were directly connected to the research instrument.

This researcher was contacted via email by four individuals with questions about the study. Three of these people wanted to participate but were over the age of 30, and the remaining person expressed general interest in the study’s subject matter. In order to avoid compromising subjects’ anonymity, this researcher did not ask for any identifying information from participants who chose to contact her with questions. The rationale for the restricted age cohort was explained to participants, and participants were thanked for their interest.

Data Analysis

The data was reviewed with the assistance of the Smith College School for Social Work statistician. A database was constructed. Descriptive statistics were used to analyze the quantitative data. There were not enough participants to conduct correlations. The data gathered enabled a rich description of the sample’s acquisition of gender identity.

Ethics and Safeguards

Research was conducted on the internet. The study was hosted on a website that allows users to create their own surveys (<http://www.surveymonkey.com>). This researcher paid a monthly subscription fee and created a private account in order to design the research instrument, collect results, and view data. This website ensured participants' anonymity and confidentiality. This researcher had one link that served as the collection agent, which grouped all participants' responses together for analysis. There was no electronic information gathered as to how participants had arrived at the study website. Subjects were given the option of reporting how they had found the study; however, this data was neither mandatory nor corroborated. Internet provider (IP) addresses were not tracked. The study could be taken from the same computer multiple times, in order to allow for access from participants using public computers in sites such as libraries or internet kiosks.

Electronically stored data was password-protected. Data downloaded from the survey website was handled only by this researcher and specific designated Smith College faculty and staff. As required by federal regulations, data will be kept secure for at least three years. If needed beyond three years, data will continue to be kept secure until no longer needed, at which time they will be destroyed.

Participation in this study was voluntary. This researcher attempted to ensure that the recruitment material was disseminated respectfully, with a non-coercive approach. This researcher attempted to emphasize that this research was only associated with Smith School for Social Work and not any other institution such as the Autism Society of America, which sent recruitment material to potential participants through its state

chapters, or <http://www.neurodiversity.com>, which posted recruitment material on its website.

Participants viewed an Informed Consent and electronically indicated that they read and agreed to the conditions before being admitted to the research instrument. Participants were encouraged to print a copy of the Informed Consent for their records through their web browser's print function before clicking "continue" and advancing to the research instrument. Minors were not eligible to participate in this study.

Participants' rights were considered in connection with the research instrument. They could refuse to answer any question. Participants were informed that they could stop and exit the survey at any time. Data related to incomplete surveys was not reported. Subjects were informed that incomplete surveys would not be used. Participants could withdraw from the study by terminating the survey prior to submitting results. Once subjects clicked "complete" at the end of the survey, it was not possible for them to withdraw from the study, due to the anonymity of participation. They were informed of this at the onset of the survey. This research was concerned with participants' recollections of their childhood related to gender identity development; however, the questions did not ask about intimate aspects of the participants' behavior, making participants at a low risk of emotional discomfort.

An important part of this research design was the administration of the investigation through the internet. It was thought that an internet survey was particularly appropriate, given that stigmatized populations are historically difficult to recruit for research (Rubin & Babbie, 2007). Experiencing life as either on the autism spectrum or with a non-normative gender presentation results in a reduced amount of privilege and

positive reinforcement from society (Parkes & Hall, 2006). For those who carry both of these identities, an increased level of societal stigma results. Gathering data on the internet had the benefit of affording participants the security of anonymity. It was hoped that this would lead to a high level of disclosure and honesty in the survey, as well as a sense of personal safety and comfort.

If participants wanted services or information, they could refer to the list of resources provided by the researcher. This included the website and phone referral service of the Autism Society of America, the Gay, Lesbian, Bisexual, and Transgender National Hotline, and the online discussion group of the GRASP GLBT Network. The list of referral sources was provided to all individuals who were interested in participation, regardless of whether they were found eligible to take the survey. The list was formatted such that the referral sources would print at the same time as the Informed Consent.

It is possible that participants benefited from being involved in this research. By taking part in this study, participants may have realized a previously unrecognized need for support and become connected with the referral sources. This researcher also believes that members of this community may feel that they are not heard by mental health professionals at present. As a result, participants may have gained a sense of personal satisfaction by having the opportunity to share their experience and contribute to the emerging understanding of gender identity development in individuals with autism. Participants may continue to indirectly benefit from this research if it incites further investigation.

CHAPTER IV

FINDINGS

This research asked if people on the autism spectrum acquire gender identity differently than those who are neurotypically developing. This question was investigated by asking a sample of young adults to recall memories of their childhood through an internet survey.

The following information is thought to be amongst the most important findings generated from this study: (1) participants' process of establishing their gender identity, (2) the interaction between autism and gender, (3) the incidence of gender variant identity in this sample, and (4) how participants received information and support. These will be expounded upon in this chapter and the subsequent Discussion.

While this study achieved a smaller sample size than initially desired ($N=29$), it provides rich descriptive data regarding participants' lives and experiences. This chapter will describe the sociodemographic profile of the sample, present findings of initial research questions, and describe common themes in participants' qualitative comments.

Demographic Data

Table 1

Age of Participants

Age	Frequency	Percentage
21	3	10%
22	1	3%
24	3	10%
26	2	7%
27	3	10%
28	1	3%
29	2	7%
30	1	3%
-	13	45%

Note. Dashes indicate missing data. $N=29$

Age of Participants

Age was an important variable in this study. It has potential implications in relation to the changing conception of autism spectrum disorder diagnoses, as well as methods of treatment and support available. Participants' age range indicates that they were born between 1980 and 1990. Even within a fairly small range, variation in age amongst young adults could potentially have implications for interpreting results. In a sample size of greater statistical significance, one might compare the responses of those in their early 20s to those in the latter part of this age cohort.

Only fifty-five percent of the sample reported their age. There were 16 valid responses and 13 missing responses ($N=29$). It is not known why such a large number of participants chose not to indicate their age. This may have been influenced by a flawed survey design, such as the decision to utilize an open field in which participants typed their response to this question. Respondents' ages ranged from 21 to 30 (mean= 25.38).

Age was screened as one of the criteria for inclusion in this study. All who were found eligible to participate indicated that they were between 20 and 30 years old. Therefore, despite the fact that the exact age of all participants is not known, one can be reasonably sure that a restricted age cohort was achieved.

Table 2

Race/Ethnicity of Participants

Response	Frequency	Percentage
Caucasian	22	76%
Mixed	4	14%
African American	2	7%
Other	1	3%

Note. The one participant who indicated “Other” specified “Cajun.” $N=29$

Race/ Ethnicity of Participants

Participants were asked to specify their race or ethnicity for the purpose of gathering data on gender identity development and autism across cultural identity. All

participants responded to this question ($N=29$). The majority of the sample identified as Caucasian (76%). Four participants stated that they were of mixed ethnicity (14%). Seven percent were African-American. One individual chose “Other” and specified Cajun ethnicity (3%).

Table 3

Sex of Participants: Assigned at Birth and Current

Response	Birth (%)	Current (%)
Female	69%	69%
Male	28%	28%
-	3%	3%

Note. Dashes indicate missing data. $N=29$

Sex: Assigned at Birth and Current

Participants were asked to report the sex assigned at their birth and their current sex. This information was sought for several reasons: (1) to report upon the participants’ current sex in relation to reported gender identity development, and (2) to compare the demographics of this population to that of autism in the general United States population.

All but one participant responded to the question regarding sex assigned at birth ($n=28$); data from 1 participant was missing (3%). Sixty-nine percent ($n=20$) of participants were assigned to be female at birth. Twenty-eight percent ($n=8$) of participants were assigned to be male at birth.

All but one participant responded to the question regarding current sex ($n=28$); data from 1 participant was missing (3%). Sixty-nine percent ($n=20$) of participants were currently listed as female on their driver's license or other state-issued id. Twenty-eight percent ($n=8$) of participants were currently listed as male on this form of id.

Table 4

Religion of Participants: Childhood and Current

	Childhood	Current
Christian	52%	45%
None	35%	28%
Jewish	7%	10%
Other	3%	14%
-	3%	3%

Note. Dashes indicate missing data.

Religion of Participants: Childhood and Current

Participants were asked to report on both their childhood and current religion. These questions were asked because of the potential influence that religion may have upon expected gender roles and norms of behavior.

Twenty-eight participants (97%) answered a survey question about childhood religion, with data missing from one participant. The majority were Christian ($n=15$, 52%). The second largest group had no religious affiliation ($n=10$, 35%). Two individuals

were Jewish (7%). One individual (3%) chose “Other” on the survey and elaborated a childhood religion of “Christian and Jewish (at various times).”

All participants but one responded to a survey question about current religion ($n=28$). Many individuals were Christian ($n=13$, 45%). The next largest group of participants stated that they had no religion ($n=8$, 28%). Four individuals chose “Other,” and respectively identified as “Pastafarian,” “Deist, believe in some sort of God,” “Pagan,” and “personal syncretic faith” (13%). A smaller number of individuals were Jewish ($n=3$, 10%).

Table 5

Childhood Community

Response	Frequency	Percentage
Suburban	21	72%
Rural	4	14%
Urban	4	14%

Note. $N=29$

Childhood Community

Participants were asked to classify the community in which they grew up as urban, suburban, or rural. This information was sought as community environment may influence exposure to heterogeneity of gender expression, as well as access to treatment. All participants answered this survey question ($N=29$). The plurality of the sample lived

in the suburbs ($n=21$, 72%). Four individuals classified their childhood neighborhood as rural (14%), and an equal number of participants grew up in an urban environment (14%).

Table 6

Childhood Socioeconomic Status

Response	Frequency	Percentage
Middle Income	24	83%
Low income	3	10%
High income	1	3%
-	1	3%

Note. Dashes indicate missing data. $N=29$

Childhood Socioeconomic Status

Participants were asked about their childhood socioeconomic status because of its potential impact upon access to treatment. Ninety-seven percent of participants responded to this survey question ($n=28$); data was only missing related to one participant (3%).

The greatest number of people classified their childhood socioeconomic status in gradations of the middle income range, with 38% ($n=11$) identifying as middle income, 28% ($n=8$) identifying as middle high income, and 17% ($n=5$) middle lower income. All together, these nuanced descriptive levels of middle class comprised 83% of the sample ($n=24$). Of the remaining participants, 10% ($n=3$) described their childhood

socioeconomic status as low income, and 3% ($n=1$) identified as growing up high income.

Table 7

Childhood Home: US Region

Response	Frequency	Percentage
Southwest	8	28%
Southeast	6	21%
Midwest	5	17%
West	4	14%
Northeast	3	10%
Multiple Regions	3	10%

Note. N=29

Childhood Home: US Region

Geographic location of childhood home was a relevant area of interest to this study, as it may potentially influence exposure to heterogeneity of gender expression, as well as access to treatment. All participants answered this question ($N=29$).

Subjects were asked to identify the primary location in the United States where they grew up. In instances in which people may have lived in more than one state, they were asked to indicate the one location where they spent the majority of their childhood. A technical quality of the survey design always allowed for participants to indicate more

than one answer to any question. As a result, it is significant to note that ten percent of participants ($n=3$) specified growing up in more than one location.

Participants chose states as their response; the data was then grouped into regions. The greatest number of participants ($n=8$, 28%) grew up in the Southwest (Arizona and Texas). A significant number of participants ($n=6$, 21%) were from the Southeast (Arkansas, Florida, Georgia, Louisiana, and North Carolina). Seventeen percent of participants ($n=5$) were from the Midwest (Indiana and Ohio). Fourteen percent of participants ($n=4$) were from the West (California, Hawaii, and Washington), and finally, ten percent of participants ($n=3$) were from the Northeast (Connecticut and Massachusetts).

Summary

In this survey, participants were most commonly Caucasian females in their mid-twenties who grew up in suburban communities of the Southwestern United States with middle-income families. The greatest number of individuals were raised with a Christian faith and currently identified as Christian. Most were assigned to be female at birth, a status that their driver's license or other state-issued id continued to endorse.

Initial Study Questions

Table 8

Prevalence of Autism and Gender Variant Identity

Response	Child	Current
No	21	19
Yes	5	9
-	3	1

Note. Dashes indicate missing data. $N=29$

Prevalence of Autism and Gender Variant Identity

Participants were asked if they identified as transgender, gender variant, or gender non-conforming, either currently or as a child. This question was considered to be of extreme import to this study, as one of the initial study questions was “How prevalent is autism and gender variant identity?” While participants might describe their childhood thoughts and behaviors in a manner that others might consider to transgress gender norms, this question allowed for participants to self-identify. Participants were asked about their current gender identity, as childhood and adult gender variant identities may interact with one another.

Ninety percent of the sample ($n=26$) responded to the question of whether they identified as transgender, gender variant, or gender non-conforming as a child. Three individuals did not answer this question (10%). Seventy-two percent of participants answered no ($n=21$), and seventeen percent of participants answered yes ($n=5$).

Participants were also asked, “Do you currently identify as transgender, gender variant, or gender non-conforming?” Ninety-seven percent of participants answered this question ($n=28$), while one individual did not indicate any answer. Sixty-six percent of participants answered no ($n=19$), and thirty-one percent answered yes ($n=9$).

Acquisition of Gender Norms

This study asked participants to consider the origin of information that they received about how to behave like a boy or a girl (gender norms), which may have come from sources either formal or informal. This theme comprised one of the initial study questions that motivated this research and spurred this study. There is little information available in the literature about how children on the autism spectrum develop gender identity. Learning about gender norms through external sources may be one component of this process.

As participants were asked to identify the source of the majority of information received about gender norms, it was initially conceived that participants would indicate one dominant source amongst all potential responses. Yet many participants chose multiple answers for these questions. It is hypothesized that the instructions for how to answer this question may have been unclear. Alternatively, participants may have felt unable to choose only one answer amongst many recalled influences. These unexpected findings of multiple answers indicated may be understood as a flaw in survey design. In addition, they may also indicate that many participants wanted to communicate the existence of multiple sources of information about gender norms.

Participants were first asked “Where did most of your informal information about how to behave like a boy or a girl (gender norms) come from?” All participants answered this question ($N=29$); however, due to the high number of participants who had multiple responses to this question, it is most useful to consider each response as an independent question. Family was indicated by 59% of participants ($n=17$). Friends were chosen by 17% of participants ($n=5$), and peers selected as a response by 38% of the sample ($n=11$). Thirty-one percent ($n=9$) chose the media. Twenty-one percent ($n=6$) indicated teachers, and seventeen percent ($n=5$) indicated friends. One respondent chose “other” and filled in the internet (3%).

Participants were also asked “Where did most of your formal information about gender norms come from (i.e., directly taught in a class or therapy)?” All participants answered this question ($N=29$); however, due to the high number of participants who had multiple responses to this question, it is most useful to consider each response as an independent question. The greatest number of individuals cited teachers ($n=16$, 55%). Two individuals (7%) chose “mental health professionals.” Six participants stated “other” and elaborated with short narrative answers (20%). Of these qualitative responses, four indicated that no formal information on this subject had been provided, one individual stated “family,” and the remaining respondent explained, “It was mostly informal, but there was a little bit of sex ed class at school.”

Participants were also asked “Some children have counseling or groups that specifically are designed to teach social skills, ranging from making eye contact to learning how to ask for a date. Did you receive social skills training that talked about gender identity?” Twenty five participants answered this question; data was missing from

the remaining 14% of participants. The vast majority indicated that they had not received any such education ($n=23$, 79%). Two individuals answered affirmatively (7%).

How does this population experience the influence of others?

All participants were asked whether they had received any negative reaction to their gender expression as a child. This question was asked in order to gauge whether others may have been displeased with participants' gender expression. A limitation of this question may be that participants may have had difficulty reading others' reactions, due to the social skills deficits commonly associated in children with autism. Eighty-three percent of participants responded to this question ($n=24$). The sample was evenly split, with forty-one percent ($n=12$) stating "no" and forty-one percent stating yes ($n=12$).

Participants who stated that they had received any negative reaction to their gender expression as a child were asked to specify its source ($n=12$). Participants frequently indicated more than one response to this question; therefore, each answer was considered independently. Thirty-one percent of participants cited a negative reaction from family ($n=9$). Twenty-eight percent identified peers as the source ($n=8$). The remaining data was comprised of friends ($n=2$, 7%), teachers ($n=1$, 3%) and mental health professionals ($n=1$, 3%).

Participants were also asked whether they had received any support of their childhood gender expression. 23 participants answered this question; data is missing from the remaining six individuals. Forty-five percent ($n=13$) answered affirmatively to this question. Thirty-five ($n=10$) percent stated that they had not received any support of their childhood gender expression.

Participants who previously stated that they had received support in relation to their gender expression were asked to specify its source ($n=13$). Some participants indicated more than one response. Family was the most common source of support ($n=11$, 38%). Friends were also a frequent choice ($n=8$, 28%). Seventeen percent cited teachers ($n=5$), and fourteen percent identified peers as supportive ($n=4$). Mental health professionals were cited by one individual (3%). “Other” was also chosen by one individual, who elaborated that this supportive individual was a “significant other/partner.”

Summary

A small portion of the sample identified as gender variant as a child, and a slightly higher percentage currently identified as such. Family, friends, and peers were frequently cited as sources of informal information about gender norms, and teachers were the dominant source of formal information. The vast majority of participants did not talk about gender identity in social skills groups. Participants were equally split regarding receiving a negative reaction to their gender expression; of those who answered affirmatively, family and peers were the most frequent source. Half of participants had received support of their gender expression, which most commonly came from family, friends, or peers.

Additional Quantitative Descriptive Data

Age of Receiving ASD Diagnosis

86% of participants ($n=25$) answered a survey question regarding the age at which they received a diagnosis on the autism spectrum; data was missing from the remaining four participants (14%). It is not known why participants may have omitted this question; however, it is hypothesized that participants may not have answered this question if they could not immediately recall their age of diagnosis.

Age of respondents' diagnosis ranged from 2 to 28 years old, with a mean of 15.4 and a median of 16. Participants responded by entering their age of diagnosis in an open-entry field; data was then grouped by decade of diagnosis. Seventeen percent ($n=5$) of participants were diagnosed when they were less than 10 years old. Forty-five percent of participants ($n=13$) were diagnosed between the ages of 10-19. Twenty-four percent of participants ($n=7$) were diagnosed between the ages of 21-28.

This question was asked because of the potential impact that age of diagnosis may have upon participants' childhood and gender identity development. Those participants diagnosed on the autism spectrum earlier in life may have had increased access to support services for themselves and their families. Those not identified as on the autism spectrum until later in life may have suffered from not having a community with which to affiliate, or a level of self-understanding that a diagnosis may provide.

ASD Diagnosis Received

Participants were asked to specify which particular diagnosis on the autism spectrum they previously received (autistic disorder, Asperger's disorder, or pervasive

developmental disorder, not otherwise specified). The vast majority of participants answered this question ($n=28$, 97%); data relating to one survey respondent is missing. This question was asked as respective diagnosis received might influence participants' gender identity development.

Most participants received a diagnosis of Asperger's disorder ($n=20$, 69%). Three participants (10%) indicated receiving differing diagnoses over time. Two participants (7%) had been diagnosed with pervasive developmental disorder, not otherwise specified; the same number were diagnosed with autistic disorder ($n=2$, 7%). One participant did not know what diagnosis had been made (3%).

Age of Establishing Gender Identity

Participants were asked "Around which age of your childhood do you have the strongest memories of establishing your gender identity?" Not much is known in the current literature about at what age children on the autism spectrum develop a sense of gender identity, and whether this is later than neurotypically developing children. Seventy-six percent of participants ($n=22$) responded to this question, with data from the remaining seven participants missing.

Most respondents responded numerically to this question; some indicated a small range of years. The numerical responses have been grouped into ranges, in order to speak generally about the data. Many participants remembered early childhood (2-5 years of age) as the most potent time of establishing their gender identity ($n= 8$, 28%). An equal number of participants had the strongest memories of this during their school-age years,

between six and twelve ($n=8$, 28%). Only three individuals (10%) indicated years during their adolescence.

The remaining participants responded to this question through short narratives ($n=3$, 10%). One individual answered “don’t know.” Another indicated that gender identity has always felt indeterminate, stating “I’ve never really had a strong sense of gender identity. Even now, I tend to lack a strong feeling of my gender most of the time.”

An additional comment described gender identity as changing over time:

For a lot of my childhood I thought of myself as being secretly a boy and was afraid people would find out. For a while, at 15-17-ish, I presented in a masculine way and identified as genderqueer. Eventually I figured it was too much trouble to deal with people's reactions so I set about figuring out how to be more of a girl. I'm still not very girly in a lot of ways, but not to an extent that gets negative reactions.

Description of Childhood Gender Identity

Participants were asked to choose a term that best described their gender identity as a child ($n=20$). This question aimed to better understand how children with autism self-identify in relation to gender. 7% of participants ($n=2$) did not respond to this question. Of the remaining 27 respondents, thirty-one percent ($n=9$) indicated “girl”. Twenty-eight percent ($n=8$) responded with “neither/neutral”. Twenty-four percent ($n=7$) chose “boy.” One individual chose “both,” accounting for three percent of the sample. Two individuals (7%) indicated “other,” and elaborated respectively with short qualitative comments, such as “tom boy,” as well as, “I labeled myself as a girl (and a tomboy) mostly because everyone else did, but as I grew up, I gradually became less and less comfortable with that identification.”

Comfort with Childhood Gender Identity

Not much is generally known about the process of gender identity development in children with autism, and even less is known about how these children feel about themselves as gendered beings. Participants were asked to rate whether they felt comfortable with their gender identity in childhood. Gender identity was defined as “your internal belief of being a boy or a girl, or something in-between and less easily defined.” Seventeen percent of participants ($n=5$) did not answer this question. Of the remaining 24 respondents, fifty-nine percent of participants ($n=17$) answered affirmatively. Twenty-four percent ($n=7$) said that they were not comfortable with their childhood gender identity.

Source of Discomfort with Childhood Gender Identity

Participants who previously stated that they were not comfortable with their gender identity as a child were asked to reflect upon the primary source of this discomfort ($n=7$). Some participants stated that this discomfort was related to external sources, i.e. the effect of others’ opinions (17%). Other participants felt that their discomfort stemmed from internal conflict (7%). One participant stated “other” and elaborated by saying, “As a child, most of my discomfort was caused by societal expectations of correct female behavior. After puberty, it has been increasingly due to feelings of gender dysphoria with my body.”

Relationship between Gender Identity Development and ASD

Participants were asked “Do you feel that your gender identity developed differently than your peers who did not have an autism diagnosis?” This question asked participants to weigh in on the overarching question of the study. Seventeen percent of participants ($n=5$) omitted this question. Forty-eight percent of participants ($n=14$) answered affirmatively. Twenty-eight percent of participants ($n=8$) disagreed. Seven percent ($n=2$) selected a response of “prefer not to answer.” To follow up on this question and allow for participants to share any of their thoughts not addressed over the course of the survey, the next question stated “If you like, please explain your thoughts further.” Content analysis was performed on these comments in order to identify common themes.

Qualitative Data

Gender Norms

One of the most dominant themes that pervaded the open-ended section of the survey was participants’ challenging relationship with gender norms. The following subjects reported that they didn’t behave as was expected of them in childhood. One individual stated, “I cared a lot less about being a ‘typical girl’ than my peers, forgoing make-up, dresses, and ‘girl toys’ in favour (sic) of bugs and other ‘boy’ hobbies and interests.” This experience was frequently intertwined with others’ reactions to their behavior. Another person said, “When I was younger, I wanted to have hairstyles, clothes or participate in certain activities that I was told by most adults and peers around me were only for girls.”

Social relationships influenced participants' behavior in many ways. One individual stated, "I seemed to have less gender conformity than my peers, but I also grew up with an openly gay father who had transgender friends. I'm not sure I can separate out growing up autistic from growing up in a family that didn't have any problems with strictly non-gender conforming roles." Another participant echoed this theme of the influence of social environment, highlighting the effect of lack of peer relationships, stating "I didn't really pick up on stuff about how to dress or wear makeup etc. I didn't really have many friends by the time I was 12-14, which could be one reason." An additional participant shared "The lack of social contact in my early years led me to believe that people did not value me as a male. Therefore, I started to value feminine traits to better be accepted. Needless to say that was a stupid idea."

Part of the reason I came back to identifying and presenting in a more girly way (at about 17-18) is that I realized being spacey and slow could be perceived as cute or funny in a more feminine person, so presenting as girly makes it easier for me to interact with other people. I still don't dress the way other girls do--I'm not against it, but I never picked up on it, and it seems so incredibly complicated I'm not sure I could pick up on it without careful study. Plus it's easier to wear softer clothes for sensory reasons. I have long hair (which I like having), wear a bit of makeup, and sometimes wear clothes with feminine patterns--but I don't really wear dresses, and I don't put together outfits. I always wear jeans.

Some participants rooted their gender variant behavior and presentation to a gender variant identity. One individual stated, "As a child, I saw myself more as a boy because I hated the dressup stuff my mom and female relatives forced me into and preferred ruffhousing (sic) with my brothers and climbing trees." Yet another individual indicated "I have felt gender neutral as long as I can remembers (sic). I am often

criticized by my family for not being sufficiently feminine but in most cases I don't even understand what is being required.”

Influence of Autism Diagnosis on Gender Identity

Some participants discussed the interaction between their diagnosis and gender identity development. One individual stated, “I might have been more comfortable with being different if I had been diagnosed sooner. I felt like I was both male and female and still do.” Another person said, “I don't feel I really had one--which may not be an ASD thing, but it does affect my reaction to not having one.” An additional participant stated, “I think my discomfort with girls is mostly due to ASD, partly because they're less straightforward but mainly because I start unfavorably comparing myself to them.”

Some participants felt that having an autism diagnosis affected their ability to anticipate others' negative reaction to their atypical gender presentation. A female participant stated “I presented as masculine for a while in high school, which was a huge mistake that ruined my ability to have friends. If I wasn't ASD I would have known not to do that.” Another participant shared similar sentiments, in the context of transgressing gender norms:

However, I am not so certain that an autism-spectrum disorder played a role in these desires. I do think it is possible that my autism-spectrum disorder did play a role in my inability to foresee the negative feedback I would receive because I expressed desires to do things that the people in my environment that was atypical for a boy.

Gender Identity

Some participants described strong feelings in relation to establishing their gender identity. One individual said, “I have always known I was a boy and never thought of myself any other way.” Another individual stated, “I identify with being a woman completely but I had to learn how to be feminine. I also experience atypical sexuality compared to most women.” An additional respondent described gender identity development thus far:

“Because my gender identity is something approximating non-gendered/none-of-the-above, I did not have the same sort of early childhood dysphoric experiences that someone MtF or FtM might. It was only in and after puberty, when my body began to change farther away from my sexless internal representation, that I began to feel true gender dysphoria rather than mere dissatisfaction at traditional gender roles, and it was not until college that I encountered the concept of being genderless or third-gender and finally found an identity that actually fit.”

Conclusion

Of the previously stated findings, the following items are thought to be amongst the most important information generated from this study: (1) participants’ process of establishing their gender identity, (2) the interaction between autism and gender, (3) the incidence of gender variant identity in this sample, and (4) how participants received information and support. These topics will be expanded upon in the next chapter.

CHAPTER V

DISCUSSION

The purpose of this study was to explore the development of gender identity in children on the autism spectrum. Data was self-reported by young adults, who answered retrospective questions in a mixed-methods survey conducted on the internet.

The information gathered in this study should help social workers and other professionals better understand the needs of this population. It is hoped that this research will stimulate general discussion of autism and gender identity development, which may subsequently assist in the development of increasingly appropriate and respectful educational, medical, and mental health interventions.

Key Findings and Relevant Literature

Establishing and Acquiring Gender Identity

Participants recalled a wide range of ages at which they established their gender identity. An equal number cited either early childhood or school-age years; however, a smaller number of participants indicated adolescence. These findings seem to be at odds with those of Abelson (1981), who found that gender identity is a function of mental age in children with autism. Nonetheless, it is challenging to compare Abelson's work to this study, as Abelson did not allow for participants to indicate a gender identity that was not

congruent with sex assigned at birth. Gender variance was therefore not a valid option. No data was gathered in this study regarding participants' cognitive level at the time of establishing gender identity; however, it seems that mental age may not be the only mediating factor regarding gender identity development in children on the autism spectrum, due to the variation exhibited in this study.

This study found that some participants were not comfortable with their gender identity as a child. It seems important to note that of this subset of the sample that were not comfortable with their gender identity as a child, four individuals identified transgender, gender variant, or gender non-conforming, and three did not. Research on children with Gender Identity Disorder (GID) in Canada and the Netherlands indicates that children diagnosed with GID have more behavior problems and difficulties with peer relationships (Cohen-Kettenis, Owen, Kaijser, Bradley, & Zucker, 2003). Support and information regarding gender identity therefore seems indicated regardless of identity, in order to support children on the autism spectrum with their emerging social lives and self-esteem.

Interaction of Autism and Gender

Participants were asked "Do you feel that your gender identity developed differently than your peers that did not have an autism diagnosis?" Many answered this question by providing detailed recollections of their childhood, with particular focus upon the topics of autism and gender identity. While most of these comments did not clearly name autism in their depiction of gender, elements of the diagnosis and experience seem implicitly present.

Many qualitative remarks referenced the impact of social relationships on gender presentation. Overarching dimensions to consider may be both quantity and quality of relationships. For example, one individual hypothesized that her difficulty understanding how to dress or wear makeup may have resulted from the lack of early peer relationships. Another pointed out that it was difficult to separate “growing up autistic from growing up in a family that didn't have any problems with strictly non-gender conforming roles.”

An additional participant explained that lacking of peer relationships made him to wonder whether he was being rejected because of being male; he therefore questioning whether he should be more feminine in order to be better accepted. Due to the small sample size of this study, it is not known whether an experience of this nature is pervasive or an aberration; however, it does seem similar to the sentiments of Kramer et al. (2005), who postulated that gender stereotypes may be the root of cross-gender identification in women on the autism spectrum. This researcher understands this statement to mean that individuals with autism could potentially embrace gender stereotypes and need assistance broadening this understanding.

The social world of individuals with autism is one domain that has received little attention, in relation to gender identity development. The frequency with which participants described their development in relation to others may indicate that this variable is particularly important. It may also be essential to consider the influence of support groups, both in-person and through the internet, upon communities of people with autism (Bumiller, 2008).

Gender Variant Identity

This small study found that many participants did not feel at home in the gender binary as children. Some participants did not ascribe to labels of “boy” or “girl;” instead, they identified as “neither/neutral,” “other,” or “both.” Those individuals who stated “other” both elaborated to describe themselves as “tomboy.” A number of participants classified themselves as transgender, gender variant, or gender non-conforming.

This researcher is not aware of any pertinent literature with which to compare this data. deVries et al. found that in a sample of children and adolescents referred to the Amsterdam Gender Identity Clinic, 7.8% were found to have an ASD (2010); however, that data is not directly comparable to this research. deVries et al. assessed those with gender dysphoria or variance for autism; in this research, autism spectrum disorder was the dependent variable. In this study, many questions were asked about gender variance; however, it was not a prerequisite. Gender identity development was the primary focus.

Support and Information about Gender

In this study, family, friends, and peers were frequently cited as sources of informal information about gender norms, and teachers were the dominant source of formal information. The vast majority of participants did not talk about gender identity in social skills groups. Participants were equally split regarding receiving a negative reaction to their gender expression; of those who answered affirmatively, family and peers were the most frequent source. Half of participants had received support of their gender expression, which most commonly came from family, friends, or peers.

Mental health professionals were not frequently cited as providers of formal information about gender norms. Neither were they a sizeable source of support in relation to participants' childhood gender expression. One participant noted mental health professionals as having a negative reaction to childhood gender expression. No participants recalled receiving informal information about gender norms from mental health professionals.

Social workers must work to create ways to support and teach children with autism. This may involve overcoming personal biases in relation to the importance of normative expression of gender expression.

Limitations

There were several limitations to this study. This was a convenience sample. The nonrandom sampling prevents generalizability. Its size enabled descriptive analysis but was too small for statistical significance. Data was self-reported and gathered retrospectively. This may have compromised the study's validity.

As the study was cross-sectional, it is not known whether the sample would have changed in important ways over time. Furthermore, the participant pool was not sufficiently diverse, particularly in regard to race and ethnicity, socioeconomic background, and childhood community environment. While quite interesting for the high percentage of women who took the survey, the sex demographics of participants were not representative of the general population of individuals with autism. Additionally, an important limitation of gathering a sample from across the county is that there may be significant variation in diagnostic norms, despite common criteria.

Implications

Mental health professionals must take a more active role in supporting children with autism in relation to gender identity development. Teachers were most frequently cited as a source of formal information about gender norms; therefore, it would be ideal if those social workers who work in schools with children on the autism spectrum could also take a more active role in discussing gender in an open and inclusive manner.

This researcher was struck by similar comments made by two participants, stating that their ASD diagnosis impeded them from realizing that there might be a negative reaction from others to a non-normative gender presentation. It is exactly this kind of nuanced discussion from which children with autism might benefit.

Conclusions

This study revealed interesting findings about (1) participants' process of establishing their gender identity, (2) the interaction between autism and gender, (3) the incidence in gender variant identity in this sample, and (4) how participants received information and support.

It is challenging to think of how to operationalize subtle hues of difference in gender identity development and expression, and more challenging still to attempt to describe a population as varied as individuals on the autism spectrum. This study attempted to begin to delve deeper and give participants the opportunity to share their stories. Autism and gender identity are in their infancy of association; there is much more to learn. This study does suggest that they are linked in ways that can benefit from careful intervention.

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Appendix A: HSR Committee Approval



Smith College
Northampton, Massachusetts 01063
T (+13) 585-7950
F (+13) 585-7994

March 24, 2010

Emily Kalafarski

Dear Emily,

Your last revisions have been reviewed. They are fine and we are glad to give final approval to your study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your study.

Sincerely,

A handwritten signature in black ink that reads 'Marsha Pruett / Also'. The signature is written in a cursive, flowing style.

Marsha Pruett, Ph.D., M.S.L.
Vice Chair, Human Subjects Review Committee

CC: Mollie Sherry, Research Advisor

Appendix B: Recruitment Letter

Have you been diagnosed with autistic disorder, Asperger's disorder, or pervasive developmental disorder, not otherwise specified?

Would you like to participate in a study?

You are being invited to participate in a research project designed to study adults on the autism spectrum and their experience of acquiring gender identity as children.

The survey should take approximately 15 minutes. Please note that identifying information will not be collected and your answers will be kept confidential.

If you would like to participate, please follow this link:

(link)

If you have any questions or concerns, please contact:

Emily Kalafarski

(contact information has been purposefully omitted from this publication)

Thank you for your interest.

Appendix C: Informed Consent

Dear Participant:

My name is Emily Kalafarski, and I am a graduate student at Smith College School for Social Work. I am conducting a study in order to complete a master's thesis in social work and for possible publication and presentation. The purpose of my study is to learn more about how individuals with autism remember learning about gender as children and developing a personal sense of identity. Gender identity may fit into society's categories of "boy"/ "girl," "man"/ "woman," or may feel less easily defined. It may match the sex assigned at one's birth or be different.

I am asking that you be a consider taking part in my study because you meet the following criteria: (1) you have previously received a diagnosis of autistic disorder, pervasive developmental disorder, not otherwise specified, or Asperger's disorder), (2) you are between the ages of 20 and 30, (3) you grew up and currently live in the United States, and (4) you are able to answer questions in English. If you choose to participate in this study, you will be asked to take a short survey. This survey should take about 15 minutes.

There is a low risk of emotional discomfort by participating in this study. If you feel as though you need additional support to deal with feelings that emerge, please use the attached list of referral sources. It is also possible that you may benefit from participating in this research. You will be able to examine your memories of childhood and how your gender identity developed, which may be interesting or enlightening. Unfortunately, it is not possible for financial compensation to be provided for participating in this study. It is hoped that this study will give useful information about

Appendix C: Informed Consent

developing improved services for children with an autism diagnosis. It is possible that the results of this study will generate further investigation into gender identity development in people with autism, as well as the co-occurrence of autism and gender variance.

This website ensures participants' anonymity and confidentiality. I will not know your identity. Electronically stored data will be password-protected. Data downloaded from the survey website will be handled only by this researcher and specific Smith College faculty and staff. As required by federal regulations, data will be kept secure for at least three years. If needed beyond three years, data will continue to be kept secure. When no longer needed, data will be destroyed. The findings of this study will be presented by combining and summarizing participants' responses. No identifying information will be included.

Participating in this study is completely voluntary. You may refuse to answer any question. To withdraw from the study, exit the webpage before clicking the "Complete" button at the end of the survey. Data related to incomplete surveys will not be recorded. It will be impossible to withdraw from the study after you have completed your survey, because I will not be able to identify your questionnaire. If you have any questions or concerns about this study, please feel free to get in touch with me at the contact information below, or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

Click "Print" below to keep a copy of this letter for your records, as well as the list of referral sources. Then, click "Continue" to begin the survey.

Appendix C: Informed Consent

BY CLICKING “CONTINUE” BELOW, YOU INDICATE THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

[Continue button]

Thank you for your participation.

If you have any questions, please contact:

Emily Kalafarski
(contact information has been purposefully omitted from this publication)

Appendix D: Survey Questions

1. Have you been diagnosed with autistic disorder, Asperger's disorder, or pervasive developmental disorder, not otherwise specified?
2. Are you between 20 and 30 years old?
3. Did you grow up in the United States?
4. Do you currently live in the United States?
5. Are you able to answer questions in English?
6. [Statement of Agreement; Option to select "Continue" on Informed Consent]
7. How old are you?
8. What is your race or ethnicity?
9. If any, what is your current religion?
10. Where did you grow up? (If you grew up in more than one place, please indicate where you spent the longest time.)
11. How would you describe the community you grew up in? (If you grew up in more than one community, please indicate the place in which you spent the longest time.)
12. As a child, how do you recall your family's socioeconomic status?
13. At what age did you receive an autism diagnosis?
14. What diagnosis did you receive?
15. If any, what was your religion as a child?
16. What sex was assigned at your birth?
17. What sex is currently on your driver's license (or other state-issued ID)?

Appendix D: Survey Questions

18. Do you currently identify as transgender, gender variant, or gender non-conforming?
19. Around which age of your childhood do you have the strongest memories of establishing your gender identity?
20. Which of the following terms most closely describes what your gender identity was as a child?
21. As a child, did you identify as a transgender, gender-variant, or gender non-conforming person?
22. Where did most of your informal information about how to behave like a boy or a girl (gender norms) come from?
23. Where did most of your formal information about gender norms come from? (i.e., directly taught in a class or therapy)
24. Some children have counseling or groups that specifically are designed to teach social skills, ranging from making eye contact to learning how to ask for a date. Did you receive social skills training that talked about gender identity?
25. Did you feel comfortable with your gender identity (i.e., your internal belief of being a boy or a girl, or something in-between and less easily defined)?
26. [If answered no to question #24,] Where did most of this discomfort come from?
27. Did you receive any negative reaction to your gender expression?
28. [If answered yes to question #26,] From whom did you receive a negative reaction to your gender expression?

Appendix D: Survey Questions

29. Did you receive any support of your gender expression?
30. [If answered yes to question #28,] From whom did you receive support of your gender expression?
31. Do you feel that your gender identity developed differently than your peers that did not have an autism diagnosis?
32. If you like, please explain your thoughts further.
33. From which website did you find this survey?