Girls with Autism Becoming Women:
A Text-based Qualitative Approach

BY

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THESIS
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This thesis is dedicated to the seven women featured in this paper; your personal narratives made it possible.
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<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>ADA</td>
<td>Americans with Disabilities Act</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
</tr>
<tr>
<td>AS</td>
<td>Asperger’s Syndrome</td>
</tr>
<tr>
<td>ADI-R</td>
<td>Autism Diagnosis Interview – Revised</td>
</tr>
<tr>
<td>ADOS-G</td>
<td>Autism Diagnostic Observation Schedule- Generic</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorders</td>
</tr>
<tr>
<td>CARS</td>
<td>Childhood Autism Rating Scale</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition</td>
</tr>
<tr>
<td>DSM 5</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition</td>
</tr>
<tr>
<td>HFA</td>
<td>High Functioning Autism</td>
</tr>
<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>NCD</td>
<td>National Council on Disability</td>
</tr>
<tr>
<td>NT</td>
<td>Neurotypical</td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>Pervasive Developmental Disability Not Otherwise Specified</td>
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SUMMARY

Girls in the U.S. are diagnosed with Autism Spectrum Disorders ASD later and less often than boys. The most recent statistics from the Center for Disease Control indicate that boys are diagnosed 4.5 times more often than girls, but the cause of this disparity is not yet fully understood. The complex genetics behind ASD could play a role, but so could cultural, ideological, and diagnostic bias based on gender. In any case, girls and women with ASD form a minority within the greater ASD community whose needs and experiences require more attention. This dissertation applies a text-based, qualitative approach to the autobiographies of seven American women with ASD to better understand the transition from childhood to adulthood. This research grows out of an interdisciplinary disability studies perspective that applies the principles of grounded theory to illustrate and examine some of the primary themes that emerge from careful review of these first-person narratives. Education, sexuality, career paths, and social networks of support are four of the central themes generated by a method of constant comparison. Careful analysis of the data reveals variables, such as date of birth and age of diagnosis, that impact the lives of women with ASD.
I. INTRODUCTION

A. **Background**

Leo Kanner is generally credited with the recognition of autism as a diagnostic category in 1943 at Johns Hopkins. Hans Asperger was simultaneously contemplating autism as a psychiatric disorder in the 1940s. Although Kanner and Asperger are usually credited with the discovery of autism, Swiss psychiatrist Eugen Bleuler had coined the term “autistic” about thirty years before, having derived the term from the Greek word “autos” meaning self (Bleuler; Stanghellini; Davidson). The connection between autism and autos emphasizes the social dimension of the impairment noted by Kanner, Asperger, and Bleuler, who described autism as a type of behavior or thought pattern characterized by aloofness, lack of social reciprocity and eye contact, difficulty communicating effectively, and repetitive behavior such as rocking and hand flapping. The social impairment associated with autism is still an integral part of modern Autism Spectrum Disorders definitions and diagnostics.

According to the most recent statistics from the Centers for Disease Control and Prevention (CDC), 1 in 68 of American children has an ASD. Boys are diagnosed with ASD 4.5 times more than girls, but this disparity is not yet fully understood. ASD is found in every racial, ethnic, and economic group. Almost half (about 44%) of children diagnosed with ASD demonstrate average to above average intellectual ability. Twin studies suggest a genetic link to ASD; when one identical twin is diagnosed with ASD, the other twin is also diagnosed between 36-95% of the time. The prevalence of ASD among non-identical or fraternal twins is still considerable, up to 31%. Furthermore, parents who have one child diagnosed with ASD are 2%–18% more likely to have a
second child also diagnosed with ASD (Christensen et al.). About 10% of children who have ASD are also diagnosed with other genetic or chromosomal conditions, such as Down syndrome, fragile X syndrome, and tuberous sclerosis (Levy et al.). Research demonstrates that children born to older parents, both maternal and paternal, have a higher chance of receiving an ASD diagnosis (Durkin et al, 2008). However, the correlation between parental age and ASD must not be misunderstood as a causative relationship. In other words, the age of parents may not actually lead to ASD. Parents of children with ASD are older when they marry and have children because they too are on the Autism spectrum. The social and communicative impairments of ASD make dating and marriage more challenging; therefore, many people with ASD form relationships and have children later. In a Dutch study presented to the International Meeting for Autism in 2015, the Netherlands Autism Register corroborated this phenomenon in which parents with autism of children with autism were older. This study also reported that parents with ASD of children with ASD were diagnosed later, had higher IQ, and were more often employed.

The Diagnostic Statistical Manual on Mental Disorder (DSM) (American Psychiatric Association) constitutes the modern standard for the definition and diagnosis of autism in the United States. The DSM-5 defines Autism Spectrum Disorders (ASD) as a range of neurodevelopmental impairment distinguished by impairments. In a somewhat controversial move, the APA introduced a new term, Autism Spectrum Disorder (ASD) that replaced the old terminology from the DSM-IV (APA). The new term, Autism Spectrum Disorders, measures autism in terms of severity, rather than assigning subgroups. In addition to the diagnostic criteria listed in the DSM 5, ASD is
often assessed utilizing developmental screening and diagnostic tools. The most common diagnostic tools are the Childhood Autism Rating Scale (CARS), the Autism Diagnostic Observation Schedule- Generic (ADOS-G), and Autism Diagnosis Interview – Revised (ADI-R).
This table reflects the most recent DSM 5 classification of ASD according to levels of severity, rather than sub-groups.

**Table 1**

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<th>Severity Level for ASD</th>
<th>Social Communication</th>
<th>Restricted interests &amp; repetitive behaviours</th>
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<td><strong>Level 3 - 'Requiring very substantial support'</strong></td>
<td>Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others</td>
<td>Preoccupations, fixed rituals and/or repetitive behaviours markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixation or returns to it quickly.</td>
</tr>
<tr>
<td><strong>Level 2 - 'Requiring substantial support'</strong></td>
<td>Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others</td>
<td>RRBs and/or preoccupations or fixedated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB’s are interrupted; difficult to redirect from fixation interest.</td>
</tr>
<tr>
<td><strong>Level 1 - 'Requiring support'</strong></td>
<td>Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions</td>
<td>Rituals and repetitive behaviours (RRB’s) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB’s or to be redirected from fixation interest.</td>
</tr>
</tbody>
</table>

*Note: Autism Spectrum Disorder Severity levels for autism spectrum disorder.*

Since the 1990s, individuals with ASD have become more visible in political discourse and vocal on Facebook, Youtube, and other online forums. Michael John Carley, founder and director of The Global & Regional Asperger Syndrome Partnership (GRASP), also published an autobiography of his life experiences with ASD. Alexander Plank is the founder of WrongPlanet.net, an online community for people with ASD. He is also a filmmaker and consultant on the FX show, *The Bridge*. In a pivotal moment in the history of autism self-advocacy, Ari Ne’eman was the first person with ASD nominated by President Obama to the National Council on Disability (NCD). Ari Ne’eman, director and co-founder of the Autistic Self Advocacy Network ASAN, served from 2010 to 2015 and worked to bring the concept of Neurodiversity to public awareness. “Neurodiversity is the diversity of human brains and minds – the infinite variation in neurocognitive functioning within our species” (Walker). The Neurodiversity paradigm recognizes autism as a natural variation of human neurology. It is a concept that dovetails with disability advocacy and activism because it emphasizes equal rights and access for a diverse group of people.

B. **Statement of the Problem**

Temple Grandin is the most famous author with autism. Born in 1947, Temple Grandin has published numerous autobiographical accounts of autism. Grandin’s first personal account of autism, *Emergence: Labeled Autistic*, was co-authored, but *Thinking in Pictures and Other Reports from My Life with Autism* was her first attempt at solo authorship. In 1999, Edgar Schneider and Lianne Wiley published their autobiographies. Since then, the field of autistic autobiography has steadily grown. Grandin’s personal accounts of autism gained wider appreciation with the release of the
2010 HBO film Temple Grandin starring Claire Danes. However, Grandin’s experience does not represent the majority of women with ASD. Grandin’s professional success and choices regarding relationships do not necessarily represent the experiences of other women with ASD writing autobiographies.

The story-tellers learn from autobiographies how to tell their tales. But that is a two-way street. Temple Grandin’s *Emergence* was written before the genre got underway, so her self-descriptions are unaffected. Today’s autistic child, brought up on children’s stories about autistic children, and who in later years goes on to write an autobiography, will give accounts that are textured by the early exposure to role models. (Hacking, 2009, p. 1469)

According to Hacking (2009), these authors were the first pioneers to begin articulating phenomena that had previously never been described. Six out of the seven autobiographies featured here come from women of the baby boomer generation, a generation born around the same time that the term “autism” first appeared in medical literature. These are the first self-representations of women with autism, a condition that had only recently been named and recognized by Kanner and Asperger (Hacking). Therefore, these personal narratives add to our cultural knowledge about women with ASD. In order to better understand the current state of cultural representations of autism, we must first analyze the origins. Furthermore, studying these first-wave representations of self by women with ASD helps to fill the epistemological gap in what we know about the pre-diagnostic experiences of those born before 1980 (Bracher).
C. **Purpose of the Study**

The purpose of this study is to better understand the processes by which girls with ASD transition toward adulthood and how they make sense of that journey. Qualitative, text-based methods from the social sciences illuminate significant themes that emerge in the autobiographies of women with ASD. The findings that these methods reveal can inform educators, clinicians, and academics interested in addressing major issues for women with ASD, such as unemployment, inadequate education, mental and physical health concerns, delayed diagnosis, and lack of social supports. Looking at these phenomena from a disability studies perspective demands a broader cultural critique of concepts such as autism, disability, race, and gender. Dominant cultural tropes of disability and gender inform the ways women with ASD interpret and tell their life-stories. When these narrative accounts are published as autobiographies, they become cultural representations with the potential to influence social ideologies and the next generation of women with ASD. This interactive exchange between the private and public domains is at the heart of disability studies inquiries into autobiography. The research presented here is meant to enhance our understanding of the qualitative ways in which girls with autism move toward womanhood and how they conceptualize this process. This dissertation excavates variables that affect the lives of girls with ASD as they move toward womanhood through first-hand autobiographical accounts.
II. CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

A. Conceptual Framework

The conceptual influences guiding my research are the theories, concepts, and intellectual genesis of a disability studies perspective that incorporates scholarly contributions from feminist disability studies, Queer theory, and the neurodiversity paradigm.

Disability studies is an interdisciplinary scholarly perspective that responds to the marginalization of disability as a category of social meaning within the academy and, more broadly, the social, political, economic, and cultural circumstances of people with disabilities. Disability studies distinguishes between medical and social theoretical models of disability. According to a medical model, disability is a biological fact embodied in particular bodies. In contrast, the social model of disability looks beyond medical definitions and instead considers ways in which disabilities are socially constructed, dependent on context, and influenced by environmental factors. The social model of disability not only demonstrates how the built environment privileges nondisabled bodies and excludes disabled bodies from access to public spaces, but unearths the deeper, more implicit ideologies that govern environmental inaccessibility and perpetuates exclusion, discrimination, and even persecution of disabled citizens (Frank; Couser, 1997, 2009; Patterson & Hughes). The ideology of ability upholds systemic inaccessibility and the dynamics of power.

The ideology of ability is at its simplest the preference for able-bodiedness its most radical, it defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual
persons. It affects nearly all of our judgements, definitions, and values about human beings, but because it is discriminatory and exclusionary, it creates social locations outside of and critical of its purview, most notably in this case, the perspective of disability. (Siebers, p. 8).

More recently, disability studies scholars have been articulating more integrated approaches that take into consideration the critique of the social model while asserting the primacy of embodied experience (Siebers).

If disability studies takes up disability as a category of social meaning, like other facets of identity, like race, class, and ethnicity, then feminist disability studies examines what happens when these categories intersect, merge, overlap, or clash with gender. Feminist disability studies offers a critique that gender, like disability and race, is not simply a biological state, but that these categories represent complex social systems of meaning and behavior (Davis; Garland Thomson; Hall; Morris). Rosemarie Garland Thomson, already a prominent scholar in the field of disability studies, explains how feminist disability studies is especially interested in the intersectionality and social construction of identities linked to gender and disability.

By probing the cultural meanings attributed to bodies that societies deem disabled, feminist disability studies does vast critical cultural work. First, it understands disability as a system of exclusions that stigmatizes human differences. Second, it uncovers communities and identities that the bodies we consider disabled have produced. Third, it reveals discriminatory attitudes and practices directed at those bodies. Fourth, it exposes disability as a social category of analysis. Fifth, it frames disability as an effect of power relations.
Feminist disability studies shows that disability—similar to race and
gender—is a system of representation that marks bodies as subordinate, rather
than an essential property of bodies that supposedly have something wrong with
them. (Garland-Thomson, pp.1557-1558).

The stigmatization of human difference, politics of identity, discriminatory
ideologies, analysis of the social meaning of disability, and dynamics of power relations
are concepts common to feminist disability studies and Queer Theory. Carrie Sandahl, a
disability studies scholar who focuses on performance art, describes the similarities
between these academic pursuits.

As academic corollaries of minority civil rights movements, queer theory and
disability studies both have origins in and ongoing commitments to activism.
Their primary constituencies, sexual minorities and people with disabilities, share
a history of injustice: both have been pathologized by medicine; demonized by
religion; discriminated against in housing, employment, and education;
stereotyped in representation; victimized by hate groups; and isolated socially,
often in their families of origin. Both constituencies are diverse in terms of race,
class, gender, sexuality, religion, political affiliation, and other respects and
therefore share many members (e.g., those who are disabled and gay), as well
as allies. Both have self-consciously created their own enclaves and vibrant
subcultural practices. (Sandahl, p. 26).

Queer Theory, like feminist disability studies, highlights how gender, disability,
and sexuality are socially constructed identities that operate to uphold sociopolitical
systems and ideologies. For example, Robert McRuer is another leading academic
forging new epistemological ground at the crossroads of disability studies and Queer Theory. McRuer demonstrates how

the system of compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness: that, in fact, compulsory heterosexuality is contingent on compulsory able-bodiedness, and vice versa. (2006, p. 2).

In a 2014 article, Neurocosmopolitan, Nick Walker, precisely defines the core concepts at the heart of the Neurodiversity paradigm and clarifies common misuses of the terminology. Neurodiversity is the biological variation of neuro cognitive functioning within our species. Neurodiversity does not solely refer to ASD, but a range of neurocognitive styles including people who have bi-polar, obsessive compulsive, attention deficit and a variety of other disorders. Rather than anthologizing these differences, proponents of Neurodiversity recognize the value of neurological diversity within our species. The Neurodiversity Movement is a cultural movement devoted to accessibility, equality, respect, and social justice for the neurodivergent. Neurodivergence and neurodivergent are terms introduced by Kassiane Sibley (Walker). Neurodivergent refers to those who deviate from the middle range, which is considered to be normal and Neurodivergence describes the phenomenon of diverging from the norm of neurotypical functioning.

Neuroqueer is a term collaboratively coined by Nick Walker, Elizabeth J. (Ibby) Grace, and Michael Scott Monje, Jr., but also articulated by others, like Melanie Yergeau (Walker).
Neuroqueer is both a verb and an adjective. As a verb, it refers to a broad range of interrelated practices. As an adjective it describes things that are associated with those practices or that result from those practices: neuroqueer theory, neuroqueer perspectives, neuroqueer narratives, neuroqueer literature, neuroqueer art, neuroqueer culture, neuroqueer community. And as an adjective, neuroqueer can also serve as a label of social identity, just like such labels as queer, gay, lesbian, straight, black, white, hearing, Deaf, or Autistic. (Walker).

Rather than comprehending autism as the lack of a social apparatus or a constellation of social impairments, individuals who identify with the concept of neuroqueer constitute an emancipated consciousness with a unique standpoint on the social constructs that Neurotypicals seem to automatically digest and reproduce. Those who identify as neurotypical or generally fit the criteria are therefore limited in their understanding of the social construction of reality. Neurotypical development prepares children to perpetuate systems of social meaning without much criticism or deviance. Theoretically, the transition from childhood to adulthood typically occurs without questioning social norms that are sexist, racist, and dangerous. However, those who perceive the world from a neuroqueer perspective have the potential to point out and analyze social norms, like compulsory heterosexuality and compulsory able-bodiedness, which seem natural and implicit to most NTS.

Nerocosmopolitanism and various schools of disability studies contemplate the diversity of physical and neurological embodiments across the human species. Feminist disability studies, Queer Theory, and neuroqueer theory examine the points where identities, embodiments, and theories of race, class, ethnicity, and religion intersect with
those of gender, sexuality, and disability. These epistemologies and paradigms form the conceptual framework for my research and guide my understanding and analysis of the ways in which girls with autism move toward adulthood.

B. **LITERATURE REVIEW**

Looking at the processes by which girls with ASD become women touches on numerous relevant bodies of literature. The following is a review of the literature broken down into eleven sections. Section one, “Autism and gender”, addresses the disparity between the number of boys versus girls diagnosed with ASD. Section two, “Autism and transition”, briefly summarizes how difficulties with change complicate developmental processes. Section three, “Physical and sexual development”, describes the discrepancy between chronological age and perceived development. Section four, “Cognitive and emotional development”, cites the high rates of anxiety and depression that set girls with ASD apart from typically developing girls. Section five, “Social development”, describes how girls with autism have less access to peer groups in which to learn and practice social behavior. Section six, “Environmental barriers and oppression”, touches on a lack of resources that limits opportunities for women with ASD and provides a short history of the exploitation and abuse directed at individuals with ASD. Section seven, “Education and autism”, presents key legislation that changed educational opportunities for girls with ASD. Section eight, highlights one of the major issues facing adults with “Delayed diagnosis”. Section nine, “Autobiography, identity, and disability studies” reviews the place of personal narratives of ASD within the greater schema of disability studies. Section ten, “Autism autobiographies”, reviews the genesis of autobiographies of autism from the first accounts by family members to the
emergence of a distinct genre of texts published by individuals with ASD. Section eleven reviews several “Similar studies” that utilize first-hand accounts of ASD.

1. **Autism and gender**

   According to the CDC, ASD is about 4.5 times more prevalent among boys compared to girls (Christensen). Males are more likely to be diagnosed with autism than females; however, the current criteria for autism diagnoses are based solely on behavior (APA, Baio). There is currently no blood work or physiological tests used to diagnose autism; therefore, some subjective bias occurs when applying the broad diagnostic category (Bumilier). This social bias includes cultural attitudes and beliefs about gender roles, which then becomes problematic because the core traits of autism impairments (social, communication, and repetitive behavior) correspond closer to male gender expectations (Cheslack-Postava & Jordan-Young). Qualities such as aloofness and autonomy are more closely connected to traditionally male characteristics within our culture (Bumilier; Davidson). In a very circular way, girls may be less likely to be diagnosed or receive services for autism because the behaviors and expectations of autism align more with our social concepts of masculinity. Consequently, ASD has been represented and stereotyped as an impairment that mostly affects boys, conceptualized in masculine terms and pronouns (Cheslack-Postava & Jordan-Young, 2012).

   Additionally, girls may be diagnosed with ASD less often because they demonstrate a different neurobehavioral profile, for example, girls with ASD appear to be more socially motivated and better at camouflaging or coping with ASD characteristics. Further, research demonstrates that clinicians are not asking girls the right questions or looking for specific behavior which would point to the presence of an
ASD (Dworzynski, Ronald, Bolton, & Happé; Frazier, Georgiades, Bishop, & Hardan; Head, McGillivray, & Stokes; Skuse & Mandy). When girls are diagnosed with ASD, support may not be readily available (Begeer et al.; Hiller, Young, & Weber; Brooks & Benson; Krahn; Simone & Willey). The factors that lead to girls with autism being diagnosed later and less often than boys need more attention, as do the ramifications and outcomes that occur due to delayed or misdiagnosis.

2. **Autism and transition**

Research shows that children diagnosed with autism usually retain the diagnosis throughout their lifespan (Billstedt, Gillberg, & Gillberg; Shea & Mesibov; Taylor and Seltzer). There are a small number of individuals, about 9%, who are diagnosed with ASD in childhood, but no longer retain the diagnosis in adulthood (Anderson, Liang, & Lord). There are several possible reasons for this movement away from the diagnostic criteria for ASD. For example, the validity of the initial childhood diagnosis and/or the effectiveness of therapies and interventions could play a role, but this phenomenon still requires more attention (Fein et al.). Nevertheless, the majority of children with autism keep their diagnosis in adulthood; they do not age out of the disorder though symptoms may abate. There is some research that analyzes the physical, sexual, and psychological changes that links childhood to adulthood, but less is known about the transition from adulthood toward older age.

Transition is defined as to include education, employment, community living, and community integration. These areas are crucial for success in adulthood for young people with disabilities, including those with ASD. (Hendricks & Wehman, p. 78).
Collaboration between students with ASD, their families, teachers, therapists, and communities is crucial to smooth transitions from childhood to adulthood.

Students often do not receive the services and supports needed to address the complex set of issues they possess. It is essential that professionals carefully plan for this transition to ensure adolescents and young adults are armed with the appropriate skills and supports needed to be successful. Individuals with ASD spend much more of their lifetime outside of the educational system than in the system; therefore, efforts to maximize this critical period are pivotal to improving outcomes (Hendricks & Wehman. p. 84).

3. **Physical and sexual development**

Many people with ASD have the same desires to express sexuality and experience intimacy as neurotypical individuals, but sexual and romantic development pose specific challenges for those who have difficulty reading social cues, such as facial expressions and body language. Misunderstandings can lead to difficulties forming and maintaining relationships. Sensory sensitivities may cause sexual and relationship problems (Gougeon; Mehzabin & Stokes). The space between physical and social development presents unique challenges for girls with ASD. For instance, this disparity affects the process of sexual maturity which encompasses physical, emotional and social development that occurs during adolescence. Sexual development becomes much more complex for girls with autism because the nature of the disability limits social awareness (Tissot). Although girls with autism physically mature at the same rate as their typically developing peers, the core symptoms of impairment influences the normal
development process (Gabriels). Girls with autism physically develop normally, but the gap between perceived physical age and emotional immaturity is problematic because society has expectations of age-appropriate behavior that may not be met by women with ASD. Hence, physical maturation occurs in contrast to delayed social development.

4. **Cognitive and emotional development**

The discrepancy between physical and emotional development often leads to increased anxiety when females with developmental disabilities may not act as mature as they appear to be. The gap between chronological age and emotional or cognitive development often leads to frustration and confusion, which can cause in anxiety and depression. Adolescent girls with autism face higher rates of anxiety and depression when compared to typically developing girls. Mayes et al. found a high prevalence of anxiety and depression among most girls with ASD. Some researchers conclude that girls with ASD, ages 8-18, resemble boys with ASD more so than neurotypical girls without an ASD when it comes to mood disorders like depression (Solomon et al.). High risk for depression, anxiety, isolation, and mental health issues have been documented in the literature (Allard). These high rates of depression among girls and adolescents with autism definitely are cause for concern and more attention.

5. **Social development**

As neurotypical girls transition toward adulthood, they tend to gain more independence from parents, teachers, and other adults. However, many adolescent girls with autism remain dependent on parents/caregivers for support in education, accommodation and occupational situations (Solomon et al.). For example, young women with autism may not achieve important cultural milestones such as getting a
driver’s license. For most American teenagers, the ability to drive a car is a rite of passage that symbolizes emerging independence and responsibility, but teenage girls with ASD may never drive or do so later in life.

Another potential issue for girls with autism is access to their peer group because they may not have the social skills that allow them to interact with their peers and learn about gender roles, sexuality, and social norms. Girls with autism may not have the social skills to form and maintain friendships; this does not mean they are uninterested in having friends. Although they may have difficulty communicating with others, they still want to engage in social life and form meaningful relationships (Jones & Meldal).

Limited access to peer groups and colloquial knowledge effects the type of information girls with ASD have pertaining to sexuality. Sociosexual knowledge plateaus around the age of puberty; individuals with AS at that age have rarely attained the maturity of the average young adult. They do not have the same experiences as adolescents in the general population (Atwood; Griffiths; Henault; Hingsburger).

6. **Environmental barriers and oppression**

One of the major reasons that girls with ASD struggle on their way toward womanhood is the relative lack of services provided to adolescent s and adults versus children with autism. “Professionals and therapeutic services may no longer be as easy to access or may not consist of a coherent network compared with early intervention services” (Gabriels). Taylor and Seltzer found evidence that services for adults with ASD may not be as helpful or stimulating as early intervention or services aimed at school age children. Longitudinal studies commonly reflect a lack of services for adolescent girls and women with autism, which often results in poor outcomes, ice
unemployment, institutionalization, and depression (Lasgaard et al.). Girls with ASD who benefited from supports in school may struggle when leaving the special education system at 22 years of age. This change in the continuity of services poses challenges for adolescent girls with autism trying to make the transition to adulthood.

Historically, misconceptions about ASD combined with economic, political, and academic opportunism have led to the abuse, oppression, and exploitation of individuals with ASD. In his seminal work, Nothing About Us, Without Us (1998), Jim Charlton describes the nature of disability oppression and resistance.

Oppression occurs when individuals are systematically subjected to political, economic, cultural, or social degradation because they belong to a social group. Oppression of people results from the structures of domination and subordination and, correspondingly, ideologies of superiority and inferiority (p. 8).

Since Kanner coined the term autism, there have been a number of damaging ideologies, alleged therapies, and scientific experiments applied to people with ASD. Bruno Bettelheim’s “refrigerator mothers” (Simpson, Hanley, and Quinn) operant conditioning and the abusive punishments prescribed by O. Ivar Lovaas, and the administration of LSD to children with autism (Freedman, Ebin, and Wilson), top the list of violence and oppression directed toward people with ASD.

Now completely discredited, Bruno Bettelheim set out his theory of autism in The Empty Fortress. Bettelheim, who claimed emotionally distant mothers were to blame for their child’s autism, separated children from their alleged “refrigerator mothers” and
admitted them into his Orthogenic School at the University of Chicago where they were routinely isolated, deprived, and abused under the auspices of therapy.

Ivar Lovaas is a pioneer in the field of Applied Behavior Analysis (ABA), one of the most widely used therapies for children with ASD today. However, the original protocol prescribed by Lovaas included compulsory verbal and physical abuse.

Training was conducted 6 days a week, 7 hours a day, with a fifteen minute rest period accompanying each hour of training. During the training sessions the child and the adult sat facing each other, their heads about 20cm apart. The adult physically prevented the child from leaving the training situation by holding the child’s legs between his own legs.

Rewards, in the form of single spoonfuls of the child’s meal, were delivered immediately after correct responses. Punishment (spanking, shouting by the adult) was delivered for intensive, self-destructive, and tantrumous behavior. (Lovaas, p. 136).

Modern ABA therapists and supporters are quick to distance contemporary ABA practices from its early origins, but more advocates with ASD are coming forward with reports of the punishment and mistreatment they received in the name of ABA (Kapp, et al.).

The 1960s were not an easy time to have ASD. In addition to Bettelheim and Lovaas, Freedman, Ebin, and Wilson conducted experiments in which the hallucinogen LSD was given to twelve “autistic schizophrenics. Since that time, the ASD community has endured countless acts of violence and oppression including the use of dangerous experimental treatments unsubstantiated by scientific evidence, like
chelation, and overt abuse by family members and care-takers. There are even some cases of people with ASD injured or killed in rituals of demonic exorcism.

Autism Memorial is dedicated to remembering those autistic people who died because of malpractice, lack of resources or support, or outright murder. Occasionally, a news story will be widely covered, but most cases receive very little memorial. Even when an autistic person is murdered by a family member and it becomes a big news story, the autistic person often becomes lost amidst sympathy for the murderer. This site is here because everyone should be valued, and everyone should be remembered (“Autism Memorial”, 2013)

7. **Education**

All the women in this study, with the exception of Erika Hammerschmidt, attended primary and secondary school before the IDEA was passed. IDEA was originally enacted by Congress in 1975 to ensure that children with disabilities have the opportunity to receive a free and appropriate public education. The law has been revised many times over the years (Center for Parent Information and Resources,). The passage of IDEA significantly changed the political landscape that governed education in the U.S. and ensured the educational rights for people with disabilities. Likewise, Hammerschmidt was the only woman who benefitted from the ADA, passed in 1990 which extended and further protected the civil rights of Americans with disabilities in all public domains.

The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination and guarantees equal opportunity for persons with disabilities in employment, state and local
government services, public accommodations, commercial facilities, and transportation. It also mandates the establishment of TDD/telephone relay services. All but one of the women in this study, Erika Hammerschmidt, went to school before this law was passed.

Despite educational reform and progressive legislation, social stigma continues to be an issue that impacts girls with autism at school. Children with ASD were more often on the periphery of their social networks, poorer quality friendships and had fewer reciprocal friendships. The majority of high functioning children with ASD struggle with peer relationships in general education classrooms. (Kasari et al.).

8. **Delayed diagnosis**

The issues surrounding late or delayed diagnosis of ASD are beginning to gain traction in academic and clinical circles. Men and women with ASD who were not diagnosed until adulthood experience both negative and positive consequences in response to an ASD diagnosis (Bracher; Huws & Jones; Molloy & Vasil). Often a late diagnosis is prompted by the diagnosis of a child or family member (APA; Carley; Wylie, Beardon, & Heath). Online communities provide another prevalent path toward the realization of ASD characteristics and eventual diagnosis (Baron-Cohen). Relevant research demonstrates how girls are diagnosed with ASD less often and later in life, in comparison to their male counterparts (APA; Bumilieri; Cheslack-Postava & Jordan-Young). The disproportionate number of women receiving an ASD diagnosis later in life is of particular concern because Portway and Johnson suggest that the risks for depression, anxiety, and health problems increases the longer one goes without a diagnosis, There is no way of knowing how many adults with undiagnosed ASD are
living in the U.S., but more research is needed to understand the unique clinical needs and emotional ramifications of acquiring a diagnosis after childhood.

In his dissertation for the University of Southampton, British scholar, Michael Bracher argues that the impact of delayed diagnosis on an individual’s identity can be manifold.

[D]iagnosis can be important in understanding aspects of self and life events associated with AS; however, one should not assume that the diagnosis in and of itself results in an unproblematic experience of self. While formal diagnosis can provide resources for making sense of everyday difficulties, differences and life events, the potential for actualization of these resources in terms of developing a liveable sense of self is contingent upon wider social and biographical conditions. (Bracher, p. 73).

Not only is there a lack of this type of research pertaining to ASD, but also other disabilities as well. The tenets of the neurodiversity paradigm require a great deal of sensitivity when comparing Neurodivergence to illness (described further below), but the social impact receiving a late diagnosis is an important subject examined by Jujus et al (2011), Nettleton (2006), and henry and Hill Jones (2011). Juuso (2011) examines pre-diagnosis meaning surrounding the experience of pain for people with fibromyalgia. Nettleton (2006) raises the issue of social legitimacy and validity of neurology patients with medically unexplained symptoms (MUS). Henry and Hill Jones (2011) provide insight into pre-diagnostic period for older women with a late diagnosis of Attention Deficit Hyperactivity Disorder ADHD. Other than these studies, there is little research
that specifically addresses the issues surrounding late or delayed diagnosis of disability (Bacher, 2013).

9. **Autobiography, identity, and disability studies**

Autobiographical writing by authors with disabilities has the power to either reconfirm tired stereotypes of disability or break with traditional narrative structures to “illuminates meanings associated with disability or illness which are invisible when the body is treated in medical terms, through the language of disease and dysfunction” (Mattingly & Lawlor). Disability autobiographies represent more than a single person’s experience of impairment; this genre reveals the attitudes, social conventions, and systemic barriers that are culturally produced and socially constructed. Thomas Couser, a British academic interested in autobiographical writing of people with disabilities, reminds us that dominant culture “filters and manipulates even seemingly ‘self-generated’ texts in various ways, protecting its interest in marginalizing and ignoring disabled lives” (Couser). Therefore, studying narratives and autobiographies of disability is important because of its interdependent relationship to the prevailing cultural narrative and legal discourse (Couser; Mitchell & Snyder).

Feminist disability studies scholar, Rosemarie Garland Thomson, articulates five traditional types of autobiography that disempower, oppress, and stereotype disability. First is the biomedical narrative that understands disability as an individual flaw that requires rehabilitation, remediation, or cure. The second is the sentimental narrative that conjures images of self-pity and suffering. Third, narratives of overcoming pervade the genre of disability autobiography. Narratives of overcoming conform to “conventional narrative scripts such as the triumphant recovery story or narratives of overcoming”
(Hall). Fourth, narratives of catastrophe represent disability as a unique and unusual tragedy. Fifth, narratives of abjection demonstrate disability as something to be avoided completely.

After years in clinical practice as a psychologist, disability studies pioneer, Carol J. Gill noticed how people with disabilities framed their identities and experiences in terms of integration:

> It is remarkable how many times the theme of integration emerges in the discourse of people with disabilities. As a psychotherapist, I heard a yearning for wholeness and belonging that surfaced repeatedly in the complaints of persons with varying disabilities and backgrounds. The theme is expressed with poignancy in the writings of disabled students, activists and artists. More recently, I detect such longings in the messages people with disabilities send through the Internet. I discern four types of integration addressed in disabled persons' discussions of who they are and where they belong. (Gill, p. 42).

Gill (2001) proposes four general ways of integrating disability into a general sense of identity: (1) 'coming to feel we belong' (integrating into society); (2) 'coming home' (integrating with the disability community); (3) 'coming together' (internally integrating our sameness and differentness); and (4) 'coming out' (integrating how we feel with how we present ourselves).

Gill also explains how the disability rights movement, disability studies, and disability pride are pushing toward a positive sense of disability identity, which is evident in various cultural manifestations, including autobiographical projects.
These paradigmatic shifts in understanding disability also pave the way to identifying with other disabled people and entering into collective action against unjust attitudes and practices. In addition to mobilizing for political change, people with disabilities are organizing to set the record straight about who they are collectively. They are broadcasting their identities by developing and implementing far-reaching disability awareness education, excavating and celebrating disability history, engaging in media activism, and writing articles, books, plays, and television scripts about the disability experience. Most affirmatively, they are declaring positive identity through disability pride and disability cultural activities, including projects focusing on the peer mentoring of young disabled people. (Gill, p. 364).

Building on Gill’s work, Dunn and Burcaw (2013) highlight six components of disability identity at work on autobiographical life-writing, they are: communal attachment, affirmation of disability, self-worth, pride, discrimination, and personal meaning. Further, a sense of disability identity appears to lead to higher rates of satisfaction and personal meaning.

Garland Thomson (2005) argues that autobiographies which promote a positive sense of disability identity resist historically negative associations with disability and transcend the limits of traditional meaning and metaphor to enter into the realm of situated theory.

These are complex, sophisticated explorations of disability issues elaborated not in the genre of the traditional critical study but rather as analyses that are thoroughly situated from the position of the disabled
woman subject. Grounding theory in life-writing, these works model feminist standpoint practice at its most effective. (p. 1569).

Georgina Kleege’s autobiography *Sight Unseen* (1999) is one example of situated theory because it challenges medical definitions and traditional stereotypes of blindness by interrogating the social meaning of vision and blindness. If Kleege’s autobiography were to focus on deficiencies and difficulties due to macular degeneration, then it would exemplify the medical model of impairment. However, “Kleege authorizes her blind gaze to wrench apart the equation of seeing with knowing, exploding conventional binaries of male and female, subject and object, seer and seen” (Mintz). Kleege’s autobiography corresponds to the social paradigm of disability because it makes cultural expectations of blindness visible.

10. **Autism autobiographies**

The first autobiographies of autism were written by the parents and siblings of people with ASD and they tended to emphasize the burdens of disability. Clara Claiborne Park’s *The Siege* and *Autism, Nightmare Without End* (Beavers) portray autism in a primarily negative light as an ongoing family tragedy. Since autobiographies published by family members preceded those written by individuals with autism, they set a negative tone for the public’s attitude about autism in the family. Therefore, the genre of autistic autobiography responds to negative attitudes bolstered by previous accounts of autism as a family tragedy or crisis. Newer titles, like Grinker’s *Unstrange Minds* celebrate autism within the family. Grinker’s book demonstrates his familiarity with the attitudes of the autistic community when he writes about Neurodiversity. Similarly, autobiographies written by siblings of people with ASD are also in dialogue with autistic

The first autobiographical accounts written by people who had ASD were included in memoirs written by parents. Sean Barron’s autobiography is intermingled with that of his mother’s in *There’s a Boy in Here*. Likewise, Jane McDonnell’s *News from the Border* includes an afterward written by her autistic son. The number of “self-authored testimonies of autistic experience” (Davidson) proliferated in the mid 1990’s. Disability studies scholar Couser notes “there have been so many recent first-person narratives by people with autism that they have been granted, or have claimed, their own generic term: autie-biography” (Couser). Building on Couser’s work, Irene Rose coined this new literary genre Autistic Autobiography (2005). Autistic autobiography or autie-biography reflects more than personal experiences; this genre reflects the interplay between the individual with autism and society. These autobiographies of autism fit into a broader cannon of disability narrative and, as such, have the same potential to reaffirm stereotypes and negative constructions of disability and autism or reject traditional scripts of disability and transcend the narratives of overcoming.

Ian Hacking comments on the capacity for autobiographies of autism to represent other individuals with ASD. In fact, the authority of the allegedly high functioning person with ASD to speak for or represent the opinions of those who cannot speak or communicate in normative ways has been an ongoing critique of the genre. However, Hacking argues:
i), that the autobiographies do not so much describe the mental life of their autistic authors, as constitute it by choosing words from ordinary language to be applied in connection with their behaviour. This is important for question (ii). If the autobiographies are straight descriptions, true or false according to the existing criteria, then it is a plain matter of fact whether those descriptions apply to less high-functioning people. But if we think of the descriptions as constituting autistic experience, it is less a question of fact than of the ways in which we will come to understand the less able. (Hacking, p.1472).

The critique that high functioning people with ASD cannot represent the inner experiences of those who cannot communicate conventionally is divisive to autism communities. First-person accounts of ASD by authors with ASD are more representative of inner life of autism than then accounts of parents, siblings, and professionals.

11. **Similar studies**

The few studies that utilize autistic autobiography form another relevant body of literature to be examined. Most of the research that looks at self-representations of autism focuses on the Internet. One study by Jones & Meldal analyzed personal websites of users with Asperger’s Syndrome found on the Internet to explore the role of social relationships in the lives of people with ASD. Jones & Meldal found that the “view of people with Asperger’s as having little or no interest in social relationships is simply not sustainable”. Rather, the authors asserted that “the degree of insight and awareness into being ‘different’ might come as a surprise to many who write on the subject of
Asperger’s” (Jones & Meldal). Other key findings include the Internet as a major resource for people with Asperger’s, an awareness of others with Asperger’s as a source of social and emotional support, the desire to become involved in social relationships, and attempts to fit in with the dominant culture (Jones & Meldal). This study support an underlying assumption for my research, that is, people with ASD want to form and maintain social relationships, but may not always have the skillset to do so.

Davidson is one of very few scholars who studies autobiographies of women diagnosed with ASD. Davidson renders experiences of ASD authors “focusing particularly on their descriptions of how the clinically pervasive triad of impairments is felt to alienate ASD women”. Davidson’s critical perspective on the environment contributes to disability studies by providing “literature on critical geographies of disabilities”. Davidson points to the disparity between rates of ASD diagnosis among girls and boys, recognizing women and girls with autism as a minority within a minority whose views and needs are often under represented and marginalized. My research responds to Davidson’s call to move the perspectives of women with autism toward the center of the discussion and increase their visibility in public discourse.

Clarke & VanAmerom cite a lack of research from the social sciences that “examine the perspectives of the major organizations devoted to AS and to compare the views expressed on their sites with those written by people who have been diagnosed with AS”. This study is important because it reveals a growing tension between the attitudes ASD advocates and goals of charitable organizations. Clarke & Amerom demonstrate a scholarly basis for an interview featured in Wired magazine. This article
written by Steve Silberman reiterates this tension between charitable organization, like Autism Speaks, which are supported mainly by parents who focus on ASD as a medical disorder of childhood that needs to be cured, whereas advocates like Ari Ne’eman uphold the principles of neurodiversity and lobby to extend civil rights and services to adults with ASD. This conflict over who reprints the interests of people with autism has been identified as a political, social, and economic issue that effects that production and substance of autobiographies written by women with autism.

In a study somewhat similar to Clarke & VanAmerom, Chamak, Bonniau, Jaunay, & Cohen compared the perspectives of persons with ASD to the prevailing scientific knowledge about ASD. Rather than analyzing websites, the French study by Chamak et al. suggests that the medical definition, diagnostics, and treatment of ASD needs to be updated to adequately reflect the perceptual and emotional components. “The most striking observations were that all of them pointed out that unusual perceptions and information processing, as well as impairments in emotional regulation, were the core symptoms of autism, whereas the current classifications do not mention them” (Charmak, 2008). Again, this research prioritizes the perspectives of those individuals who have ASD and forwards that feedback to the benefit of scientific knowledge. This project also looks for guidance from individuals with ASD to better understand the experiences and embodiment of individuals with ASD.
III. METHODS

This is an exploratory study that uses qualitative methods to identify issues that emerge as girls with autism become women with autism. My research does not seek consensus among authors with autism, but will highlight significant themes that surface as girls with autism transition out of childhood and into adulthood. My dissertation analyzes autobiographies of women with autism to understand which supports were either available or lacking during this pivotal transition to adulthood. Text-based qualitative methods that rely on autobiographical data are especially suited for research in autism. These autobiographies give women with ASD a voice to describe and conceptualize their own disability. Moreover, this genre provides authors with a venue to explain their social predicament, correct false assertions, and critique pervading scientific paradigms of autism. Since the proliferation of these narrative texts, more venues for autistic expression have emerged, namely, online communities of autistic people. Girls and women with ASD are developing networks and cyber communities to share their experiences, support each other, and redress the general public’s misunderstandings.

Autobiographical testimonials of ASD upset the pathological ideology that simplifies autism as a neurological impairment with subsequent verbal, social, and behavioral deficits, rather than as a complex and generative experience. When special education, occupational, physical or ABA therapies focus on autism as pathology, the voices of students with autism are lost. Instead, educators and professionals spend time correcting or eradicating particular behaviors identified as problematic. Any subsequent research conducted in these disciplines often results in research practices that mirror
and reinforce already established beliefs and practices. These preconceived beliefs manifest in the classroom and clinical settings. The absence of individuals diagnosed with autism in much of the developmental disabilities and rehabilitative literature further informs my methodological and ethical concerns. My ethical concern for the dignity, respect, and civil rights of women with ASD, leads me to text-based qualitative research methods that elevate first person narratives of autism over other types of data. Grounded theory is a research method that satisfies these ethical concerns because it centers the perspectives and voices of these women with ASD.

Glaser and Strauss introduce the core concepts and guiding principles of grounded theory research in their book, *The Discovery of Grounded Theory*. Strauss and Corbin explain that grounded theory “is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon”. In this approach, a critical analysis of the data generates the theories and hypotheses. Data informs theory, rather than data manipulated to support a given thesis. Grounded theory follows certain steps to achieve an accurate description of a phenomenon. This process can be described as an iterative process due to the switching back and forth between data collection, coding, categorizing, and theoretical validation (Jones & Meldal). This flip-flopping technique of systematic comparison works well in autobiographies and other narratives that are freely submitted, not a response to a specific inquiry, so the data remains authentic and resists the influence of the research process (Huws et al.).
Although there are several autobiographies written by women with ASD, there are few studies that utilize these accounts as data for academic research. The methodology of constant comparison was chosen for this study because it offers the voices of American women with autism an authoritative and primary position within the national discourse on autism. Furthermore, constant comparison allows themes, findings and theories to develop from the data itself. Every effort was made to avoid oversimplifying details and forcing data into preexisting categories. As themes emerge, they were compared to findings compiled before and after, allowing the data to drive the research rather than forming preconceived hypotheses and then attempting to organize the data into those categories.

A. **Design**

   This research design derives from previous studies that applied grounded theory to autobiographical materials. This methodology consists of nine procedural steps.

   1. Consider intellectual influences and scholarly perspectives.
   2. Establish a general research question and clarify key terms.
   3. Gather sample materials and begin data collection.
   5. Transcribe, print, and separate significant sections into data segments.
   6. Physically sort data segments into flexible categories and name them. Consider and question themes as they emerge and overlap (open coding).
   7. Remove data segments that seem insignificant or outside the scope of my inquiry.
8. Begin to hypothesize possible correlations, connections and cross-listing of content (axial coding).

9. Rigorous analysis of the relationships between themes raised by axial coding. Build a conceptual framework and test hypotheses in reference to my research question: What is it like for American girls becoming women? (Selective coding).

10. Tape the results of coded content onto paper and enter results into Microsoft Word files.

(Denzin; Fleichmann; Huws et al.; Jones & Meldal; Strauss & Corbin).

B. **Sample**

When a sample was gathered in 2009 a list of autobiographies written by American authors with ASD was compiled using the WorldCat via Firstsearch, an academic search engine accessed through university libraries. This list was checked against Google searches and Amazon listings.

**Autobiographies Written by Authors with ASD**


After limiting the list to American authors, it was further distilled to eliminate books that were co-authored to guarantee individual, ‘single-voice’ autobiographies. I excluded from the sample essays found in anthologies that were written in response to a specific topic, rather than traditional autobiography that fits developmental processes into a wider image of identity. After reading and coding the remaining 18 autobiographies, indicated above in bold print, the data set was still immense. Based on emerging themes and my interest in gender, I decided to focus on the seven autobiographies written by women with ASD. A table containing author’s names, date of birth, diagnosis, age of diagnosis, and educational background.
**Table II**

Author Demographic Information

<table>
<thead>
<tr>
<th>Author</th>
<th>Diagnosis</th>
<th>Date of Birth</th>
<th>Status</th>
<th>High school Grad.</th>
<th>College Grad.</th>
<th>Grad School</th>
<th>PhD</th>
</tr>
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<tbody>
<tr>
<td>Cowhey, Sharon P. (2005)</td>
<td>Autism (46)</td>
<td>1956</td>
<td>Remarried, 2 children</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Hammerschmidt, Erika. (2005).</td>
<td>Autism, Tourette 's, OCD (childhood)</td>
<td>1981</td>
<td>Married, no children</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Prince-Hughes, Dawn. (2004).</td>
<td>Autism (36)</td>
<td>1964</td>
<td>Married, one child</td>
<td>Yes, later</td>
<td>Yes, later interdisciplinary anthropology @ Universitat Herisau in Switzerland</td>
<td>Yes, interdisciplinary anthropology @ Universitat Herisau in Switzerland</td>
<td></td>
</tr>
<tr>
<td>Thorsos, Deborah. I. (2000).</td>
<td>Autism (childhood)</td>
<td>1957</td>
<td>Married</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Northwestern Virginia Community College, U of Maryland</td>
<td>No</td>
</tr>
</tbody>
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The following material provides some biographical information about the seven women selected for this research.

**Sharon Cowhey**

Sharon Cowhey’s autobiography generally follows a sentimental narrative style that attributes the many abuses and tragedies she has suffered to the role of autism has played in her life (Garland Thomson). Sharon Cowhey was born in 1959, before the IDEA and ADA were passed. She attended a Catholic parochial school, but did not have an autism diagnosis at that time. As a child, she found comfort rocking in a rocking chair for hours on end. This reliance on rocking followed her throughout her life, and her feelings about it were somewhat ambivalent. The rocking chair provided necessary comfort, but she also regrets the amount of time she spent rocking. Furthermore, her parents were only slightly concerned about her fixation on rocking, but never followed up thoroughly. During adolescence, she tried to stop rocking, but this resulted in unbearable stress and anxiety.

Cowhey blames her father for genetically transmitted autism to her. In Cowhey’s opinion, her father used alcohol to cope with autism in the same way that she used her rocking chair. Cowhey’s troubled relationship with her alcoholic and possibly autistic father appears to have primed her for a lifetime of troubled relationships with men. As a teenager, she dropped out of high school and ran away from home with a boyfriend. Running away may have physically removed her from a stressful situation, but it did not solve any of her problems and only made her more acutely aware of the crucial life skills that she was missing. When Cowhey returned home, she was unwed and pregnant. A few years later, she married her first husband. This marriage was to be another chapter
in her unfortunate history with abusive and predatory men. She eventually discovered that her husband was sexually molesting her daughter and divorced him.

The next example of Cowhey’s victimization at the hands of white, non-disabled men led to her ASD diagnosis. Cowhey was referred to a counselor to address sexual harassment that she was experiencing in the workplace. It was within this context that she finally found a word or label for the assorted communication, sensory, and social difficulties she had experiences throughout her life. When Cowhey was eventually diagnosed with autism, she was married to her current husband, Barry with whom she has a son who is not on the autism spectrum. She was worried about how Barry would react to her diagnosis because his family already rejected her on the basis of her unusual demeanor and behavior. In fact, Cowhey was very sensitive to the ways others perceived her. As a child, she saw a mentally ill woman living in an asylum and worried whether that might become her own fate. She revealed the emotional pain that she experienced because the symptoms associated with autism made her seem unusual or standoffish. Cowhey was afraid that other people saw her as “crazy”, “bitchy”, or addicted to drugs. Her overall attitude about autism is not very positive; she blames autism for the majority of her struggles and worries that the stigma surrounding autism will negatively impact the way others view her children and grandchild, none of whom have an autism diagnosis. Likewise, she does not support integrated education for children with autism. This opinion grows out of her own integrated education, which was integrated not by legislation, but by default because she was undiagnosed. Sharon’s experience was more representative of a student “falling through the cracks” of the educational system, rather than uninformed, unintentional integration. Her attitude on
integration, however, seems more consistent with a mother of non-disabled children, rather than a disabled former student. In her defense, Cowhey lived longer as a mother of nondisabled children than as a woman with an autism diagnosis, so her perspective makes sense given her background; her identity as a woman with autism is relatively new.

When Cowhey completed her autobiography, she had only recently started thinking about herself as disabled or autistic. At this point in considering her newfound autism identity, Cowhey relates her autism to her husband’s alcoholism. In a seemingly codependent relationship, Cowhey explains how she accepts her husband’s alcoholism and frequent DUI arrests; in exchange, Barry accepts her eccentricities due to autism. Her marriage to an alcoholic is not surprising, given that many children of parents with alcohol addiction also marry someone who is addicted to alcohol (Kearns-Bodkin & Leonard). Cowhey achieved her goals to become a wife and mother, but is just beginning to integrate her newfound autism awareness into a cohesive sense of self (Dunn and Burcaw; Gill).

**Temple Grandin**

Born in 1947, Temple Grandin is the most well-known woman with autism, both in this study and the larger world. Her numerous narrative and academic publications have been widely circulated. Grandin’s fame, success, and celebrity affords a unique status among the other authors featured here, some of whom know and refer to her. Furthermore, Grandin’s place in the public eye distinguishes her as an autism representative and role model in a culture where women with autism are rarely seen. Her academic and professional success grew out of personal talent, but the support of
her family and mentors was integral. At an early age, before IDEA, ADA, and widespread knowledge about autism, Grandin’s mother engaged her in activities that we would now call early intervention. She credits her mother for these early efforts, stressing the importance of this type of intensive one-on-one attention that she received. At home, she was included in all aspects of family life; she was expected to demonstrate polite table manners at family dinners, play family board games, and attend church, just like her nondisabled siblings. She often attributes her success to her “1950s style” childhood, an era typified by traditional family values and social structures along with more formal and rigid social conventions. These rules and routines, Grandin argues, made it easier to understand and fit into a sometimes bewildering world.

Not only did her mother and immediate family help support Grandin on her path toward adulthood, but the efforts of her extended family, mainly her aunt, was instrumental to her personal and professional development. It was her aunt’s ranch in Arizona that first piqued Grandin’s interest in cattle and that ranch became an early training ground for her impressive career in the cattle industry. Her exposure to cattle and ranch life spurred on her academic and personal ambition, but was also key to Grandin’s understanding of herself. Further, her passion was a constant source of motivation from adolescence to adulthood. During that time, Grandin learned to channel her emotions and control her behavior in order to pursue her education and professional goals. The Grandin family also had the resources and dedication to send her to a boarding school that catered to her interest in ranch life and animal husbandry. It was at that school where she met another key figure in her life, a science teacher that became
a valued mentor and major source of emotional and academic support during college and beyond.

Grandin's educational and professional success may have come at the expense of her personal life. She never attempted to form an intimate relationship or marry, instead discounting her personal relationships for the sake of business contacts. Unlike the six other women in this study, Grandin decided to forego romance altogether because she argues the symptoms of autism seemed too insurmountable for an intimate relationship. Rather than acknowledging and addressing the sensory, social, and communicative impairments that, for example, make intimate relationships challenging for many people with ASD, Temple abandoned the pursuit for romance altogether. Grandin accepts autism and embraces the concept of neurodiversity. That is, she sees neurology as a range in which autism constitutes another, equally valid and worthy form of neurological embodiment. Neurodiversity envisions neurology itself as a spectrum in which neurotypical people occupy the majority position, while people with autism and other neurological differences representing various constellations along the spectrum. This perspective views autism as another mode of being in the world. Perhaps autism is alternative, but certainly not inferior, invalid, or necessarily impaired. This attitude is apparent in her autobiography, as well as her public appearances and other speaking engagements. However, this attitude downplays the impairments that are disabling too many people with ASD. When Grandin distances herself from disability, she de-emphasizes the mitigating role that her family's emotional and financial support provided. In a time before civil rights legislation, Grandin was fortunate to have the resources that made her education and career possible. Without the efforts
of her educated, upper middle class family, autism may have been a more disabling neurological impairment. Grandin’s attempt to distance herself from disability could be read as a narrative of the abject, because she is trying to avoid the stigmatized identity and negative cultural associations of disability. However, Grandin’s spectacular success engages the cultural imagination because it epitomizes the most commonly represented literary theme, the narrative of overcoming (Couser; Hall; Garland Thomson; Mitchell & Snyder).

**Erika Hammerschmidt**

Born in 1981, Erika Hammerschmidt is the only woman in this study young enough to benefit from civil rights legislation, such as the ADA and IDEA. Therefore, she was the only one with an ASD diagnosis to be integrated alongside her typically developing peers. With support from special education, resource rooms, and paraprofessional teacher’s aides, Hammerschmidt stayed within the mainstream for the majority of her education. Hammerschmidt’s education and self-esteem were bolstered by her dedicated, well-educated parents who were both physicians and had the financial resources and medical awareness to support her in her life’s pursuits. From an early age, they sought out accurate diagnoses, appropriate educational settings, and interventions. The efforts of the Hammerschmidts, coupled with progressive civil rights legislation, enabled Hammerschmidt to be successful in school and life.

Hammerschmidt was successful in many areas of school in part because IDEA and ADA ensured her place in the public education system. Although she was given to opportunities to act in school plays and win spelling bees, she could not escape the social stigma associated with disability. Hammerschmidt, like many students on the
Autism spectrum, was bullied and ostracized by her classmates. She thus presents a more ambivalent image of the pros and cons associated with integrated education. In general, the opportunities and choices ushered in by IDEA and ADA outweighed the drawbacks of stigma and alienation, but legislation is only part of the equation.

Hammerschmidt’s parents are both pediatricians who consistently supported their daughter’s education and creative interests. They encouraged her to express herself through language, literature, and the arts. They had the economic resources that allowed Hammerschmidt to cultivate her prodigious aptitude for foreign languages, sending her to language intensive summer camps. These camps provided Hammerschmidt with an opportunity to sharpen her foreign language skills and an environment in which common interests outweighed perceived deficits, creating a space where she could thrive socially. In a sense, her differences were lost in translation because everyone was speaking a foreign language. Any lapses in fluency or voice modulation were accepted as part of the process of foreign language acquisition.

Hammerschmidt is not the only person with an ASD to express a greater comfort within foreign cultures, especially in relation to interpersonal relationships. Stephen Shore also describes how some of his autistic traits get lost in translation when he interacts with his wife who is originally from China. Hammerschmidt underscores this phenomenon with a summer romance at a Spanish language immersion camp. Summer camps became a social oasis for Hammerschmidt during her teen years when her feelings of alienation and isolation intensified.

The high school years are generally a time when adolescents grant more independence from adult supervision and assistance. Hammerschmidt, however,
struggled to assert her independence at school because she had a paraprofessional aide shadowing her. Then it is not surprising that adolescence was the period in which Hammerschmidt began to articulate the feeling of being an alien or “born on the wrong planet”. This feeling of being “born on the wrong planet”, which is also the title of her autobiography, is a double pronged experience of alienation and “Alien-ation”. On one side, she felt alienated from others in the traditional or existential meaning that social theorists like Marx, Weber, Durkheim and Sartre pondered. On the other side, she felt “Alien-ated” in the sense of being like an extra-terrestrial being from another planet, the human personification or embodiment of a space alien. Hammerschmidt is not the only person with autism to express deep feelings of “Alien-ation”, Temple Grandin also reports a very strong connection to the fictional Vulcan alien, Mr. Spock from Star Trek (Grandin). Nevertheless, Hammerschmidt explains how these feelings of “Alien-ation” gradually began to subside, in part, through writing and imagining science fiction civilizations. Through her attention to the building blocks of fictional civilizations, she became more fluent and more comfortable within her own nonfictional human culture.

College marked a turning point in the formation of a disability identity for Erika Hammerschmidt. While in college, she began to experiment with different ways of integrating her disability into a more cohesive identity. A more accessible environment combined with accommodating professors and compassionate classmates gave way to greater comfort within a nondisabled culture or Gill’s first type of disability identity integration, ‘coming to feel we belong’ or integrating into society. Further, Hammerschmidt used the Internet to develop a vast network of friends and peers with
autism, which gave her a sense of Gill’s second type of integration, ‘coming home’ or integrating with the disability community.

Hammerschmidt ultimately met her future husband through her college network of ASD friends and mutual acquaintances. She graduated from college with a bachelor’s degree, but chose to work in a store stocking shelves. Although she may be overqualified for this work, Hammerschmidt stands behind her decision to continue in this line of work, which may point to evolving sense of disability identity and integration.

In Gill’s third type of psychological integration ‘coming together’, people with disabilities begin to internally integral our sameness and differentness. Hammerschmidt exemplifies this process by weighing her personal needs and desires against those of society and making strategic decisions to support herself economically and purse her dream to become an author. Toward the end of her autobiography, Hammerschmidt’s comfort with her own differences and the way those differences are perceived by others supplies evidence for Gill’s fourth type of integration, ‘coming out’ or integrating how we feel with how we present ourselves. According to Dunn and Burcaw, Hammerschmidt also fulfills the six elements of disability identity at work in autobiographical life-writing, they are: communal attachment, affirmation of disability, self-worth, pride, discrimination, and personal meaning.

Far from reproducing old stereotypes of disability and gender, Hammerschmidt’s autobiography is one of the few examples that enters the realm of situates theory. Hammerschmidt’s narrative fulfills Garland-Thomson’s criteria for situated theory (2005) because it questions and criticizes the social, political, and economic forces that mold cultural representations of disability and gender.
Dawn Prince-Hughes

Born in 1964, Dawn Prince-Hughes was eventually diagnosed with autism after a tumultuous childhood, adolescence, and early adulthood. Although Prince-Hughes had emotionally supportive parents, they had limited financial resources. Without knowing that their daughter had autism, they could only guess how to best support her. However, they supported their daughter when they became aware of potential issues. For example, her parents intervened to support Prince-Hughes after she came out in early adolescence. Concerned about the impact of their daughter’s stigmatized sexual identity on her self-esteem and social development, the Prince family sought out a Lesbian Gay Bi-sexual Trans (LGBT) support group. The challenge of having an “alternative” sexual orientation and an “alternative” undiagnosed neurological condition was very difficult at that time and cultural moment. Being an openly gay adolescent at that time was unusual and highly stigmatizing, but her awareness of this marginal status may have been complicated by the social and communicative impairments associated with ASD. If Prince-Hughes did not have autism, she may have made different choices to manage stigma and abuse she suffered at the hands of bullies and other unsympathetic peers. The bullying and ridicule Prince-Hughes endured in high school due to her sexual identity and undiagnosed autism was so overwhelming that she sought escape through alcohol.

Prince-Hughes writes that life began to turn in a positive direction when she found work as an exotic dancer. This somewhat ironic turn of events was only made possible because the establishment where she worked was run by women who were
former dancers. The compassion, concern, and health benefits the owners gave their employees made it a supportive environment where Prince-Hughes felt comfortable and accepted. Her job satisfaction was also predicated on the type of exotic dancing she performed and the performance setting. There was never direct contact between dancers and customers because it was a peep show format in which the dancers and audience were separated by glass and customers had to pay to open a window and view the dancers. She was successful in this career because it catered to her sensory needs and allowed her to express and explore her sexuality in a safe, supportive environment. The confidence and stability Prince-Hughes developed during her exotic dancing career served her well in the next phase of her life.

Starting a new job at the Seattle Zoo represents another pivotal shift in the autobiography of Dawn Prince-Hughes. Her fascination with the social behaviors of captive mountain gorillas became a looking glass into human culture. Studying gorillas in captivity gave Prince-Hughes greater insight into her behavior and human social behavior in general. It was around this time that she received an autism diagnosis. Having a diagnosis also gave her a deeper understanding of the unique way in which she perceived the world and her part in it. With support and accommodations from her teachers and university administrators, Prince-Hughes successfully completed a Ph.D. in interdisciplinary anthropology at Universitat Herisau in Switzerland.

The personal narrative presented by Prince-Hughes perhaps comes closest to Neuroqueer situated theory because of the way she probes social norms, like compulsory heterosexuality and compulsory able-bodiedness (Garland-Thomson). Rather than adhering to age-old patterns of disability narrative, Prince-Hughes asserts a
complex and critical standpoint on the various facets of her identity and their social
construction. Prince-Hughes demonstrates her connection to a broader disability
community through her communal attachment, affirmation of disability, self-worth, pride,
discrimination, and personal meaning (Dunn and Burcaw). Prince-Hughes also
exemplifies four types of disability/identity integration as she gained a sense of
belonging within the wider culture, a place within Neuroqueer circles and the gorilla
nation, the confidence to integrate her sameness and differentness, and increasing
comfort with her presentation of Self (Gill).

**Therese Ronan**

Therese Ronan was born in 1956, at a time when knowledge about autism was
not widespread. She received a diagnosis in childhood, which put her on track for
segregated special education. Ronan’s family demonstrated a pattern of behavior that
did not support her integration or inclusion in most facets of daily life. She was not
encouraged to fully participate in the spiritual life of the family, for example. This pattern
of exclusion from religious life began in childhood when her parents decided she would
not join her peers in the First Communion ceremony, a major milestone in the Catholic
Church. Her family continued to exclude her from religious observance when she was
overlooked as godmother to her nieces and nephews, an honor that was normally given
to an aunt. Ronan was deeply insulted that her disability became grounds to keep her
from assuming her rightful place in the spiritual life of her family and the church.

Once again, Ronan’s family fell short when advocating for her education. In an
age before legislation insured the rights of people with disabilities access to an
education and other public systems, Ronan’s education was left in the hands of
unsympathetic administrators and efforts made by her family. Unfortunately, this meant the same type of exclusion that Ronan suffered in the religious practices observed by the family. Her education was very inconsistent, both in quality and quantity. She attended at least five different educational institutions, but the ultimate lapse in support systems was the two year period during adolescence when she did not attend school or receive any services. Sadly, Ronan blamed herself for displaying inappropriate behavior while meeting a school administrator who had the power to bar her from attending that school. She may not have had legal recourse to address her miseducation, but there is little evidence that her family made much of an effort to find an alternative arrangement.

Therese Ronan became interested in boys at an early age and had a very active fantasy life based on teen heart-throbs and real life crushes. The depth and detail of her fantasy life was quite remarkable, which may have resulted from the lack of potential partners and interference from her family. The Ronan family disregarded her choices when it came to romance to the extent that they intervened to end a relationship. When she finally made a romantic connection and they announced their engagement, both families intervened, with the help of police, to swiftly end the relationship. Consequently, Ronan is the only woman in this study who wanted to marry, but never fulfilled this desire. It seems that Ronan’s distrust in the social systems of her family and church translated into disdain for formal social service systems, like vocational rehabilitation. She became disillusioned by discrimination in the work place and poor job training. Although she wanted to pursue a career in the beauty industry, the decision makers controlling vocational rehabilitation denied her training based on the outcome of her IQ scores.
Despite having an unsupportive family, an inconsistent education, no support from an intimate partner, and systemic discrimination, Ronan resisted the forces that tried to limit her choices; in fact, she displayed a critical awareness of stigma and institutional social inequality. In this respect, she unknowingly deployed a social model of disability that locates the challenge of duality in inaccessible social systems that exclude people with disabilities from full participation in most aspects of daily life. A social model of disability does not forward the idea that disability is solely located in imperfect or impaired bodies that refuse to conform to the built environment; this ideology is more consistent with a traditional medical model of disability that does not account for the monumental impact and variety of environmental factors, like curb cuts, audible crossing signals, visible signs and audible cues on public transportation, non-fluorescent lighting, civil rights legislation, and an overall mindset that limits the freedom and diminishes the value of people with disabilities. Throughout her autobiography, Ronan referenced cultural norms that devalue people with disabilities. Rather than simply absorbing and internalizing the negative cultural messages about her own alleged inferiority, she held social systems accountable for limiting her education, career, participation in religious life, and love life. Instead of accepting and believing in her own inferiority and invalidity, Ronan questioned and resisted the social conventions and authorities telling her that she was not a suitable lover, daughter, sister, aunt, mother, godmother, student, or employee. In this regard, Ronan’s disability identity played an important role in the production of her autobiography. Her critical awareness of the systemic oppression of people with disabilities and resistance to it elevates
Ronan’s text to the level of situated theory (Garland-Thomson, 2005). Ronan’s autobiography also raises the themes of communal attachment, affirmation of disability, self-worth, pride, discrimination, and personal meaning consistent with a sense of disability identity (Dunn and Burcaw). Ronan’s disability identity comes through in the pages of her narrative, as does her sense of ‘coming home’, the second type of integration described by Gill. However, her enduring feelings of marginalization, stigmatization, and discrimination within multiple social systems (domestic, religious, educational, social, and vocational) keeps Ronan from other type of identity integration, such as ‘coming to feel we belong’. Furthermore, the ongoing and overall conflict between Ronan, her family, her religious upbringing, and mainstream society deters her from the other forms of disability identity integration and synthesis such as ‘coming together’ and ‘coming out’ (Gill).

**Deborah Thorsos**

Deborah Thorsos was born into a Jewish family in 1957, too early to benefit from the IDEA in elementary school. However, she was allowed to begin her secondary education at the local public high school on October 2, 1973, only six days after the Rehabilitation Act of 1973 was enacted. Long before any legislation that granted Thorsos a free and public education, her family made her education a priority. Starting with her diagnosis in childhood, Mrs. Thorsos sought out early interventions and the best placements available within a flawed and discriminatory educational system. In fact, Mrs. Thorsos played a significantly supportive role in her life, especially in relation to her education. Her mother continued to comprehensively support Thorsos after she
graduated from high school. Thorsos and her mother even relocated together to be close to a well-chosen college.

The early and consistent separation from peers signaled negative social values about her social status. Thorsos' lengthy career in special education appears to have influenced her deep internalization of these messages about her differences, inferiority, and inequality. Her supportive family made sure that she received the best possible education, but this prolonged exposure to systemic segregation and discrimination appears to have permeated her sense of self. In any case, this example of autobiographical life writing straddles the line between a biomedical narrative and one of overcoming because Thorsos measures her success according to her ability to correct or “rise above” the core traits of autism (Garland-Thomson).

Although largely negative, this biomedical/narrative of overcoming still reveals examples of a disability identity. Their mutual awareness of discrimination and tentative communal attachment brought Thorsos together with her husband Chris, a visually impaired man she met while using public transit (Dunn and Burcaw). Her marriage also provides Thorsos with a sense of ‘coming home’, which is one of the types of integration articulated by Gill.

**Lianne Willey**

Lianne Willey was born in 1959. In the foreword of her autobiography, Willey admits that she does not have an official diagnosis, but self-identifies with ASD based on similarities to her daughter. In childhood, Willey was evaluated and labeled as a “gifted student”. This label may not have been pejorative or stigmatizing, but her
intelligence and early academic success led Willey, her parents, and teachers to expect future success. Lianne had friends and was well integrated into the social fabric of her elementary school. However, the arrival of adolescence and puberty marked a turning point at which Willey began to notice differences between her development and that of her peers.

According to her autobiography, adolescence ushered in the first signs that Willey’s developmental trajectory differed somewhat from the neurotypical pattern of maturation. Wiley’s autism was less obvious during childhood, when social interactions were simpler. The increasing complexity of socialization during adolescence occurred faster than she could process, understand, or participate in new social behaviors. For example, Willey found the complex social interactions involved in flirtation to be confusing and illogical. Willey knew her girlfriends were behaving differently around boys, but felt bewildered by flirtatious behavior and fashion trends. She pondered her differences, often concluding there must be something intrinsically wrong with her that kept her from assimilating to mainstream social life. Willey did not realize these signs might predict a choppy transition toward adulthood.

When Willey left the comfort and safety of her well-established and supportive childhood community, she struggled socially and academically. She failed to establish friends and peer groups within the new, less structured environment of campus life. She stopped attending classes because spatial and sensory impairments prevented her from finding them and getting there on time. If adolescence signaled an emerging awareness of developmental differences, the early adulthood solidified these concerns. Looking back, Willey states that she would have made different choices concerning her
education if she had known about her autism, for example, choosing a smaller university equipped with resources to meet the social and academic demands of college life.

Willey did not know why she struggled through her college education. Despite her social struggles, she formed a romantic relationship while working on her bachelor's and master's degrees. Her husband also prefers the company of a few close friends as opposed to large crowds and big gatherings. They both enjoy the format and structure of campus life, so she happily to follow Tom to the University of Houston, Texas. After an initial period of successful adjustment, Willey began to struggle with the transition to her new surroundings and then she was unexpectedly fired from a job.

After having their first child, Willey gave birth to a set of twin girls, one of whom was diagnosed with Asperger's at seven years of age. When her daughter was diagnosed, she started to see the how ASD affected her own development Michael John Carley discusses this phenomenon, in which a child's diagnosis prompts a parent’s realization that they too are on the Autism spectrum. In his autobiography, Carley encourages his self-diagnosed constituents to seek out formal diagnoses.

For many people, not having an official diagnosis can prevent them from having the conviction to be able to move forward. Very few people, for instance, go out and spend hard-earned money on books about AS with the same drive as someone who knows they have AS. That alone is reason to get a clinician's opinion. (Carley, p. 56)

Willey's autobiography does not correlate to traditional stereotypes of disability narratives, but moves toward an account of situated theory (Garland-Thomson). Rather
than overcoming or remediating the symptoms of autism from their lives, Willey attempts to integrate her sameness and differences into a coherent cohesive identity in an act of ‘coming together’. This narrative also represents Willey’s efforts to integrate her newfound autism identity into the wider culture, ‘coming to feel we belong’. She may be in the early stages of ‘coming out’ or making peace with her presentation of self, though a formal diagnosis might facilitate that process. Willey’s narrative also illustrates her attempts to integrate disability into her identity and a growing connection to the disability community, ‘coming home’ (Gill). Overall, her autobiography reflects her emerging disability identity based on a communal attachment, affirmation of disability, self-worth, pride, awareness of discrimination, and personal meaning connected to autism (Dunn and Burcaw).

C. Procedures

The research process followed general grounded theory standards (Denzin; Fleichmann; Huws et al.; Jones & Meldal; Strauss & Corbin). The first step was to clarify my perspective and consider pre-existing assumptions. In this initial stage, it was important to critically think about disability studies perspectives that apply to research utilizing autobiographical materials. Secondly, I formed a broad research question to set the parameters of my interest in autobiographies of autism written by women and, in particular, the transition from childhood to adulthood. I narrowed down my interests into a more specific research question to guide this study, which was: how do American girls with ASD transition toward adulthood? I then considered key concepts like autism, transition, and the politics of gender. Third, I collected autobiographies written by American females with autism. After collecting the autobiographies for analysis, the
fourth step was immersion in the data, reading and re-reading texts, taking notes and flagging passages that dealt with relevant experiences. Due to the physical limitations of my vision impairment, I scanned all materials to create rich pdf texts that are accessible by screen reader. Fifth, Microsoft Word documents were created for each author containing notes, reviewed passages, and page numbers (data segments). Sixth, data segments were assigned labels and organized into emerging categories. For example, any commentary on romantic relationships were grouped together (open coding). In an effort to exhaust all relevant data, creating pdf files allowed me to perform keyword searches throughout all texts when a theme was raised. In other words, when the theme romantic relationships emerged, the search terms “romance”, “romantic”, “relationship”, “love”, “boyfriend”, “girlfriend”, “husband”, and “wife” were entered and evaluated for the contextual relevance. In the seventh phase, I compared categories and themes to propose some initial thoughts about connections, overlapping themes, and relationships between texts and authors (axial coding). The eighth step involved a holistic examination of the data in reference to the existing literature on girls with ASD transitioning toward womanhood. These findings were reviewed to develop concepts and theses based on the material (selective coding). The final step consisted of writing up the findings and conclusions based on the first 8 steps.
IV. RESULTS

The results derived from this inquiry into the processes that affect girls with autism as they become women with autism are featured here. The results consist of four thematic sections that reflect key social systems at play in the development from girlhood toward womanhood. These themes emerged from utilizing a grounded theory approach to analyze seven autobiographies written by American women with autism. The four thematic areas are further broken down into smaller sections that address more specific phenomena related to each major theme. The four major themes are as follows: A. “Educating Women with Autism”, B. “Women with Autism Develop Interests and Pursue Career Paths”, C. “Women with Autism Experience Sexual Development and Romantic Relationships”, D. “Women with Autism Access Networks of Support”. The women in this study highlight how these four areas played a significant part in their development toward womanhood.

A. **Educating women with Autism**

“Educating Women with Autism,” features six thematic sections that reveal how education impacted the transition from childhood to adulthood for seven women with autism. In the first thematic section, “Political ideologies of education informs self-image”, demonstrates how labeling and segregation negatively impacted the formation of her self-image. In the second section, “Education Interrupted,” describes circumstances that led to expulsions and early exits from various educational programs. The third section, “Integration is imperfect” looks at the drawbacks to inclusive education and reveals some of the pitfalls that come with integrated educational

1. **Political ideologies of education informs self-image**

   This section illustrates how the educational policy of segregation negatively impacts the lives of students with disabilities (Inclusive Education and Implications for Policy – TASH). Thorsos, born in 1957, remembered how she felt when denied access to the same schools her nondisabled siblings attended. Without the legislation offered by IDEA or the ADA, Thorsos had very few educational options and had little recourse to address her placement in school. In the following excerpt, Thorsos interpreted the segregated learning environment as a sign of her different and unequal status.

   I felt I was somewhat inferior to them and that was the reason behind not attending the same school. I hated the idea of having to go to a different school from what my brother and sister attended since that made me feel that I was being cast out as being different. I wanted to be just like them and be provided the same opportunities in attending the same schools and making more friends from the neighborhood. It was the idea of attending school for the emotionally disturbed that made me emotionally disturbed more than anything else. I felt helpless in this situation in that I
couldn't change the minds of those in charge of the educational system to change for me. (p. 42).

Thorsos envied her nondisabled siblings throughout her academic career because they were allowed full participation in the neighborhood public school, while she was bussed further away to a segregated institution specifically for students with disabilities. Thorsos was not born thinking that autism made her different, inferior, or disturbed; rather, these were the implicit and explicit messages that came with her placement outside the margins of mainstream public education.

This process of comparing herself to her siblings became a trend that followed Thorsos throughout her education. When Thorsos watched her brother graduate from high school, she was forced to seriously question whether or not she could receive her diploma and make a similar transition to college.

I was happy for my brother to pass this milestone. I wondered if I ever would be able to graduate from high school and go on to college too. I harbored doubt about my future since I was painfully aware that I didn’t fit in with my peers due to my social ineptitude (Thorsos, p. 71).

Rather than planning to graduate high school like her brother had, Thorsos apprehensively wondered whether she could make a similar transition. Thorsos was anxious about the possibilities and limitations of being an woman with autism in part because she was not aware of anyone else who had made this transition. Unlike Ericka Hammerschmidt, for example, who was aware of Temple Grandin's
overwhelming success, Deborah Thorsos was a proverbial pioneer forging ahead without a role model to guide her.

Thorsos’ anxiety about the potential future for an adult woman with autism manifested as a fixation on childhood. To avoid imagining a bleak future with limited choices, Thorsos resisted growing up and yearned for the routines and lifestyle of a younger child.

The focus of my obsession shifted from wanting to be the first one off the bus to having half days of school in the mornings and getting home early in the afternoon. I wanted short school days every day so I could get home early and watch all the afternoon cartoons. I was jealous of the little children who went to school a few hours a day and had more free time. I felt resistance to growing up and wanted to remain a child where I had fewer responsibilities. (p. 57).

Not only does this passage point out the segregated political landscape that determined where she went to school, but also how Thorsos internalized the messages about her second class social status. Thorsos did not feel “emotionally disturbed” until she was labeled as such, separated from her peers, and associated with a highly stigmatized group of people.

In the next passage, Thorsos described how she felt when she entered the educational mainstream: “I began to attend Theodore Roosevelt High School on October 2, 1973. I was very thrilled to finally go to a regular public school. It felt good to be able to take classes with typically developing students” (Thorsos, p. 95).
It made sense that Thorsos wanted to attend the same school as her siblings to avoid being stigmatized as emotionally disturbed. Thorsos inferred messages about her status based on the various education environments she inhabited; internalizing both the initial rejection from public elementary school, and also her eventual acceptance to a public high school.

In this section, Deborah Thorsos remembered how her placement in a school for emotionally disturbed damaged her self-image. Thorsos began a lifelong process of comparing herself to her siblings which began when she was initially separated from them and sent to a different school. Also, segregation forced Thorsos to seriously question her future prospects. Thorsos was concerned that the inequality that governed her education would continue into the future and limit choices in adulthood.

2. **Education interrupted**

Despite the time period and shifting politics that governed ideologies of education, the women in this study did not enjoy the continuity of a typical education. In fact, they often changed schools and programs, having to start over each time. Unlike Thorsos, Therese Ronan spent two years without attending any school whatsoever. Without the civil rights insured by the ADA or IDEA, Ronan spent two academic years like 1.75 million disabled students before 1970 who were “completely excluded from public schools” (TASH, p. 1).

The meeting between Mom and the psychologist ended, and we left. Two weeks later, Mom received a call from the school district. Because of my immature action, the superintendent refused to let
me enter their public program. If only I had known what the consequences for my behavior would be, I wouldn’t have done what I did. For the next two years that we lived in Pennsylvania, I couldn’t attend public school. I do not think that the Bethlehem School District was very fair to me. I still have issues about their not giving me the education I wanted. So, while the other kids were in school, I stayed home every day and watched TV (Ronan, p. 46).

The above quote demonstrated how Ronan’s disability became the justification for her exclusion from school based on one man’s momentary assessment of her behavior. Neither did Ronan’s family feel empowered to appeal the decision of the superintendent, nor did they have any legal basis or recourse to address the fact that her civil rights were being violated. Ronan demonstrated how instability and inconsistency in educational environments exacerbated the challenges of transitioning toward adulthood.

Like Ronan, Temple Grandin also had her education interrupted when she was expelled from school, but her experience improved when she went to a private boarding school:

I was kicked out of a large girls’ high school after I threw a book at a girl who teased me. High school was the worst time in my life. Going away to a specialized boarding school where I could pursue interests such as horseback riding, roofing a barn, and electronics lab was the best thing that happened to me (Grandin, p. 120).
Unlike Ronan’s family, Grandin’s family had the financial resources to provide Temple with a private education that supported her educational needs. Ronan was frustrated by a deeply flawed educational system of segregation that allowed a culture of bullying and abuse to develop. Ronan explained how inadequate and misguided teachers perpetuated this culture of inequality and, in many cases, spearheaded the harassment and mistreatment. Ronan, with great insight, described how she internalized or absorbed the negative messages that lead to the abuse:

My schooling consisted of five different schools for children with disabilities. Some taught only social skills; others included academics. Some teachers were good; some were witches, who would constantly tease and humiliate me in front of my peers. I remember they called me fat and ugly and told me to go on a diet. Then my peers would also taunt and pick on me. They would lie to the teacher to get me in trouble, and the things they said to me and about me sent me into real crying spells. I couldn't yell back, so I took everything they said to heart and cried myself to sleep a lot (Ronan, p. 17).

Ronan went to school during an era in American history when segregation pervaded the political landscape and limited the educational options of disabled Americans and African Americans alike. Without civil rights legislation in the form of IDEA and ADA, Ronan had very few choices when it came to her education. Ronan was at the mercy of decision makers who did not have a stake in her future and were not concerned with fairness or equality for all students. Little planning or thought went into
maintaining a sense of continuity in Ronan’s education, nor was there much preparation for the transitions from one school to another. These numerous and unanticipated transitions may have been even more challenging for Ronan because difficulty making transitions is often characterized as an autistic trait. When Ronan was twelve years old she tried going outside the realm of public education and enrolled at Woods Boarding school with high expectations for improved academic instruction.

I couldn’t figure out why there was almost no education at this school. I begged the school authorities ‘to give me more of an education, but my pleas fell on deaf ears. Now I know that they didn’t think that I was able to be educated. I wish that they would have come right out and told me why I wasn’t having reading, writing, and history classes, but they kept it from me. Due to the fact that this school was frightfully expensive, I had to discontinue my stay there. I remember leaving school for summer vacation. Little did I know that it was for good. (Ronan, p. 41).

Ronan was offended that this institution was not upfront with their assumptions about her intelligence and capacity to learn; the attempt to conceal their beliefs about her intellectual capabilities insulted Ronan. Unlike Thorsos, Ronan resisted many of the unfavorable assumptions about her allegedly diminished intelligence. It seems that Ronan was more resistant to the thoughts and attitudes of other people whereas Thorsos was more susceptible to absorbing the implicit and explicit philosophies that limited her educational opportunities. Ronan hoped that the
expensive private institution would offer a better education, but the Woods School marked another bumpy chapter in her academic career.

Although Sharon Cowhey was born in 1956, the same year as Therese Ronan, Cowhey avoided the segregation and special education classrooms that Ronan was subjected to for two reasons. First, Cowhey was not yet diagnosed with autism in childhood. Second, Cowhey's parents sent her to a Catholic parochial school instead of enrolling her in the local public education system. Cowhey remembered some of the nuns utilizing corporal punishment, but she focused more on her personal shortcomings rather than the abusive environment: “Trapped in the world of autism for me was living a very unhappy, depressing, lonely, and suicidal life. School was never a happy time, but somehow I made it to my junior year and then I quit school.” (Cowhey, 2000, p. 42)

In the above excerpt Sharon Cowhey referred to the world of autism as the place she inhabited and cause of her misery without highlighting the negative role that the educational environment played in her depression or decision to leave school prematurely. Having undiagnosed autism was challenging, but the stigma attached to being openly gay at that time compounded her poor academic performance and led to further physical and social exclusion.

My grades, due to my old problems with people, emotions, and senses, coupled with the verbal and physical harassment brought on by my new status as a lesbian, continued their steady decline. … Because of complaints by girls who thought I would “rape them” in the locker room, I was taken out of physical education class and
allowed to sit in the library until the end of the school day (Prince-Hughes, p. 55).

Prince-Hughes may have avoided some of the stigma associated with the autism diagnostic label, but the symptoms of autism still set her apart. Also, the social and communicational deficits associated with autism may have impeded her ability to handle the stigma of being gay in school at that time.

He immediately hit me and knocked me down, He said, “I don’t think you heard me right. Are you a queer?” Failing to see why his show of brutishness would affect my answer in any way, I asserted the truth once more. He hit me again. This pattern repeated another time or two. Then the bell rang, he gave up, and we went inside.

High school was downhill from there (Prince-Hughes, p. 55).

After enduring relentless abuse and resorting to alcohol to cope, Prince-Hughes eventually dropped out of high school and became homeless.

To summarize this section, Therese Ronan demonstrated how her education was interrupted by the whim of one academic administrator. Without the rights insured by the IDEA and ADA, Ronan was relatively powerless to redress this injustice. Temple Grandin, like Therese Ronan, went to school before the legislation guaranteed her right to attend school. When Grandin reacted violently to being bullied, she was expelled. Fortunately, Grandin’s family had the financial means to seek out a private institution that could better meet her needs. Ronan described how she attended five different special education schools with a range of experiences, one of which was a year spent at an expensive boarding school with poor academics. Sharon Cowhey may
have avoided segregation by attending a Catholic parochial school, but her education ended abruptly when she dropped out of high school. Lastly, this section described how Dawn Prince-Hughes managed to avoid segregation because she was not yet diagnosed with autism during her school days. Nevertheless, Dawn was bullied mercilessly and tormented by other students based on her unusual behavior and sexual orientation.

3. **Integration is Imperfect**

After the landmark legislation of the IDEA and ADA were passed, integration did not erase many of the issues faced by girls with ASD in integrated educational settings (TASH, 2009). Social stigma related to autism still exists in American schools (Kasari, et al.; Harrower, & Dunlap). Erika Hammerschmidt and Dawn Prince-Hughes both remembered feeling utterly different from their peers, regardless of having a diagnosis or not. Dawn spent her childhood adolescence and early adulthood without having an autism diagnosis; all the while, she questioned what it was that caused her to feel so estranged from human society. Although she displayed some of the symptoms associated with autism, Dawn Prince-Hughes did not have an autism diagnosis or label during her childhood or adolescence. Regardless of the label, Prince-Hughes still faced social and academic challenges common to students with autism without knowing why.

I stood out as a freak in school: my tics, my monologues, my sensitivities, my imperviousness to criticism and suspicion of authority, my disdain for connection and avoidance of social interaction, my political convictions, my obsessions with philosophy
and anthropology, and my odd style of dressing and speaking all led to total ostracism and active aggression. Determined to last out my high school career, I tried to find new ways to get through the day (Prince-Hughes, p. 60).

During her childhood, Prince-Hughes displayed many attributes associated with autism, but did not know it at the time. Looking back, Prince-Hughes recognized the characteristics or symptoms of autism that cued her peers to her neurological difference and set her apart from them. Prince-Hughes not only struggled with undiagnosed autism, but also with the stigma of her sexual identity. During adolescence, the undiagnosed symptoms of autism continued to negatively impact her education; however the stigma and harassment that she endured due to her sexual identity exacerbated her growing anxiety.

Erika Hammerschmidt was never denied access to public school, but she had to endure the pain of labeling and stigma associated with disability. Hammerschmidt was mainstreamed with help from a special education paraprofessional who went to class with her. At the time, she resented the control that her aide exerted over her and the unwanted attention she attracted. Looking back, she believes that she needed that support to stay on task and out of trouble.

I resented the control. It was worst when the person in class with me had no respect for me, and just ordered me around in a patronizing tone of voice. When I liked the person, it was better, but I still complained that the surest way to ruin a friendship was to put one friend in control of the other. It also bothered me somewhat that I stood out so noticeably from
other students because I had someone following me around (Hammerschmidt, p. 190).

Hammerschmidt was annoyed because the paraprofessional signified her disability status and kept her from blending in with the other students. She could not avoid the label or stigma of disability because of her visible association with special education.

Hammerschmidt and Prince-Hughes remembered feeling utterly different from their peers, regardless of having an autism diagnosis. Dawn Prince-Hughes spent her childhood, adolescence and early adulthood without an autism spectrum diagnosis, and always wondered what it was that set her apart and different from most people. Hammerschmidt felt stigmatized by stereotypes of students in special education; she complained that they spoke to her like a young child and assumed she was cognitively challenged. Hammerschmidt was badly teased throughout school which enraged and hurt her. These feelings of being misunderstood during adolescence stayed with her into adulthood. However, Erika resisted the negative messages she interpreted about her disabilities, she did not internalize messages about her inferiority and worth, like Cowhey or Thorsos did.

The paraprofessionals and educational aides that accompanied Erika Hammerschmidt to the educational mainstream may have been a crucial part of her success, but their presence also visually signified her disabled status and embodied evidence of a diagnostic label. Like Dawn Prince-Hughes, Erika Hammerschmidt was sometimes ostracized or bullied by her peers, but Erika had the social support,
legislation, and diagnostic label that enabled her to showcase her skills as an actress, artist, and spelling bee champion:

In addition to being the class weirdo and class clown, I had something of a reputation as the class artist. When my fourth grade acted out Romeo and Juliet - a fact briefly mentioned in the local o’clock news - I was widely acclaimed as the best in the play. The few clips that were featured on TV included one of my big scenes. In fifth grade, when I was in a school that went up to eighth grade, I won the school-wide spelling bee, and placed high enough in the district-wide level that I went on to the city-wide one. By junior high I had gained an interest in how I did in my classes. By the middle of high school I was frequently, though not always, doing my homework without parental encouragement and paying at least polite attention in all my classes. (Hammerschmidt, p. 64).

Since the ADA was passed in 1990, integrated learning environments became more prevalent. However, integration opened up a different set of issues related to stigma and social acceptance. Hammerschmidt is the youngest author in the sample, born in 1981; she was nine years old when the ADA was passed, so it makes sense that she had more opportunities to integrate into school life.

It is difficult to make a direct comparison between Erika and Dawn because of several variables. First, Erika had a diagnosis while Dawn did not. However, if Dawn had been diagnosed in childhood, the ADA would not be passed until 1990, when she was 26 years old. However, the IDEA was passed when Dawn was eleven years old and on the verge of adolescence, but without having a diagnosis it is
difficult to predict whether this legislation would have had any impact on Dawn’s education.

Like Prince-Hughes, Willey was also undiagnosed during her school years, but Willey managed to avoid the social stigma associated with autism. In fact, Willey was labelled as a “gifted” student as opposed to a “special education” student. Willey’s lack of diagnosis kept her out of the special education classroom and her extraordinary intelligence lead to placement in gifted classes; Willey was an excellent student in high school, putting her “on a college and graduate school course early.” (Willey, p. 39)

I was aware that college would bring many changes in my life. I knew the geographic and academics and amount of responsibilities and kinds of challenges would be different, but I never gave thought to how different the social life would be. I had no way of knowing that AS left me without an intrinsic awareness of what it means to make and keep friends, to fit in and mold, to work cooperatively and effectively with others. Most people who come from supportive families learn to jump from their childhood to their young adulthood as if they are on a trampoline (Willey, p. 42).

Willey pondered how having undiagnosed autism during childhood may have affected the choices she made later in adolescence and adulthood. For example, Willey may have benefited from the types of support that Thorsos or Grandin utilized for success in college. Willey was not overly stressed about the prospect of womanhood because she was well adjusted to her primary and secondary schools, had a supportive network of friends, and had no reason to expect major challenges prompted by
transition to adulthood. Willey’s childhood and adolescence proceeded relatively smoothly, she was designated as intellectually gifted and thought of herself that way. Willey’s lack of anxiety during adolescence did not require the development of coping strategies; however, Willey struggled in college and early adulthood without previously establishing these skills.

I never understood group dynamics, particularly casual friendship dynamics that work on giving and taking, role playing and modeling, rule following and turn taking. Somewhere along the way, I had learned to cope with the intricacies of young friendships well enough to manage one friend. Any more spelled disaster sometimes in very real forms (Willey, p. 17).

She was accepted by every school to which she had applied and received an academic scholarship. (Willey) No one suspected that she “needed special counseling or special tutoring or mentoring. I did not seem to need anything more than the typical college freshman needed—a stack of textbooks, a rigorous academic schedule and a dorm room to call home.” (Willey, p. 40) Lianne Willey felt emotionally exhausted by the time she finally finished her 4 year degree after 6 years. Though Willey did not know it then, in retrospect, it was clear that the traits of autism interfered with daily tasks like finding a classroom or sitting through a lecture.

I was aware I should have been attending every minute of my classes and yet, for one reason or another I did not. Though I was not to know it then, it seems obvious to me now that it was my AS behaviors which kept me from simple accomplishments like finding a classroom or sitting
through a lecture. I was not simply a young college student interested in going through life at a casual pace without regards to outcomes and consequences. I think the person I used to be was unwittingly caught in a game of cat and mouse with AS. (Willey, p. 41)

Willey’s entrance into college was one of the pivotal factors that eventually lead to an ASD diagnosis in adulthood. Willey’s difficulties in college stood in sharp contrast to her achievement in school during her youth and adolescence. As a result, it took her six years to complete a four year degree and compromised the way she thought about herself. Cowhey, Prince-Hughes, and Willey were not diagnosed with Autism Spectrum Disorder until later in their adulthood. Unlike Prince-Hughes, whose negative childhood experiences predicted her negative adolescent and adult experiences, Willey’s achievements as a gifted student in high school stood in sharp contrast to her later difficulties in college. Willey was unprepared for the less structured flow of university life.

Sharon Cowhey, like Dawn Prince-Hughes and Lianne Willey, was not diagnosed with autism until adulthood. Unlike the others, Cowhey attended a private Catholic school that would not have been subject to the ADA or IDEA because it was not a public institution. Regardless, Cowhey could not benefit from either law because they had not yet been passed. With so many factors working against Cowhey, it is not surprising that she felt the need to escape.

Integration may have improved the educational opportunities for girls with ASD, but there are still issues unresolved but progressive legislation. The above section
reveals how these authors struggled to fit into the social fabric of their schools and stood out in classrooms regardless of whether or not they had an ASD diagnosis at the time.

4. **Escape**

The difficulty of attending school with an ASD is compounded when that condition has not yet been diagnosed (Portway & Johnson). Sharon Cowhey and Dawn Prince-Hughes were integrated into their schools because they had not yet been diagnosed, but undiagnosed autism negatively affected both the academic and social aspects of school. Sharon Cowhey coped with her anxiety about growing up by attempting to escape from it. Whereas Prince-Hughes sought emotional escape through the use of alcohol, Cowhey spent hours rocking in her rocking chair trying to escape both physical and emotional pain.

> I preferred to stay to myself and rock as fast as I could, to escape from any embarrassing or painful situation that I would manage to get myself into. Rocking was a constant pastime for me. I rocked for hours and hours, I love rocking. It was all I knew and all I cared about. I seem to do a lot of rocking even to this day I will rock to escape just not as much as I did growing up (Cowhey, p. 12).

The difficulties of having undiagnosed autism may have contributed to Sharon Cowhey and Dawn Prince-Hughes dropping out of high school before receiving their diplomas. Though it was unplanned, Cowhey avoided a long, drawn out period of adolescence by prematurely entering into motherhood.

> Running away from home at seventeen was not a smart thing for me to do. I knew nothing about having a relationship with a boy, I
knew nothing about what to do in any kind of life's situations, and all I knew was how to rock with music blasting in my ears to escape into my world. Here I am in Maine with a gorgeous thief and I had no idea what the hell to do (Cowhey, p. 20).

Once again, Cowhey and Prince-Hughes took similar paths in that they both coped with pain they experienced in high school through forms of escapism: Prince-Hughes opted for alcohol and Cowhey sought solace in her rocking chair. Ultimately Prince-Hughes and Cowhey left high school before completing their education. It seems that both women dealt with the pain of undiagnosed autism by seeking forms of escapism.

Dawn Prince-Hughes coped with her adolescent stress and anxiety by escaping the emotional pain through the use of alcohol. During adolescence, the undiagnosed symptoms of autism continued to negatively impact her education; however, the stigma and harassment that she endured due to her sexual identity exacerbated her growing anxiety.

[k]ids admired my drinking prowess and the nerve I seemed to have; I would get drunk right on the school grounds. To avoid the abuse of my classmates, I would run as fast as I could to the "drop-point" that my mother's friend and I had agreed upon as the hiding place to leave the alcohol. I would stay there, drinking until the bell rang again (Prince-Hughes, p. 52).
Ultimately, Dawn Prince-Hughes escaped from the pain of high school altogether by leaving before her education was complete. Prince-Hughes found escape to be the best way to cope with the abuse and anxiety she faced at school on a daily basis, so it follows that Dawn eventually dropped out of high school to physically avoid the abuse she suffered there. Since Prince-Hughes was undiagnosed during her school years, she did not receive any interventions or methods to appropriately deal with anxiety related to autism. It is unclear whether having an autism diagnosis in early childhood would have offset some of the challenges that Prince-Hughes faced in adolescence. In simpler terms, having autism may or may not have played a significant role in the amount of bullying she experienced because her bullies were focused more on her sexual identity than unusual behavior. However, the unusual mannerisms, that Prince-Hughes later attributed to autism, seem to pale in comparison to the stigma of being gay at that particular place and time.

Again, Cowhey and Prince-Hughes were both undiagnosed during childhood, so neither woman knew that autism might be causing some of the anxiety and need to escape. Cowhey and Prince-Hughes were forced to cope with autism without knowing they had autism. In addition, they did not have access to any type of autism intervention or support that could teach them more effective coping strategies than avoidance and escape. To conclude this section, Sharon Cowhey learned to escape from anxiety while seated in her rocking chair. The need to escape from the anxiety of school eventually led Cowhey to quit school before she was finished. Dawn Prince-Hughes used alcohol to escape from the stress of her daily life at school. Like
Cowhey, Prince-Hughes’s penchant for escape resulted in her leaving high school without receiving a diploma.

5. **Effective coping**

On the path toward adulthood, many girls with ASD report feelings of alienation and discrimination, depression and anxiety, fear about the future, and sensory overload (Allard; Calhoun et al.; Rosenblatt; Solomon). These are serious issues that require effective coping strategies. Despite the different political environments and subsequent educational system, both Grandin and Hammerschmidt developed creative and effective coping strategies or mechanisms that enabled each woman to meet her personal goals and succeed in school.

Reading and writing helped Hammerschmidt to understand her world. She accidentally realized that her passions helped her reach adulthood with some degree of dignity and success because reading and writing contributed to her understanding of her social environment. This may be a useful lesson that these activities help people with autism better understand their world and lead to positive adult experiences. For Hammerschmidt, it was a happy accident, but proceeding to teach future children with autism these practices might lead to even better opportunities to achieve a level of integration and belonging to society.

A lot of kids with Asperger Syndrome have a deep fascination with something, and I was lucky - one of my fascinations was language. Besides studying the structure of languages and how they developed, I was interested in anything else that had to do with words, especially books. I didn’t deliberately set out to learn about human behavior by
reading and writing stories, but that was a helpful side effect of my passion for words. Every time I read about people having conversations, I picked up colloquial phrases, facial expressions and gestures. I figured out from context what they meant, and then practiced using them in the stories I wrote. When I wrote fiction, writing was good practice for social interaction. I also wrote essays about the problems I faced, using words to express to other people what I was feeling. I wrote in my diary to relieve anger and to figure out how to articulate my ideas, and I wrote science fiction when I needed to escape from this planet altogether (Hammerschmidt, p. 186).

Hammerschmidt was somehow able to understand social customs and practices of her own human culture by creating and contemplating social behavior in science fiction writing. Hammer also coped with her adolescent anxieties by escaping into science fiction and creative writing.

As I have become more familiar with the culture I live in - the human culture - creating new worlds has stopped being a way for me to escape from the "real" world and make myself a place to fit in. It’s now just a way to have fun and entertain my friends. But when I first knew the feeling that I had been born on the wrong planet, it was a means of survival (Hammerschmidt, p. 96).

Grandin performed a similar maneuver, in which she took on the perspective of a cow, and felt comfortable within the culture of cattle; she then inferred rules about human behavior based on her understanding of social behaviors in cattle.
In a phenomenon I call touchstone perspective, Grandin and Hammerschmidt both took on the perspective of a culture that was not human and this touchstone (cow or alien) gave them the awareness to better understand human social behavior. Dawn Prince-Hughes also exemplifies this phenomenon of triangulating human social behavior based on the perspective of another outside group: captive Silverback Gorillas. The concept of touchstone perspective and Prince-Hughes' application will be discussed more in section B.

Grandin struggled with increasing levels of anxiety and frequent panic attacks throughout adolescence and early adulthood. She built the first human squeeze machine in response to this increasing and overwhelming anxiety. Grandin designed her squeeze machine based on her observation of the calming effect compression had on cattle in livestock yards. Grandin’s profound empathy with the anxiety experienced by cattle led her to design a literal, physical coping mechanism to manage her own human anxieties.

I copied the design and built the first human squeeze machine out of plywood panels when I returned to school. Entering the machine on hands and knees, I applied pressure to both sides of my body. The headmaster of my school and the school psychologist thought my machine was very weird and wanted to take it away. Professionals in those days had no understanding of autistic sensory problems (Grandin, p. 59).
Grandin developed a key coping strategy during adolescence that enabled her to transfer feelings of anger and displays of violence to more socially acceptable sadness and tears. When Grandin was expelled from school for a violent outburst, she became highly motivated to find an alternative method of coping with anger and frustration. Grandin was able to sublimate, or shift, the emotional energy from anger to sorrow.

After I was kicked out of a large girls’ school for throwing a book at a girl who teased me, I learned to change anger to crying. I was unable to change the intensity of the emotion but I could switch to a different emotion. At my boarding school, horseback riding was taken away after I got into several fist fights due to teasing. Since I wanted to ride the horses, I immediately switched to crying.

Switching to crying enabled me to not lose a job due to either hitting or throwing things (Grandin, p. 164).

This process of transference or sublimation of feelings allowed Grandin to follow the rules in school and maintain her horseback riding privileges. However, this process of sublimation came at a personal cost; Grandin may have avoided conflict or punishment, but her anxiety, panic attacks, and depression increased. This example illustrates one of the key points made by Skuse and Mandy, that girls with ASD have better coping skills and are more likely to present internalizing (depression, anorexia) versus externalizing (tantrums, violence) behavior.
To summarize this section girls with ASD who are allowed to pursue their interests benefit socially, emotionally, and cognitively when they are allowed to pursue their interests. Hammerschmidt and Grandin both followed their passions which inadvertently led them to a better understanding of human social behavior. Grandin also revealed how her interest in cattle inspired the construction of a squeeze machine that soothed Grandin in much the same way compression soothed cattle in livestock yards. Finally, Grandin recognized the needs to cope with her frustration and anxiety by transferring the emotional energy from outrage to sorrow.

6. **Successful transitions**

Women with ASD appear to make successful transitions from girlhood with the help of Supportive families and early diagnosis (Portway & Johnson; Lasgaard et al.). Temple Grandin and Erika Hammerschmidt were both diagnosed in early childhood and also received substantial emotional and financial support from their families. Although Grandin did not benefit from disability legislation or widespread knowledge about autism, the Grandin family had the financial means to provide her with the educational support that allowed her to flourish and succeed in school. As opposed to Grandin, Hammerschmidt was fortunate to be born after IDEA was passed; in addition, she was only nine years old when the ADA was passed. The women who were aware of their disability in childhood and had families that supported their education appear to have made easier academic transitions toward adulthood. Grandin’s academic success was the result of her prodigious intelligence, support of her family, an environmental structure and wide repertoire of coping strategies. First, taking on the perspective of a cow taught Grandin about the underlying rules of human behavior and
inspired the construction of her squeeze machine. Second, sublimating angry feelings and suppressing violent tendencies led to more fluid continuity in her education because she wasn’t being expelled for inappropriate behavior. Another set of skills that helped Grandin to successfully navigate her way to an eventual Ph.D. was visualizing a symbolic system, such as doors. “During my life I have been faced with five or six major doors or gates to go through. I graduated from Franklin Pierce, a small liberal arts college, in 1970, with a degree in psychology, and moved to Arizona to get a Ph.D.” (Grandin) Another key component of Temple Grandin’s academic success was her system of utilizing visual symbols to represent major milestones and moments of transition.

Deborah Thorsos was diagnosed with autism at a young age and although her education pre dated idea, she consistently received educational interventions beginning in early childhood. Since Thorsos was accustomed to receiving social support and special education services throughout her academic career, she anticipated that she would continue to need similar help for success in college. Thorsos decided to first register at a community college and later transfer to a four year university. In 1976 Thorsos began classes at Northwest Virginia Community College, conveniently located walking distance from her home. Living at home with her family enabled Thorsos to build independent living skills in a safe and familiar environment. In 1978 Thorsos received an Associate of Arts degree and decided to transfer to the University of Maryland, which was only made possible when her mother moved to Maryland with her. On one level, Thorsos had the foresight to realize she would continue to need support in college. On another level, Thorsos had internalized the lessons that years of
intervention, rehabilitation, and special education had taught her about dependence, ability, and vulnerability. In other words, it is unclear whether Thorsos made choices about her post-secondary education based on knowledge and insight or was she following the extensive programming and indoctrination into the rhetoric of disability as dependent, needy, and vulnerable. In any case, Thorsos graduated from the University of Maryland with a BA in 1980.

Hammerschmidt’s childhood and adolescent experiences in public school were not always pleasant, but seem to have prepared her for college life. In fact, she found university life easier than her previous experiences. Hammerschmidt found college more inclusive and easier to navigate than grade school had been: her teachers were more helpful and friends were more forgiving.

When I grew older, things got better. People were much more understanding in college than in grade school. Teachers asked me what the problem was and how they could help me, rather than immediately sending me to the principal's office. Friends were uncomfortable during my insanity, but later, when I said I was sorry, they would accept my apology and seem more concerned than offended (Hammerschmidt, p. 45).

Hammerschmidt found the college environment coupled with her personal development to produce better social interactions and experiences in college. In addition, the Internet was helpful for making friends.

Socially, college was also easier than previous levels of school. By that time I had overcome many of my social problems, and the
other students in college were more accepting than the students in grade school or high school... When I was having trouble finding friends at college, the Internet helped a lot. Discussion groups online are a way to enjoy social interaction without having to worry about body language, voice tone and facial expressions. There are groups for just about anything, and I found ones for several of my interests (Hammerschmidt, p. 187).

Three out of four women who had ASD diagnoses from childhood successfully transitioned through their educational careers, though there were significant challenges. Grandin, Hammerschmidt, and Thorsos had parents who planned for the future and prioritized their academic success, but Therese Ronan’s family did not take steps nor plan for her elementary, secondary, or post-secondary schooling. This last section on successful transitions highlights one of Grandin’s most effective coping strategies that enabled her to make major transitions in life. Grandin’s system of assigning symbolic meaning to physical doors allowed her to visualize key milestones in her personal and academic life. Deborah Thorsos was able to smoothly transition from high school to junior college and then to a four year college with the support and guidance of her family. Erika Hammerschmidt explained how her integrated education prepared her for a smooth transition to college life.

This section featured a brief discussion of pertinent legislation followed by six thematic sections that highlight key experiences these seven women with autism had while transitioning through education systems and moving toward adulthood.
B. **Women with Autism Develop Interests and Pursue Career Paths**

This area explores how women with autism form interests in childhood that could potentially translate to careers in adulthood. There are seven intriguing themes that emerge in respect to career development for girls with ASD, they are as follows: section one, “Touchstone perspective”, connotes my original contribution to the state of knowledge pertaining to an effective coping mechanism utilized by three women with ASD. Section two, “Summer camp sparks career goals”, illustrates ways in which summer day camps inspired potential career paths for women with ASD. Section three, “Utilizing vocational rehabilitation services”, reveals deep flaws, prejudices, and shortcomings of various forms of vocational rehabilitation. Section four, “Getting to work”, describes the use of public transportation and addresses some of the issues surrounding the acquisition of a driver’s license. Section five, “Job advancement and successful employment” describes the circumstances that lead to gainful employment and success at work. Section six, “Discrimination and abuse at work”, examines abusive power dynamics that potentially alienate or degrade women with ASD. Last, sub-section seven, “Unemployment”, details the prejudices and barriers the impede women with ASD from getting, and keeping a gratifying job.

1. **Touchstone perspective**

I use the term “touchstone perspective” to describe a unique coping strategy used by individuals with ASD to better understand human social behavior. Temple Grandin, Dawn Prince-Hughes, and Erika Hammerschmidt unknowingly utilized this coping method that parlayed their interests into more comfort and a better comprehension of interpersonal relations. These three women were able to extrapolate
lessons about human socialization based on the social behavior of another culture. Grandin and Prince-Hughes inferred parallels between the social behavior of humans and the animals they studied, cattle and mountain gorillas respectively. Both Grandin and Prince-Hughes discuss how social behavior among the animals they studied acted as a touchstone or constellation of reference to understand human social behavior. In the same fashion, Hammerschmidt performed a similar operation, but, rather than using animals as her touchstone for social behavior, she imagined alien civilizations and wrote science fiction that became touchstones for a deeper understanding of her own culture. Grandin and Prince-Hughes based their careers on the unique empathy they felt toward animals.

Grandin first began to see the world from a cow’s perspective in childhood when she spent time at her Aunt’s ranch in Arizona: “My connection with these animals goes back to the time I first realized that the squeeze machine could help calm my anxiety. I have been seeing the world from their point of view ever since” (Grandin, p. 167).

Grandin identified with the way cattle perceive reality because she was often disturbed by the same sensory stimuli that caused the cattle so much anxiety. The realization that there were multiple ways of perceiving reality provided Grandin with a greater sense of comfort and belonging within a diverse spectrum of perception. Taking on the perspective of cattle gave Grandin greater insight into the myriad ways that others perceive reality, visual, linguistic, symbolic, or otherwise.

My experience as a visual thinker with autism makes it clear to me that thought does not have to be verbal or sequential to be real. I
considered my thoughts to be real long before I learned that there was a difference between visual and verbal thinkers. I am not saying that animals and normal humans and autistics think alike. But I do believe that recognizing different capacities and kinds of thought and expression can lead to greater connectedness and understanding (Grandin, p. 191).

Assuming a cow’s viewpoint was the touchstone by which Grandin was able to look back at human society with greater understanding and appreciation. The cow’s perspective gave Grandin the intellectual space to contemplate human society from a more objective viewpoint. By taking on a cow’s perspective, Grandin was able to take a step back from the overwhelming sensory and emotional stimulation of human culture, which created a more comfortable atmosphere to calmly observe human social behavior. Touchstone perspective was not only beneficial to Grandin in her personal understanding of her own human culture, but also became the basis for an exceptionally successful career.

Like Grandin, Prince-Hughes formed an attachment to animals; in her case it was captive mountain gorillas. Prince-Hughes explained how she came to understand the challenges of housing wild animals in captivity because she identified with the feeling of being a captive animal. Moreover, Prince-Hughes came to a better understanding of human social groups after observing the social behavior of these gorillas.

By applying the bodily and verbal language components I had learned from the gorillas, I was beginning to have more social
success; this led to less tension for me when I was in social situations, and that in turn enabled me to relax and read people better. This process allowed me to return to the gorillas, knowing more about how human society worked, and learn about the feelings and motivations that underpinned the gorillas’ actions and patterns as individuals and as a group. I learned on a new level that communication is meant to convey and evoke a visceral feelings, not just rational or mental feelings. Though I had understood what fear and anxiety felt like on a gut level, I now began to understand other, more complex emotions (Prince-Hughes, p. 137).

Although Dawn Prince-Hughes had early hopes and dreams to become an anthropologist, her career ambitions seemed limited by the challenges of undiagnosed autism, persecution for her sexual identity, homelessness, and drug abuse. However, there is a certain degree of similarity between her childhood dreams of becoming an anthropologist and her eventual success studying animal culture. When she was young, she wanted to be an anthropologist because she loved prehistory; it was simpler and there were fewer people. Prince-Hughes saw a parallel between early human development and her own disabled development.

I was fascinated with early humans and knew that I would be an anthropologist someday ... This was something I could really understand. After all, anthropologists lived among those whose ways of being were totally foreign to them in order to learn more about their culture (Prince–Hughes, p. 46).
Dawn Prince Hughes appears to have transferred her anthropological gaze to the culture of gorillas and then related that knowledge back to her understanding of human social behavior.

Like Dawn Prince-Hughes, Erika Hammerschmidt became more comfortable in human society through her interest in other cultures. Whereas Dawn Prince-Hughes inferred lessons about human socialization by exploring gorilla behavior and Grandin performed a similar operation with cattle, Hammerschmidt better understood her own social environment by inventing alternate civilizations in the pages of her science fiction writing.

By the time I was thirteen, my parents' house was full of my "books," stapled-together sheets of paper on which I had written tales of fantasy and science fiction, of humor and adventure, of children in grade school and people who traveled to magical, secret worlds or met alien creatures. The more familiar I became with science fiction, the more my ideas leaned in that direction (Hammerschmidt, p. 91).

At an early age, Hammerschmidt decided to follow her passion for writing and become a professional author; she also knew that she needed to support herself financially. Hammerschmidt decided to seek employment that allowed her to continue focusing on her writing and efforts toward publication. In the following passage, Hammerschmidt revealed her belief that others have low expectations of her ability to function effectively in the workplace:
Really, I just wanted to be an author. I had reasoned that few authors make a living at writing and that I would need another job. But I realized that I didn’t want my other job to be something that monopolized my brain. If I just stocked shelves for a living, for example, I could devote most of my thinking to the ideas that really fascinated me. I didn’t mind that a job like that would pay less than translating. ... I work about forty hours a week, and I do surprisingly well. There are 'stresses', but seldom anything that sends me into panic attacks or sensory overload (Hammerschmidt, p. 137).

Rather than focusing mainly on her education and career at the expense of other facets of life, she strove for greater balance. Hammerschmidt passion and aspiration to become an author was not the only factor that motivated her throughout childhood and adulthood; she was also motivated by friendship and romance.

Grandin may have utilized touchstone perspective to advance a stellar career, but she did so at the expense of interpersonal relationships. Realizing long ago that intimate friendships and potential romance was overwhelming and difficult, Temple channeled those energies toward her career instead. Temple Grandin and Dawn Prince-Hughes developed careers based on their unique insights into animal behavior. Grandin’s route was more direct, but she had several advantages in this regard. For example, Grandin had a diagnosis from early childhood, whereas Prince-Hughes was not diagnosed until well into her adulthood. Prince-Hughes suffered a long detour that led away from
fulfilling her professional goals without a diagnosis and appropriate social supports; she dropped out of school and became homeless until she began working at the Seattle Zoo. Like Grandin, Erika Hammerschmidt discovered her passion for creative writing and science fiction in childhood, but she was born in a different era in which she had more opportunities available to her. Unlike Grandin, Hammerschmidt had the benefit of attending school during a time when integration was legally mandated by IDEA and ADA, so participation in all components of the school day allowed her to pursue multiple interests, like art and acting. Grandin, on the other hand, was not legally guaranteed any education, but had to rely on the strong support of her family to ensure a good education. It seems logical that the extra energy it took Grandin to justify and maintain access to an education diminished the time she had to socialize and discover other interests. In order to succeed at that time, it appears that Grandin had to focus on her education and career at the expense of other facets of life like friendship and romance. In any case, the phenomenon of touchstone perspective may be a useful concept to aide other individuals with autism who are eager to better understand social interactions and meaning. This concept also reinforces the efficacy of supporting girls with ASD as they pursue their passions and developing strategies that incorporate these findings regarding touchstone perspective.

2. **Summer camp sparks career goals**

   Summer camps offer opportunities for girls with ASD to socialize and develop interests outside of school (Goodwin, & Staples). At camps, Deborah Thorsos
discovered a passion for art and Erika Hammerschmidt developed her love for foreign languages and cultures in language immersion camps. Unfortunately, their respective artistic and linguistic talents could not be harnessed for a future career.

Although Hammerschmidt decided to pursue her ambitions to become an author, writing was not her only interest or talent; she also had a passion and proclivity for foreign languages. Hammerschmidt honed her fluency in several different languages at immersion summer camps throughout her childhood and adolescence. Erika Hammerschmidt rejected the idea that she needs a high paying or prestigious job to signify success; she was content to work in a stockroom for a decent wage and health benefits while she worked toward her primary goal to become a published author. Coincidently, Hammerschmidt achieved her professional goals by publishing the autobiography featured in this research.

Every summer, from the year I was seven until the year I was eighteen, I went to language camp. I had learned German at the same time I learned my mother tongue of English, so it began with Waldsee, the Concordia Language Villages' German camp in Bemidji, Minnesota. Later I added Spanish to my repertoire, and started going to the same organization's Spanish camps in various sites. Early on, I took two-week sessions, and later four week sessions, sometimes more than one a year (Hammerschmidt, p. 117).
Hammerschmidt thought about harnessing her aptitude for foreign language for the purposes of a career as a translator, but this career path was not well planned and never came to fruition.

As a kid, I had wanted to be a translator. The more I found out about that occupation, however, the less attractive it seemed to me. I had been interested in written translating, not spoken interpreting; I didn't feel I had the mental reflexes to think on my feet as fast as would be required. But written translating seemed a lot like schoolwork. I imagined every day would be a battle with my willpower, trying to force myself to sit down and do the day's assignments, the way I had struggled with homework in school. As with my homework, I could probably have done it well, but I wouldn't enjoy it. Furthermore, I couldn't find any translating services that would hire someone without a special degree in translation. (Hammerschmidt, p. 136)

In retrospect, Erika was not upset that a career as a translator never materialized because her primary goal was to become an author.

Like Erika, Deborah Thorsos also attended summer camps that offered opportunities for self-expression and discovery. At camp, Thorsos pursued her passion for art. When Thorsos was absorbed in artistic endeavors, her autistic identity took a back seat to her identity as an artist: “When I worked on my art, I was like any other artist with or without autism. During the moment it was as if I didn’t have autism, I was
just an artist pursuing art. For the time being I was like anyone else in my art classes” (Thorsos, p. 126).

Thorsos could not pursue a career in the arts due to limitations in vocational training, transportation and general support. Thorsos never aspired to work in a cafeteria during her youth, but that was one of the few career paths open to her. Despite a college education, passion for art, and desire to work with other disabled people, Thorsos was limited by lack of opportunity and training, employers’ assumptions about her abilities, and the pressure to avoid being financially dependent on her family.

For Hammerschmidt and Thorsos, summer camps presented more opportunities for self-expression, socialization, and developing talents. Although they were unable to transfer their respective passion for art and foreign language into career paths, they still gained crucial social skills and exposure to peers. Since summer camps were such a positive experience for Hammerschmidt and Thorsos, it stands that other girls with autism could also benefit from similar recreational opportunities outside of school.

3. **Utilizing vocational rehabilitation services**

This section explores the role that vocational rehabilitation services play in the career development of women with ASD. Contemporaries Therese Ronan, born in 1956, and Deborah Thorsos, born in 1957, were unsatisfied with the job training they received. Therese was not allowed to pursue her professional interests or make decisions about the type of vocational rehabilitation she received. Although Deborah Thorsos had a bachelor’s degree, passion for art, and interest in working with people who had disabilities, she was trained in a sheltered workshop and subsequently
became a cafeteria worker. Erika Hammerschmidt represents a younger generation of women with autism: born in 1981, received less formal vocational training, but was still limited to menial work in a stockroom. Hammerschmidt, however, was satisfied with her employment because it gave her the time and energy to focus on becoming a published author.

Therese Ronan received job training for menial work in high school, which was not helpful for job advancement: "I was trained to do restaurant clean-up work and other janitorial jobs that didn't allow me to get ahead in the work force. I later found out that I would never get any jobs other than clean up in public restaurants--at least not for a while" (Ronan, p. 50) Ronan was not interested in janitorial work; she wanted a career in the beauty industry, but was denied based on her IQ score. She though the vocational rehabilitation she received would help her find a job, but she was disappointed.

The transition from high school to the real work world was exciting at first. But then I was naive about trusting that the vocational rehabilitation people would someday find me a more suitable employment situation. Bah humbug! I lived in my parents' house during this time. I joined a workshop for a while. One day, I called the workshop and lied to them. "I have a new job," I said, because after several months of the extended promise that they would find me a job, I decided that I'd had it with them (Ronan, p. 53).

Ronan was repeatedly disappointed by the vocational rehabilitation she was offered, but more let down by the services she did not receive. Ronan hoped
vocational rehabilitation would advance her career, but she was told her IQ was not high enough.

I went through rehab for job advancement. I expressed the sincere desire to attend beauty school and would have graduated from beauty school with flying colors. Nevertheless, I didn't score well on my IQ tests, and vocational rehabilitation people decided they really didn't have the funds for me to attend. Folks like that put way too much emphasis on IQ scores and not nearly enough on how much more the person who has developmental delays is really capable of. In other words, the dis is always put before the abilities. And it's only because of our labels that we are denied the jobs that we deserve as much as a so-called normal person (Ronan, p. 124).

Hammerschmidt had little formal job training or vocational rehabilitation. She was not offered services via public school, but had some assistance from a private job counselor. Hammerschmidt did not find the job counselor services to be crucial to her job search.

The job-searching process was a lot of work, and I got some help from a job counselor that my mom had found. The job counselor mainly explained things like how to put together a resume and how to fill out applications. When I got a job, I felt that I probably would have been able to do it without that help, but the help sure made it a lot easier (Hammerschmidt, p. 136)
If Erika had better job training, she might have been able to pursue her career aspirations more effectively. Perhaps earlier vocational rehabilitation services could have been employed to help Erika apply her vast foreign language skills to the job market or discover more direct routes to authorship.

When Deborah Thorsos first switched to a new school, she was hopeful that it would help her learn job skills that could further her career ambitions. At the very least, the Adams school provided her with a tangible transition toward adulthood because she earned money and practiced utilizing public transit independently for the first time.

I liked the idea of doing things for money, though I never had had summer or after-school jobs. Even the transportation seemed like I was going to and from a real job. I commuted both ways on the subway. It was much easier than going to my other school (Thorsos, p. 91).

Thorsos, however, was disappointed by the job training she actually received courtesy of the Adams school. Rather than building on her strengths and interests, Thorsos found herself in a sheltered workshop environment.

I was interested in learning practical skills that I could possibly apply in the job market. The Adams School made contracts with several of the area’s businesses to provide repetitious jobs for the students in a sheltered workshop-like setting. About thirty adolescents including myself met for an hour a day in a large room, where tables were set up for basic tasks, primarily packaging things
such as emery boards and plastic covers for record albums. We were each paid piece-meal rates, which came out less than minimum wage (Thorsos, p. 90).

Thorsos thus revealed the limited employment reality for a woman with a developmental disability at that particular time and place. Rather than considering her talents and skills for a rewarding career, she was relegated to menial labor for less than minimum wage. Furthermore, having her career aspirations squelched by vocational rehabilitation compromised the confidence she had to assert her will and pursue her own interests. Thorsos’ experience highlighted a widely-held social attitude that adolescents with developmental disabilities will never develop into full-fledged adults. The system perpetuated her dependence on others and limited her choices. In this way, Thorsos was denied the American values of independence and liberty.

Unlike Deborah Thorsos, Erika Hammerschmidt had very little job experience during adolescence. Although Thorsos grew up in a different era and received vocational training, both women graduated from college in similar predicaments and struggled to find employment.

After graduating from college, it took me a long time to find a job that paid enough for me to live on. I had worked a little bit before graduating - I had put textbooks on shelves in the store at my college, and I had volunteered doing odd jobs for a co-op and a little acting group. In all those jobs, I had been preoccupied with what people thought of me; I had been haunted by a constant fear that maybe I was doing things wrong and the managers didn't like
me. I also didn't trust my own work ethic very much; every place I had worked, I had found myself being somewhat lazy, not trying hard enough to find things to do. So I was quite scared of having a job I would depend on for the basic necessities of life (Hammerschmidt, p. 135).

When Hammerschmidt began her job search after graduating from college, she had little previous experience or formal support from vocational rehabilitation. In the above passage, she reveals how the social, interpersonal component of the workplace was more troublesome than the actual work itself. At that point, she did not have much confidence in her ability to adequately perform her job duties nor did she have confidence in her ability to effectively work with others. This once again begs the question of whether or not more job training, relevant experience, and formal support would have given Erika a greater sense of confidence as an employee and co-worker.

Despite the fact that Thorsos and Hammerschmidt were born in different eras, both women with autism graduated from college, a major milestone that often signifies a transition toward adulthood, and they both struggled to find meaningful employment afterward. Thorsos received vocational rehabilitation in the guise of a sheltered workshop that paid less than minimum wage, which seemed to prepare her for employment that could not support an adult.

4. **Getting to work**
Sensory and perceptual differences pose unique challenges for women with ASD when accessing public transportation or driving a vehicle. This thematic sub-section describes the ways in which these women with ASD travel to work. The only two women in this study that have driver’s licenses are Lianne Willey and Temple Grandin. Although Grandin acquired a driver’s license, she recalls the sensory difficulties that made driving a challenge. Deborah Thorsos took driver’s education courses through her high school, but was not able to pass the road-test. Thorsos was excited, however, to use public transportation on her own because it signified a major step toward independence and adulthood.

In order to pursue her career, Grandin needed to drive a car, or more specifically, a pickup truck. In the mostly rural, male-dominated world of ranching, public transportation was not an option. Grandin’s motivation to succeed in her career was so strong she was willing to put in the extra time and attention it took to master driving a car. As in other facets of her life, Grandin was highly motivated by her career and put most of her energy toward that end.

Often I am asked how I can drive if I cannot multitask. I can drive because the operation of the car, steering and braking, has become a fully automatic skill. Research has shown that when a motor skill is first being learned, one has to consciously think about it. When the skill becomes fully learned, the frontal cortex is no longer activated and only the motor parts of the brain are turned on. I learned to drive on ranch roads in Arizona and I did not drive on the freeway or in heavy traffic for a full year. This avoided the
multitasking issue because when I finally started driving in traffic, my frontal cortex was able to devote all its processor space to watching traffic. I recommend that people on the spectrum who are learning to drive spend up to a year driving on easy roads until steering, braking, and other car operations can be done without conscious thought (Grandin, p. 118).

Grandin thus attributes the challenge of driving with autism to difficulties with motor planning and multi-tasking. She was able to manage the challenge of learning to drive by understanding how her brain processed motor information, which required considerable practice.

Willey, who also drives, identified with ASD later in life, so there was nothing to suggest that driving would be a challenge. Willey did not anticipate having trouble driving or how it would impact her career.

Everything about my job was darn near perfect, except for one crippling element - the school's physical location. Unfortunately, the campus I worked on was located in a terribly busy and overcrowded urban area; a nightmare I had to contend with day in and day out. I was never able to find my way to school without first getting lost in some capacity; be it driving the wrong way down a one way street or missing my exits or following the wrong detours, To make matters worse, I drove a mini-station wagon that did not have an automatic transmission or air conditioning; in other words, a vehicle that did very little to comfort me in the hot and humid
Houston weather. All these elements forced my sensory integration
dysfunction into a high state of chaos. Without fail, I would arrive at
the university sweating, sticky, anxious, dazed and confused.
Luckily, my interest in teaching students and the college campus
environment usually carried me beyond the brink, so that after my
sensory systems defrosted, I completely loved my job (Willey, p.
52).
In a general way, Willey explores the same issues that Temple raises,
sensory overload and difficulty with motor planning, but without using scientific
language. Willey knew driving was stressful, but because she was not diagnosed, she
did not know why it was so challenging.
Willey enjoyed her first job after college, but did not anticipate how getting
to her job would affect her performance. While she was very satisfied with her work, she
did not realize how her commute would impact her ability to successfully function in the
work place. Although Willey may not have realized the extent to which transportation
affected her job performance, her employers were acutely aware and it eventually cost
her a job that she enjoyed.
Like other teens, Thorsos looked forward to the independence signified by
attaining a driver’s license, so she enrolled in driver’s education at her school. However,
the sensory overload that Grandin and Willey described was too overwhelming for
Thorsos and she failed her road test.
As part of my high school curriculum, I took driver’s education
offered at the school, which included both classroom and on the
road instruction. I thought it was good for me to learn how to drive, even though I didn’t have plans to get a car soon, just in case I would need to for my independence (Thorsos, p. 108).

Unlike Grandin who needed a driver’s license to further her career, Thorsos lived in an urban setting where driving was not necessary to insure her employment or independence later in life.

That was the last time I drove anywhere. After my mother told me that many people flunk their driver’s test the first time too, I didn't feel so bad about my failure. I realized that I didn't need a license since I didn’t feel that I would drive anyway (Thorsos, p. 109).

Although Thorsos felt reassured that a driver’s license was not critical to her independence, this lack ultimately limited her employment opportunities.

I hooked up with an agency that specialized in services for those with challenges, the Resources for the Handicapped based in Bothell, a community on the northern shore of Lake Washington. Through that agency I was sent to a few job interviews for live-in attendant care for people with various physical disabilities. I was turned down because they needed someone with a car and who could drive (Thorsos, p. 179).

Thorsos was kept from pursuing a career working with other people who had disabilities in part because she lacked a driver’s license. The job opportunities open to Thorsos were not only limited by stereotypes pertaining to the skills of disabled employees, but further limited by access to transportation via a driver’s license. If
Thorsos lived in a rural setting like Grandin did, where she could practice on open country roads for a long period of time, she would have been more motivated to attain a license. However, Thorsos made peace with her reliance on public transit and eventually came to see the benefits, especially after meeting her future husband on a public bus.

Driving a car can be an overwhelming sensory and cognitive processing experience for women with ASD. Grandin made a major effort to learn how to drive and it took years of practice. Willey achieved the rite of passage that a driver's license represents in American culture, but did not know why driving caused her so much anxiety and confusion. Grandin and Willey utilized driver's licenses to pursue their career goals, while Thorsos illustrated how her career suffered because she could not drive.

5. **Job advancement and successful employment**

This section explores some of the variables that help women with ASD find work, keep a job, and excel in the workplace. Although Erika Hammerschmidt was over qualified, she was satisfied with the highly structured environment and clear feedback that her job in the stockroom offered. Thorsos and Grandin, on the other hand, did not fully recognize the role that the external environment played in their career paths; rather, they tended to emphasize their personal efforts to succeed. In this way, Grandin and Thorsos typify the overcoming narrative so common in autobiographies of disability. Grandin may have focused more on her own endeavors to succeed in the workplace rather than environmental factors, but readily admits that role-models and mentors were crucial for her success.
Luckily, the work is very structured, and it's usually very clear what I'm supposed to do, so I don't find myself being lazy for lack of an obvious task to carry out. My "performance numbers" always show that my performance is excellent. All in all, it's working out fairly well. Someday I'd love to become as successful as an author that I don't need another job, but until then, my job will be in the stockroom (Hammerschmidt, p. 138).

Although Thorsos was initially content working behind the scenes, she eventually expressed a desire to work directly with customers. Thorsos felt she benefitted from more exposure to other people and social situations where she could hone her social skills through daily practice. Deborah Thorsos credits an improved personal appearance and social fluency for job advancement.

My prayer of working out in the front serving people directly was answered. During the lunch service hours, I was assigned to serve on a hot food line where I was in direct contact with customers. Apparently, the managers began to feel more comfortable to have me face the patrons and provide direct service as my more autistic facial and bodily expressions had gradually given way to a more outgoing look (Thorsos, p. 260).

Thorsos accepted the rationale that her personal appearance and mannerisms associated with autism were too inappropriate for interfacing with customers. Rather than criticize the system that was inaccessible and prejudiced against her, Thorsos focused on her personal defects and strengths.
Like her contemporary Deborah Thorsos, Grandin also emphasized her individual gains and personal choices rather than exclusive employment practices within a discriminatory system.

I still remember taking that vital first step in establishing my credibility in the livestock industry. I knew if I could get an article published in the *Arizona Farmer Ranchman*, I could go on from there. While I was attending a rodeo, I walked up to the publisher of the magazine and asked him if he would be interested in an article on the design of squeeze chutes. He said he would be, and the following week I sent in an article entitled “The Great Headgate Controversy.” It discussed the pros and cons of different types of chutes. Several weeks later I received a call from the magazine; they wanted to take my picture at the stockyards. I just could not believe it. It was plain old nerve that got me my first job. That was in 1972. From then on I wrote for the magazine regularly while I was working on my master’s degree (Grandin, p. 112).

Grandin demonstrated a pattern of thought and reactions to professional situations that emphasized her actions rather than systemic patterns of exclusion or primary support roles played by helpful coworkers.

I quit the job at Corral Industries and continued to write for the *Arizona Farmer Ranchman* while I started my design business on a freelance basis. Freelancing enabled me to avoid many of the social problems that can occur at a regular job. It meant I could go
in, design a project, and leave before I got into social difficulties. I still don’t easily recognize subtle social cues for trouble, though I can tell a mile away if an animal is in trouble. When a new manager took over the *Arizona Farmer Ranchman*, I did not realize that he thought I was weird and I was in danger of being fired. A fellow employee told me that he was turned off by me. My pal Susan saw the warning signs, and she helped me assemble a portfolio of all my articles. After the manager saw how many good articles I had written, he gave me a raise. This experience taught me that to sell my services to clients; I always had to have a portfolio of drawings and photos of completed projects. I learned to avoid social problems by limiting my discussions with clients to technical subjects and avoiding gossip about the social life of the people I worked with (Grandin, p. 114).

The irony of the situation captured in the above excerpt is that Grandin’s job was saved because a friendly coworker intervened, but she still could not see the importance of nurturing workplace friendships. In contrast, Temple came away from this scenario with the message to further limit social interactions in the workplace.

Contrary to Thorsos and Grandin, Dawn Prince-Hughes recognized the impact that supportive coworkers and supervisors had on her job satisfaction. Despite the nature of the work, Dawn found exotic dancing to be a positive and empowering job because of the environment and the people who worked there. It was not Dawn’s
childhood ambition to become an exotic dancer, but it was a major step toward stability and reintegration into social life after years of homelessness and drug abuse.

Our dancing establishment, called the Amusement Center, was unique as a business. To start with, it had glass all around the stage so no one could touch the dancers. Visitors dropped quarters into a meter to get a screen to go up, for about twenty seconds a quarter. More important, though, the establishment was managed by women who were themselves dancers and knew the grueling demands of the work (Prince-Hughes, p. 72).

Unlike Grandin who received an autism diagnosis in early childhood, Prince-Hughes was not diagnosed with autism until later in her adulthood. There was no expectation that Prince-Hughes might require early interventions or ongoing social support to guide her into adulthood, so Dawn fell through the proverbial cracks in the educational system and became homeless, addicted to alcohol, and deeply depressed.

Grandin may have downplayed the crucial role that friends and coworkers had on her professional development, but she never hesitates to stress the importance of role models and mentors in her professional life. Grandin realized that role models were an essential part of her academic and professional success.

I was a miserable, bored student and I did not study until I was mentored by Mr. Carlock, my high school science teacher. Over the years I have observed that the high-functioning autistic individuals who became successful have had two important factors in their lives: mentoring and the development of talents. The students who
failed to have a good career often had no mentors and no
development of their talents. I ended up in a career where I could
use my visual skills to design cattle-handling facilities (Grandin, p.
116).

Grandin reiterates how important it was to have understanding mentors
and role-models that valued her unique talents and strove to guide her toward success.

I learned how to draw engineering design by closely watching a
very talented draftsman when we worked together at the same feed
yard construction company. David was able to render the most
fabulous drawings effortlessly. After I left the company, I was forced
to do all my own drawing. By studying David's drawings for many
hours and photographing them in my memory I was actually able to
emulate David's drawing style (Grandin, p. 13).

Grandin gave credit to her friend David, who taught her to draft, and Mr.
Carlock, who taught and guided her through adolescence into adulthood, but may have
not fully appreciated how critical friendships, coworkers, and other relationships were to
her professional success.

Environmental factors such as the structure of work, social biases toward
people with disabilities, helpful coworkers, positive role-models, and supportive
employers played a key role in the careers paths of these women with autism. Personal
will and ambition certainly seems significant, but the built environment and social norms
also affect the potential for women with autism to succeed in their chosen careers.
6. **Discrimination and abuse at work**

Women with ASD are at risk for internalizing the underlying assumptions inherent in acts of discrimination. (Gabriels; Taylor and Seltzer). In this section, Cowhey and Thorsos reveal how they have been indoctrinated into thinking of women with disabilities, primarily autism, were less valuable employees and more vulnerable to be victimized by predatory sexual behavior.

Thorsos explains how the attributes associated with autism impinged upon her success on the job. She appears to have internalized the social prejudice that made her unacceptable and unworthy of working with customers directly: “My poor posture, crude gait, and speech impediment apparently made people feel uncomfortable placing me in direct contact with the patrons. I didn't mind since I was content in doing solitary work that allowed me to daydream” (Thorsos, p. 198). Although Thorsos usually attributed her challenges to the symptoms of autisms, she did have moments in which she expressed anger about discrimination and exclusion. Thorsos saw parallels between discriminatory practices in the workplace and earlier memories of her school days: “My emotions about discrimination boiled to the surface as I associated the feelings of being devalued at work to the childhood discrimination that also affected my self-esteem” (Thorsos, p. 294).

While Thorsos often accepted and internalized criticism of her speech, gait, and body language, she was also aware of systemic biases that undervalued her potential and contributions. Thorsos was not the only woman who noticed discrimination in the workplace. Sharon Cowhey’s feelings about discrimination and abuse in the workplace were far less ambiguous than Thorsos’ mixed emotions. Cowhey placed the
blame squarely on the shoulders of an oppressive system that bred exploitation of employees with disabilities.

The working environment is another difficult place to be. You have to watch out for predators. Supervisors can take major advantage of workers with disabilities. I know, I was one of them (Cowhey, p. 158).

Based on repeated experiences of abuse in the workplace, Cowley learned to suspect and fear authority figures. The negative encounters she had with nondisabled male supervisors and coworkers resulted in a general distrust for authority figures: “Trusting is hard enough, but when you cannot trust certain people in authority, for instance police officers, supervisors, or maybe an ex-husband, or a vindictive friend” (Cowhey, p. 66).

After Cowhey was sexually harassed by a supervisor at work and her ex-husband was charged with molesting her daughter, she became increasingly apprehensive of nondisabled men in positions of authority. The sexual harassment Cowhey suffered at work was incredibly painful, but her eventual diagnosis was an unexpected consequence occurred when she sought out crisis counseling for employees at her workplace. Although Cowhey started seeing a counselor due to the sexual harassment experienced at work, it was this mental health professional that recognized and finally diagnosed Cowhey with autism. With the support of her counselor Sadie and family, Cowhey gathered the strength to leave her job and sue for damages. “She wanted me to contact a lawyer. Barry agreed, so I contacted a lawyer
who handles sexual harassment cases, her name was Mary. With the help of Mary I was finally free! I quit my job and sued them” (Cowhey, p. 41).

Clearly the sexual abuse Cowhey suffered at work was devastating, but finding out about autism was a key step toward self-acceptance and understanding. Perhaps Cowhey resisted the impulse to blame herself for discrimination and abuse in the workplace because she was not aware that she had autism.

Whereas Thorsos was diagnosed with autism in early childhood and was always aware of her autistic traits, Cowhey did not realize some of her attributes and difficulties came from having autism. Thorsos appears to have internalized the negative messages she received about autism because she had been indoctrinated into this way of perceiving autism from such an early age. Thorsos had more time to absorb the logic that autism rendered her actions and behavior as inappropriate, undesirable, and deserving to be hidden from view. Cowhey avoided this early indoctrination that taught Thorsos to constantly surveil herself for the traits of autism and subsequently blame herself for the discrimination she encountered.

7. **Unemployment**

Unemployment and underemployment are major issues for women with ASD (Gabriels; Taylor & Seltzer). Sharon Cowhey, Therese Ronan, and Deborah Thorsos struggled to find satisfying employment that paid a decent wage or provided health benefits. After years of sporadic, poorly paid employment, Sharon Cowhey found work at a factory that paid an adequate wage. However, Cowhey eventually became discouraged and disillusioned by the sexual harassment and general abuse she suffered at work, so she eventually quit and applied for Social Security Disability.
Although Therese Ronan also resisted the harassment and subjugation she endured working at a restaurant by quitting and then using her unemployment benefits to reorganize and find better work, Therese interpreted unemployment as a personal assessment of her worth and worried about the social meaning of accepting food stamps.

Cowhey eventually decided that she did not belong in the workforce, partially due to the stress caused by trying to fit in or pass. The anxiety of her childhood years in school continued into Cowley’s working life.

The few jobs that I worked through the years were usually low paying. But in the time I was married to Greg I worked at a factory, and making what was to me a decent salary. In my world I was quiet and odd, but out in the real world I was a fruitcake! All the years of watching and studying what the normal people were about, I created my own piece of normality. In the eyes of my co-workers they thought of me as the crazy lady, bag lady, or a drug user. By the end of the day I was exhausted. Not only from working, but portraying something I'm not, NORMAL! Just like in my school days, I couldn't wait to go home and rock (Cowhey, p. 29).

Cowhey noticed a parallel between the pressures of school and later, employment. When Cowhey was employed, she was neither satisfied with her work nor was she successful in her efforts to fit in with coworkers and pass as normal. Cowhey responded to the stress at work just as she had during her school years: she attempted to escape from her anxiety by spending hours in her rocking chair.
Thorsos was unemployed for an extended period of time while unsuccessfully looking for work. Like Therese, Deborah took this difficulty quite personally and blamed herself and her disability when she could not find work.

I was hurt that I wasn't picked for employment. Perhaps I wasn't good enough to be hired even at a food service establishment. This confirmed my feelings of inferiority. I had difficulty making a favorable impression on prospective employers who didn't know me or understand my challenges with autism (Thorsos, p. 125).

This is yet another instance in which Thorsos seems to have internalized the negative messages she received about employees with disabilities. Thorsos rarely criticized the social or environmental barriers that kept her from equal access to employment, just as she shied away from criticizing other social institutors like school.

Therese Ronan, on the other hand, refused to tolerate the harassment and exploitation she suffered at work.

I finally quit my job at that restaurant, and I haven't regretted it for a minute. The harassment that I received while I was working there got to be more than I could mentally handle. They probably don't miss me either. However, I was in contact with a few other employees. I also have received unemployment compensation. I used that money to purchase stamps and other things that I need to place me back on track. (Ronan, p. 128)
Unlike Deborah Thorsos, who felt pressured to take any job to avoid dependence on her family or public assistance, Therese Ronan quit her unsatisfying job and utilized food stamps while finding a more rewarding path.

Sharon Cowhey echoes Ronan’s disenfranchisement with discriminatory employment practices. After years of underpaid labor, sporadic employment, and unsatisfying jobs, Sharon Cowhey’s employment history ended when her negative experiences culminated in sexual harassment by a coworker: “Barry works very hard to pay the bills, I am on disability. I applied for Social Security Disability after I left my last job. The experience from my last employment was so devastating that it created a great fear in me.” (Cowhey, p. 43)

Cowhey reached a threshold when she could no longer cope with inhospitable work environments, hostile coworkers, or predatory supervisors. Somewhat ironically, Cowhey’s final job turned into an avenue toward diagnosis because it was the workplace crisis counselor who finally recognized the symptoms of autism. Unfortunately, it took a case of sexual harassment to ultimately reveal Cowhey’s ASD to a professional. Cowhey figured she had suffered at the hands of abusive employers and coworkers long enough to justify her use of public assistance.

While Sharon Cowhey felt entitled to public assistance, Deborah Thorsos easily qualified for food stamps based on her need and disability status; however, she was uncomfortable accepting public assistance because of its negative connotation of financial dependence. It is clear that Thorsos absorbed the cultural value placed on economic independence: “Though I appreciated getting the food coupons to cover my food costs, I wanted to be hired somewhere with adequate pay and health care
benefits” (Thorsos, p.165). Deborah Thorsos wanted to work and earn a living; she did not want to rely on the government or her family to meet her daily needs. As an educated woman, Thorsos believed she should be able to find a decent job; however, employers were not motivated to hire workers with developmental disabilities at that time.

Since the passage of the ADA in 1990, employers are prohibited from discriminatory hiring practices that exclude Americans with disabilities, but there is a growing body of evidence that suggests many highly educated people with autism are still unemployed. The preceding section illustrates some of the issues surrounding unemployment for Sharon Cowhey, Therese Ronan, and Deborah Thorsos. All three women expressed frustration and self-doubt when unsuccessfully looking for work. When they were fortunate enough to gain employment, the jobs usually consisted of low-paying menial labor which was not personally fulfilling or financially adequate.

This area illustrates some of the complex variables that contribute to the success or difficulty the women in this study had in their journey from childhood to adulthood. Temple Grandin, the most well-known woman with autism, achieved her success through a combination of personal talent and social support, but she had the benefit of a supportive family, talented mentors, and personal initiative. Erika Hammerschmidt and Deborah Thorsos had supportive families, but were not able to apply their college education or natural talents toward a meaningful career. Sharon Cowhey did not have the support of her family, a high school diploma or supportive employers and she ultimately resigned from the workforce to collect Social Security. Therese Ronan was in conflict with her family and was not permitted to train for a career.
in the beauty industry, but resisted the pressure to conform to a marginal or subservient status. Dawn Prince-Hughes had supportive parents, but struggled through her childhood, adolescence, and into adulthood. Prince-Hughes had to contend with the social stigma of being openly gay and missing an autism diagnosis, but ultimately achieved her educational and professional goals. Lianne Willey anticipated having a successful career, just as she had with her college education, but without a diagnosis, she struggled to understand the issues that lead to difficulty and anxiety.

C. **Women with Autism Experience Sexual Development and Romantic Relationships**

This area examines some of the themes that emerged in the lives of these women as they transitioned through the physiological changes brought on by puberty. First, “Disparities between sexual and emotional Development”, reveals a unique issue for girls with developmental disabilities like ASD. Second, authors discuss ways in which they had “Difficulties Understanding the Unwritten Rules of Romance.” The third section, “Disability Identity and romance”, reveals how disability identity played an integral role in their search for partnership and marriage. Fourth, “Importance of Practice”, stresses the importance of past relationships and crushes that were helpful learning experiences. In the last section, “The role of family and community”, shows how families and communities influence sexual development.

1. **Disparities between sexual and emotional development**

Girls with ASD are often aware of the changes taking place during puberty, but sometimes feel a disparity between their emotional development and chronological age (Gabriels; Tissot). Deborah Thorsos and Sharon Cowhey were aware
of the physical and hormonal changes occurring during puberty, regardless of any
developmental delay or the social and communicative impairments associated with
autism. Deborah Thorsos and Sharon Cowhey described a gap between physical
maturation and emotional development that shaped a feeling of discomfort with the
overall process of puberty.

Deborah Thorsos explained how early physical maturity stood in contrast
to her emotional immaturity. This distance between physical development and
psychological maturity was exacerbated for Thorsos who began puberty earlier than
other girls her age.

A few months before my tenth birthday as I was about to enter
puberty, my hormonal level started to act up and affect me. I
became more moody, irritable, and depressed. I began to develop
physically at a very young age while I was still emotionally
immature (Thorsos, p. 45).

Thorsos described how psychological and emotional delays seemed more
pronounced by her early entrance into puberty. The physical changes occurring during
puberty became more challenging for Thorsos because she felt unprepared to deal with
the social and emotional changes. For example, Thorsos did not feel emotionally ready
to handle the hygienic responsibilities that came with menstruation.

When Sharon Cowhey reached adolescence, she was acutely aware that
her “interest in boys started becoming stronger.” (Cowhey, p. 19) Like Thorsos, Cowhey
reported a lapse between physical and emotional development that became particular
problematic during adolescence. Although Cowhey was aware of her sexual
development, she did not feel emotionally equipped to handle the responsibility of becoming sexually active. "I knew nothing about having a relationship with a boy, I knew nothing about what to do in any kind of life's situations, and all I knew was how to rock with music blasting in my ears to escape into my world" (Cowhey, p. 20).

Cowhey yearned to escape from her life as an adolescent girl with undiagnosed autism. Throughout her life, Sharon Cowhey coped with anxiety by rocking for hours in a rocking chair. The rocking chair may have prefaced a general need to escape from stress and anxiety rather than managing negative feelings in a more productive way. The need for escape was clearly demonstrated in childhood, which is when her addiction to rocking began. Before adolescence, Cowhey’s methods of escape were limited to emotional acts, i.e., forgetting her worries in the motion of the chair and accompanying music. During adolescence, Cowhey had greater opportunities and more freedom to physically remove her from stressful situations. After becoming sexually mature, Cowhey was able to physically escape from the anxiety of her daily life by running away from home with a boyfriend. However, many of the same issues that troubled Cowhey at school followed her after she left and became problematic in this romantic relationship. As this relationship ended, Cowhey became involved with another young man who had a criminal record. Once again, Cowhey’s social, sensory, and communication difficulties threatened her desire to have a healthy mature relationship. “My relationship with Jeter was coming to an end. After all, at that time I didn't even know the definition of the word relationship. If he asked to have sex, I would” (Cowhey, p. 21).
Cowhey’s underdeveloped comprehension of the fundamental principles of sexuality or lack of sociosexual knowledge has been demonstrated in the existing research on autism and sexuality. Lack of sociosexual knowledge is the first of these factors. Sociosexual knowledge plateaus around the age of puberty; individuals with AS at that age have rarely attained the maturity of the average young adult. They do not have the same experiences as adolescents in the general population (Atwood; Griffiths; Henault; Hingsburger). Thorsos and Cowhey recognized that their bodies and feelings were changing, but did not always feel prepared for the challenges that came with sexual development. Thorsos, born in 1957, and Cowhey, born in 1959 were contemporaries; however, Thorsos was diagnosed in early childhood and received ongoing outside support whereas Cowhey was not diagnosed until adulthood and struggled to understand the reason behind her social awkwardness and overwhelming anxiety. Nevertheless, both women recognized a disconnect between physical and emotional development that became increasingly obvious during the transitional period of adolescence.

2. **Difficulties understanding the unwritten rules of romance**

Women with ASD report feelings of confusion and frustration when trying to comprehend the complicated, unwritten rules of romance and courtship (Gougeon; Mehzabin & Stokes; Tissot). All of the women in this study corroborate this phenomenon. Prince-Hughes may not have commented on her confusion over romance during adolescence, but she definitely reported these issues in adulthood. She already had to contend with undiagnosed autism, the stigma of being openly gay during a time when it was not socially acceptable, being bullied because of her sexual identity,
Willey was aware that her typically developing girlfriends were interacting with boys in new ways, but flirtatious behavior was difficult to interpret and harder to emulate. Willey remembered this period as a pivotal departure from mainstream social development.

They were giggling and laughing and tossing their hair behind their shoulders, gently putting their hands on the boys’ arms, looking totally lost in the limelight of the attention they were getting. I could see their formula but I could not bring myself to follow it … Only then did I realize that I had been tossed aside. … I never understood their vernacular. Suffice to say that, at that point, I was unable to read between the lines. Subtext and innuendo may as well have been birds flying by my window. (Willey, pp. 45-46)

In the excerpt above, Willey maintained that she understood flirtation on a very basic level, but the deeper subtext eluded her. She was aware that her peers were interacting in new and different ways; further, Willey had some insight into how these shifting conventions of behavior worked. However, Willey had trouble understanding the more subtle cues presented by flirtation, and also how to implement these new modes of conversation and behavior.

Willey may have felt she had some insight into romance during adolescence, albeit very limited. By the time she reached adulthood, Willey had formed serious doubts about her ability to communicate well enough to initiate or maintain a
romantic relationship. Her romantic experiences during adolescence and early adulthood contributed to deeper reservations about her ability to effectively communicate with another person well enough to have a romantic relationship.

By the time I met my husband I was pretty well convinced I would never understand anyone well enough to maintain something everlasting. ... My AS behaviors – the sensory integration problems, literal mindedness, perseverance and rigid thinking tendencies – acted like arrows tipped in poison that stood poised and ready to pierce every relationship I ever found. ... From the moment I met Tom, I sensed he was a great deal like me. (Willey, p. 62).

Based on her adolescent experiences, Willey doubted her ability to understand and interpret the verbal and nonverbal forms of communication well enough to satisfy a romantic partner. The fact that Willey had not been diagnosed with autism during her development appears to have exacerbated the confusion she felt when trying to understand why she had so much difficulty with interpersonal relationships. Willey’s doubts about finding an intimate partner were fueled by both her confusion in romantic scenarios and also because she did not know that autism was the reason behind her confusion. Although Willey was undiagnosed during adolescence, the communication impairments associated with autism were still problematic for her.

Sharon Cowhey, like Lianne Willey, was not diagnosed with autism until she reached adulthood. Likewise, Cowhey reiterated Willey’s narrative about the struggle to find romance given the social and communication impairments of autism. Cowhey saw autism as a hindrance to her sexuality because the symptoms of autism
made it difficult to interpret the social norms governing courtship and attraction: “Autism has prevented me from being sexy and romantic so having sex for the first time was for me a very painful unwanted pleasure” (Cowhey, p. 21).

Cowhey, like Willey, was frustrated by her difficulty understanding and interpreting sexual behavior. She wanted to feel sexy and romantic but, like Willey, Cowhey did not have an autism diagnosis which would help to explain why this was so challenging. Cowhey’s lack of healthy sexual life skills resulted in more than frustration. Cowhey had a child as an unwed teenage mother. Her first marriage ended because her partner was sexually abusing her daughter. Cowhey also became a victim of sexual harassment at work. Although she expresses some satisfaction in her current marriage, Cowhey’s husband abuses alcohol, which causes problem in their relationship.

Although Hammerschmidt was diagnosed with autism in early childhood, she still wrestled with the same type of frustration with romance that distressed Wiley and Cowhey. Unlike Willey and Cowhey, she knew why she had difficulties with style and socialization, but this awareness did little to offset her feelings of alienation and inadequacy.

I wore tight, low-necked shirts, but didn't know I was supposed to wear anything under them for modesty. I wore lots of makeup - too much, and the wrong colors. I had no idea what went with what. And even when I did manage to look beautiful, it didn't make up for being a weirdo. I had the same desire for love and popularity that all girls had, but it took me a long time to learn to fulfill it in a healthy
way. Throughout my childhood, teens and young adulthood, I struggled to fit in (Hammerschmidt, p. 5).

In adolescence, Hammerschmidt became increasingly frustrated by the challenges of understanding, interpreting, and implementing standards of personal appearance and interpersonal communication. I was angry that nobody desired me - that I probably wouldn't ever have any chance of losing my virginity. I didn't know how to dress to attract men, even how to talk to attract them. Angry at myself because, whenever I found a guy attractive, I just came up to him and made a crude joke about wanting to tear off his clothes, and as a result he neither felt comfortable with me nor took my desire seriously. (Hammerschmidt, p. 84)

Hammerschmidt resented the fact that she felt so bewildered by the opposite sex and seems to have turned this anger inward, blaming herself and her disability for this confusion. Romance and relationships appears to have followed a general rule of feeling alienated from others, a feeling that permeated every aspect of Hammerschmidt's life. Just as the title of her autobiography Born on the Wrong Planet suggests, Hammerschmidt related to human society as if it were an alien culture. Her alienation was twofold; on one level, she felt alienated, as in set apart or separated from others in an existential way, while on another level she related to the fictional alien Spock from Star Trek because she found human society to be just as foreign as another planet. (Grandin also reported a particular affinity for the character Spock for similar reasons.)
I had reached a point where I had resigned myself to being single,
and wasn't sure I could handle a romantic relationship anyway.
"There are times," I had recently written to Internet friends, "when I
fear that this 'alien trapped in a human body' feeling goes as deep
as my sexual orientation, and I am simply not attracted to people
from this planet." All my life I'd had trouble with romance.
(Hammerschmidt, p. 140).

Like Willey, Hammerschmidt reached a point where she became resigned
to the idea that she might never form a long term relationship. Hammerschmidt looked
toward the future with apprehension because she doubted her ability to attract a
romantic partner or exert her own sexuality successfully. Her transition into adulthood
was filled with self-doubt concerning her ability to date or marry.

Whereas Hammerschmidt directed her anger inward, Therese Ronan
realized that her romantic opportunities were limited based on discrimination against
people with disabilities. Therese Ronan sees disability as an obstacle in her romantic
life. Ronan’s history of negative experiences with love reinforces her tendency to
fantasize about romance, rather than experience it first-hand. Her first love interests
were movie stars or teen heart throbs. As a teenager, a friend’s brother became her
“first, non-fantasy-world crush” (Ronan, p. 38). Unfortunately, Ronan’s feelings were not
shared by many of her crushes which she attributes to her disability.

If you have a mental disability, you may have a crush on a guy, but
your chances of his liking you as well are much less. I got crushes
on guys who weren’t even in my life. I figured if they didn’t know
me, then they couldn't respond to me with hateful emotions. So there are several differences that I know for a fact between those with disabilities and those without (Ronan, p. 29).

Ronan distinguished herself from the other women in this study because she was the only one to point to stigma and discrimination, rather than the communication and skills associated with autism.

Erika Hammerschmidt, like Deborah Thorsos, was diagnosed with autism in childhood. However, Erika was born in 1981 whereas Thorsos was born in 1957, so Hammerschmidt attended integrated schools with her peers while Thorsos was segregated in special education from an early age. Perhaps Thorsos absorbed these messages more easily because she was diagnosed in early childhood and grew up in an era of widespread educational segregation, both based on race and disability. Thorsos may have eventually accepted the negative messages about autism that were ingrained in systems of segregation and special education. In the following example, Thorsos provided a text book sounding account of her social deficits and how they infringed upon her ability to find a quality companion: “My deficits in appearance, social skills, and self-confidence, which were painfully obvious, made it challenging for a man I would be interested in to make me his girlfriend” (Thorsos, p. 211).

Thorsos appears to have wholeheartedly internalized the defining features of autism without much resistance. “Besides what they heard or read in the media, those on the spectrum have also personally received negative messages about certain autistic traits over which they have no control.” (Dubbin) Thorsos responded to the hegemony of segregation built into the social systems that pervaded her life from early
childhood. After years of early intervention, special education, and rehabilitative efforts, Thorsos saw herself from a medical perspective that emphasized deficits and impairments over and above the social or political circumstances that limited her opportunities. It seems to have accepted the professional assessment of her impairments without question.

Temple Grandin, a contemporary of Deborah Thorsos, disregarded her chances for romance completely and opted for an asexual lifestyle. Grandin does not explicitly discuss adolescent events connected to romance or crushes, but one might speculate that the absence of these formative experiences influenced her later decision to avoid intimacy altogether.

Although business relationships can easily be learned by rote, dating is difficult. The social skills one needs to rent an apartment and keep a job were easier for me to learn than the social skills for dating, because I have very few emotional cues to guide me during complex social interactions (Grandin, p. 155).

Unlike Thorsos, who still made efforts to form intimate relationships despite the social impairments that make intimacy challenging for people with autism, Grandin completely avoided romance. Although she had learned that she possessed poor communication and social skills, Thorsos was still interested in pursuing romantic relationships; though Thorsos thought it was doubtful, she still made an effort. Grandin, on the other hand, appears to have rejected romance outright. Apparently, Grandin also absorbed and transmitted the negative message that romantic relationships were simply too difficult for people with the social and sensory impairments of autism: “I’ve remained
celibate because doing so helps me to avoid the many complicated social situations that are too difficult for me to handle. For most people with autism, physical closeness is as much a problem as not understanding basic social behaviors” (Grandin, p. 154).

Except for Grandin, the other women in this study voiced a desire for intimate relationships with a significant other. However, these women did not always understand the unwritten rules of romance and courtship. Grandin is the only woman in this sample to actively choose abstinence. Willey, Cowhey, Hammerschmidt, and Thorsos married, while Dawn Prince-Hughes is in a committed partnership. Therese Ronan wanted to marry, but was thwarted by the efforts of her family who intervened to end the engagement.

All the women in this study agreed that understanding and participating in romantic relationships was very challenging. Willey, Cowhey, Hammerschmidt, Thorsos, and Grandin all pointed to the core impairments of autism that made communication and socialization difficult, especially in potentially romantic scenarios. Dawn Prince-Hughes experienced the same sort of confusion, but her experiences were limited to adulthood. Therese Ronan was the only woman to move beyond blaming the symptoms of autism for restricting her love life and took a more socio-political stance, highlighting stigma and prejudice against people with disabilities.

3. **Disability identity and romance**

This section looks at the ways women with ASD connected with romantic interests through the common experience of disability. Special education presented early opportunities to form crushes, flirt, and begin dating. Hammerschmidt had several young loves during childhood and early adolescence. After enduring a frustrating period
of time with very few romantic prospects, Hammerschmidt developed a circle of friends and acquaintances on the Autism spectrum in college. Through this network of friends, Hammerschmidt met her future husband. Thorsos also dated several people on the autism spectrum, but found that they were incompatible. Ultimately, having a disability identity brought Thorsos into contact with her future husband, a man who was visually impaired and also relied on public transportation.

One of Hammerschmidt’s young relationships developed at a summer camp for children in special education.

In junior high school I spent part of one summer in a special ed. summer program, where the students did things like going to parks, swimming pools, and libraries and so on. One of the guys said quite bluntly to me one day at the pool that he wanted to be my boyfriend. Having no other romantic prospects in sight, I agreed. We never kissed, but we sat together on the bus every day with our arms around each other (Hammerschmidt, p. 77).

Having a disability community was crucial for Hammerschmidt’s first introduction to romance and dating, and later became an integral support system that lead to her meeting her husband.

We exchanged several emails and phone calls before arranging a date. He talked about how struck he was by my cleverness at the party, and later by my website and an article he had read about my book. He had ordered the book online and looked forward to reading it. He never said outright that he was in love or had a crush
on me, but it glared out from between the lines (Hammerschmidt, p. 142).

So after years of frustration trying to meet someone, she found a sense of community with a fellow Aspie. They eventually married and adopted a parrot, but do not plan to have children. From her first childhood experience of puppy love at that special ed. camp, to eventually finding her mate at an Aspire party, Hammerschmidt had more success dating in the disability community.

Thorsos found her first boyfriend at school; he also had some language irregularities due to mild autism. At that point in time, Thorsos found it difficult to tolerate his intense speaking style due to her own sensory issues.

In school there was one boy, Stuart, in my class and van who was attracted to me. He was like my first boyfriend. He sat next to me as much is possible. We liked each other very much and we gave each other cards for birthdays and holidays, including Valentine’s Day. He was very intelligent and had mild autism. He, like me, talked too much and loudly. However unlike me, he talked on and on with excessive details on technical matters. This made it more difficult for me to listen (Thorsos, p. 35).

Although this relationship was short lived, Thorsos had this early opportunity to practice some of the customs of courtship. Her relationship with Stuart may have set the stage for future intimate relationships based on a shared disability identity.
This was my very first real date. The main problem was that he talked non-stop and I had difficulty listening to him. I was unable to process the onslaught of all that auditory information due to my sensory overload and attention problems. He must have picked up that I wasn't taking in everything he said to me though I tried very hard to listen the effect became a strain on me after just a few minutes of his monologue. The strain was compounded by my not having much to say myself. At the end of our only date, as I was getting ready to go home, he decided to break up with me. I didn't blame him and I wasn't hurt. I realized he wanted someone to act as a sounding board which was beyond me; anyway the breakup was a relief to me. I wasn't ready to sustain an intimate relationship such as having a boyfriend. Carrying on conversations wasn't one of my fortes, one of the major qualities that enhance intimacy (Thorsos, p. 93).

Her first date with Stuart was complicated by the fact they both had autism. In that instance, the nuances of their disabilities caused them to clash with each other. Stuart ended the relationship at the end of that first date, but the overall experience was constructive for Thorsos because it gave her an example of a type of relationship that would not work. Thorsos' break up with Stuart provided her with the insight that she was not ready for an intimate relationship and required someone with a different personality type.
A shared experience of disability was a major factor in the relationship between Thorsos and her husband Chris. Although Chris was visually impaired and Thorsos had autism, they each identified with disability as a formative factor in their world views and personal development.

After Chris and I talked to each other about our past and the challenges we endured, we were drawn to each other by a mutual understanding of having a disability and dealing with it, even though our problems were very different. It was love at first sight, there was a mutual attraction and both of us felt that we were right for each other. Chris was impressed with my college education and intelligence and, likewise, I was impressed with his. He was also close to my age being only 3 1/2 years older than me (Thorsos, p. 217).

Thorsos was ready for intimacy at that point in her life and she had the past experience to realize what she truly wanted in an intimate partner. She may not have had the skills or opportunity to form an intimate relationship in the past, but it seems that practice improved her confidence and deepened her understanding of intimacy.

Special education provided Hammerschmidt and Thorsos with a peer group based on disability, which was instrumental to forming their first romantic relationships. These young romances based on a shared experience of disability may have set the stage for future intimate relationships also built on a common sense of disability identity.
4. **The importance of practice**

Adolescents and young adults with autism often have limited opportunities to effectively learn or practice utilizing their social skills. To effectively develop social skills, young people with autism require opportunities to practice and receive feedback from others (DeMatteo et al.). In this section, Hammerschmidt and Thorsos reveal the importance of having opportunities to practice and strengthen social skills that could foster intimate partnerships. Summer camp and employment were two structured domains that allowed Hammerschmidt and Thorsos, respectively, to practice socializing with others and build confidence in their abilities.

Hammerschmidt remembered one of her significant early relationships formed at a language immersion summer camp for kids who wanted to learn another language. Having a common interest with her typically developing peers enabled Hammerschmidt to thrive socially and form a romantic attachment at camp.

We kissed in public, so addicted to the new feeling that we didn’t care what other people thought. We kissed in the nurse’s office when I was sick for a few days and he was allowed in to see me. We kissed once when I was wearing my retainer (Hammerschmidt, p. 122).

Her relationship with Pablo coincided with overall social success at camp that summer, reinforcing the idea that building social skills can bolster romantic relationships. Erika had two more love interests during junior high school which allowed her to exercise some of these emerging skills. However, she was greatly disappointed
when her chances to practice her burgeoning skills when opportunities receded in high school.

Those three situations were the closest I got to romance for many years. Each one took up only a few weeks of my childhood, with long lonely months and years in between. Looking back, it's hard even to think of them as boyfriends, but as I went through high school without a love interest, I wished I hadn't gotten tired of them so fast (Hammerschmidt, p. 78).

Hammerschmidt was frustrated by the romantic lull she faced in high school and wished she had savored those earlier relationships. Hammerschmidt may have not have has as much experience as she would have liked, but her relationship with Pablo and others provided her with some basic experiences and practice.

Thorsos also highlighted the importance of daily exposure to other people with which to practice appropriate social exchanges. She credited regular employment for providing her with a structured environment to practice her social skills: "As I intersected with many kinds of people day to day at work, I experienced a growth in social skills that enabled me to form intimate relationships with a close friend and even a steady boyfriend" (Thorsos, p. 224).

Thorsos demonstrated how exposure to other people on a regular basis bolstered her confidence and skill set to enter into and maintain deeper relationships. Having been afforded opportunities to interact with others during high school and work, Thorsos looked back on past experiences to learn from her mistakes and measure the strides she had taken toward improving communication and social skills.
This section reveals a potentially political issue tied up in this need for practice, that is, many adults with autism are underserved by social services and often become unemployed. Without typical peer groups, knowledge of social skills, or opportunities for employment, adults with autism have very few outlets to develop and utilize social skills. Without these vital social skills, many adults with autism are again limited in their chances for romance.

5. **The role of family and community**

Families and communities may influence the romantic development of women with ASD (Atwood; Van Pelt). The families of Therese Ronan and Dawn Prince-Hughes impacted their romantic relationships in very different ways. For Therese Ronan, family played detrimental roles when they intervened to end her engagement. After finding someone who returned her affections, Ronan’s family ended the relationship with the help of law enforcement.

I dated a young man named Tom for a while and was engaged to him for two days. I had met him at a mental health meeting. He was a tall, thin brunette. One night we went to a motel in a nearby town. We planned to run away and get married the next day. In the morning after breakfast, he decided to take me ring shopping. We took a cab to the shopping center. To our surprise, when we arrived, the police, my dad, and Tom's mom were there. We had to go home. That was the end of our friendship. I don't know how they
knew where we were. I saw Tom another time after that. Then we broke up (Ronan, p. 63).

Ronan’s family demonstrates their discomfort with her sexuality in this example; they also display the amount of authority they have over her life choices. Her family reinforced the idea that Ronan was developmentally disabled and that she did not have the capacity to become an adult. This situation reveals the dichotomy between mental and chronological age in which fully grown adults are denied full participation in society because they deemed to be children mentally or emotionally. Ronan’s family ignored her needs when they refused to accept her as an adult and insist she remain a child forever.

On the other hand, Dawn Prince-Hughes benefited from parents who supported her during the process of discovering her sexual orientation.

As I told them about my feelings, my parents listened carefully and did not make much comment. Soon afterward my mother started driving me down to the nearest city of any size (an hour away) so that I could explore a group run by gay and lesbian people. I had no interest in dating for sexual reasons and still felt that sexuality ran on a continuum (Prince-Hughes, p. 58).

The members of her gay support group were compassionate and sincere though they did not always understand her. Although Dawn Prince-Hughes did not receive an autism diagnosis until she was fully grown, her family’s support during adolescence allowed her to claim a sexual identity without knowing she had autism. Several conclusions could be drawn from this data: one is that family support might
outweigh the importance of having a diagnosis during the transition from adolescence to adulthood.

The group was also crucial in addressing her alcoholic behavior during adolescence: “I think the other people involved cared about me and wanted to be supportive, even if at times they didn't understand me. I know they worried about my drinking as well” (Prince Hughes, p. 59).

The group provided Prince-Hughes with a safe haven without knowing she had autism. This supportive community may have enabled Prince-Hughes to come to terms with her sexuality and alcoholism long before she was diagnosed with autism. Dawn’s family played an important role smoothing the transition from childhood to adulthood in terms of recognizing and accepting her sexuality.

In very opposite fashions, Ronan and Prince-Hughes demonstrated how influential their families and communities were on their romantic development. Ronan’s family refused to recognize her as a mature woman and exerted their power to overrule Ronan’s will. In contrast, Prince-Hughes’ family was a rare oasis of support enduring her tumultuous adolescent years. More than simply supporting her directly, they sought out a support group to assist her in finding a healthy sexual identity.

The preceding section showcased five themes that the women in this study encountered during their transition from childhood to womanhood. In the first thematic section, Sharon Cowhey and Deborah Thorsos addressed Disparities between sexual and emotional developments. Then Cowhey, Thorsos, Hammerschmidt, Willey, Ronan, and Grandin were featured in Difficulties Understanding the Unwritten Rules of Romance. In Disability Identity and Romance Hammerschmidt and Thorsos revealed
how a shared experience of disability figured into their romantic histories. In the Importance of Practice, Thorsos and Hammerschmidt stressed how crucial it was to have environments to learn and practice emerging social skills. Finally, Therese Ronan and Dawn Prince-Hughes exposed the powerful influence that families and communities can exert during adolescent sexual development.

D. **Women with Autism Access Networks of Support**

This section considers the importance of family, religion, friendship, and systems of socialization in the lives of women with ASD. These social systems play integral roles in the development of girls with ASD on their path toward adulthood. The women who reflected on this process reveal how communities based on family, faith, and friendship helped or hindered the transition from girlhood to womanhood. There are nine thematic sub-sections that address these issues. Section one features the instrumental role played by “Supportive families”. Section two. “Lack of information compounds family stress” relays the difficulties of baby boomer women with ASD growing up with a diagnosis that had only recently been named by Leo Kanner in 1943. Section three, “Genealogies of Neurodivergence” addresses the genetic transmission of ASD from one generation to the next. Section four, “Family shapes attitudes about disability” describes the family dynamics that influence self-image. Section five, “Family as a conduit to formal systems of support” outlines how parents can steer girls with ASD toward support groups and other organizations. Section six, “Participation in the spiritual life of the family” and section seven, “Exclusion and abuse in religious life” examine how the religious life of a family can include or exclude members with ASD. Section eight, “Struggling with friendship” explores a common concern for children and adults with
ASD. Section nine, “Developing friendships” reveals some helpful strategies and positive outcomes used by women with ASD to meet and keep friends.

1. **Supportive families**

   The support of family is critical to the success of women with ASD during school and beyond (Hartmann; Plumb). Temple Grandin and Deborah Thorsos successfully received their high school diplomas during a time in American history before laws like IDEA and ADA were passed to ensure the civil rights of people with disabilities. Staying in school was a major accomplishment at a time when others, such as Therese Ronan, missed two years of school. Erika Hammerschmidt reinforces the importance of supportive parents to provide a supportive and loving home life in which she was able to pursue her creative interests and express her personality.

   Temple Grandin stresses the importance of the type of individual attention her mother gave her on a daily basis. Given the period in which Temple was born and raised, keeping her in school and out of the institution was no easy task.

   My mother spent thirty minutes five days a week for several months teaching me to read. ... Mother had a knack for recognizing which people could help me and which ones could not. She sought out the best teachers and schools for me, in an era when most autistic children were placed in institutions. She was determined to keep me out of an institution (Grandin, p. 46).

   Grandin realizes that it was not only her mother, but a network of caregivers and professionals that supported her education and success: “I am lucky in that I responded well when my mother, teachers, and governess kept encouraging
social interaction and play. I was seldom allowed to retreat into the soothing world of rocking or spinning objects. When I daydreamed, my teachers yanked me back to reality.” (Grandin, p. 43).

The above excerpt demonstrates the need for a strong network of support, but also her perspective on self-stimulation or stims that often accompany an ASD diagnosis. In fact, the presence of repetitive, stereotyped movement are still a defining feature of an ASD diagnosis according to the DSM 5 (APA, p. 50). However, not all people with ASD share this viewpoint.

Hammerschmidt’s parents enabled her to better understand her environment and find a comfortable way to connect with it. Hammerschmidt’s parents supported her creative endeavors which aided her to comprehend and envision a future that held a place for her.

Mom and Dad have always supported me in my struggle to come to terms with my Asperger Syndrome, and perhaps they sensed that writing and other forms of artwork play a large role in this struggle. I have learned to understand the rest of the world by writing about it, and when I have been unable to understand it, I have taken refuge in other worlds I’ve created through writing, painting and drawing. I cannot remember a time when my creative urges were not met (Hammerschmidt, p. 27).

The support of her parents at an early age enabled her to face adulthood with a hopeful and positive attitude. Whereas Grandin credits her parents for keeping her engaged in reality, Erika is thankful that her parents allowed her the freedom to
retreat into her own world. Allowing Erika to retreat into her fantasy world turned out to be beneficial because it was in that imaginary space where she gained a greater understanding of her own culture. Throughout her autobiography, Erika explains how her imagination and writing served as a parallel to human culture and eventually became a metaphorical bridge to actual human civilization.

Deborah Thorsos recognized her dependence on her family beginning in girlhood, but this knowledge guided her towards positive choices that supported her future development: “Since I didn't have a strong social network outside my immediate family due to my autism, it was even more vital that I continue to live where I could receive the support of my family” (Thorsos, p. 94). The support of her family was a compelling factor behind Deborah’s successful transition into adulthood. Thorsos benefitted from having a supportive family, but also the personal realization that being in close proximity to her family was critical to her development.

Therese Ronan remembers her family being generally supportive, but also relates how her family underestimated her intelligence and treated her in an unequal way. Ronan portrays a more complex relationship between herself and family members; though she feels they have been supportive, she also feels belittled by their low assessment of her intelligence.

It was nice that they remembered me with all the hassle that I put them through. All of my brothers and their wives came to the party. It's times like these that I really am grateful for such a wonderful family. Whether I'm autistic or disabled, they have been real good to me for the most part of my life. Nevertheless, I also feel that I
was treated as if I were without a brain. But they have stood by me through thick and thin. (Ronan, p. 122).

Looking back, Ronan appreciated the general support of her family, but presents her family history as a mixed bag of emotion and experience. Had Ronan's family been more positive in her youth, she may have had a better opinion of her status in the family.

Hammerschmidt, Grandin, and Thorsos consistently present positive images of their families and the beneficial role they played in their lives. Ronan, on the other hand, remembers a more complex relationship with her family who often relegated her to a secondary place.

2. **Lack of information compounds family stress**

Coming of age during the era immediately following the identification of autism as a diagnostic term in 1943 brought particular challenges for baby boomer women with ASD (Baron-Cohen; Hacking). Temple Grandin was born only four years after Kanner introduced the term autism as a diagnostic label. Prior to Kanner it was Bleuler who used the term autism to describe a type of schizophrenia (Clifford; Davidson; Stanghellini).

In an era when little was known about autism, Grandin's parents pursued a diagnosis when she failed to reach early developmental benchmarks: “Mother first realized that something was drastically wrong when I failed to start talking like the little girl next door, and it seemed that I might be deaf.” (Grandin, p. 33) In Grandin’s situation, the strength of her parents’ conviction lead to a diagnosis that was not widely publicized or well-known, as it is today. This diagnosis lead Grandin’s mother to employ
extraordinary means to communicate with her daughter, which may have primed Temple for future success with interpersonal communication.

Deborah Thorsos, born ten years after Grandin, still grappled with the limitations of having an ASD diagnosis at that particular time.

The challenges of caring for a person with a disability, especially when very little was known about it, tended to affect the dynamics of the entire family including me. It was emotionally draining for my entire family especially when I exhibited enigmatic behaviors and was unable to communicate (Thorsos, p. 20).

Thorsos explores how public knowledge about autism, or lack of it, influenced the ways her family interacts dealt with her disability. The family’s perspective on her disability was informed by the lack of information about autism at that time and this was an ongoing issue through the life cycle.

Grandin and Thorsos outline the central roles that parents and families play in their lives. Though imperfect, these women report that their families provided communities that supported their transition from girls with autism to women with autism.

3. **Genealogies of Neurodivergence**

Research suggests that ASDs are genetic and are often transmitted from one generation to the next (APA; Hu-Lince et al.; Jamain et al.; Muhle, Trentacoste & Rapin). In an emerging phenomenon, many adults receive an ASD diagnosis after their child or close relative receive a similar diagnosis. For example, Lianne Willey began to identify with ASD after her daughter was formally diagnosed. In a similar fashion, those diagnosed with ASD look to past generations for evidence of autism in their parents and
other family members. Thorsos and Cowhey identify their fathers as the genetic source for their own autism. Neither father was formally diagnosed with autism, but they had certain characteristic traits consistent with autism. Thorsos listed her father’s autistic-like behaviors:

“My father had some autistic characteristics although he was never diagnosed as a child. He displayed autistic behaviors: nose picking in public, poor table manners, compulsive behaviors, imbalanced emotions, and social ineptitude.” (Thorsos, p. 16)

Thorsos felt her father’s affection in spite of his difficulties that she attributes to autism: “Beneath his disability, I felt his love of the family including me. He had difficulty raising us children. But, it was basically my mother raised us since she did not have autism.” (Thorsos, p. 17)

The parenting responsibilities fell mainly on the shoulders of Deborah’s mother because her father did not have the capacity to emotionally support his children. This may have taxed the relationship between her parents because they eventually divorced. However, had he been diagnosed, Mr. Thorsos could have provided a different and unique type of social support that could have been instructive to Deborah while making that transition into adulthood.

Cowhey, like Thorsos, also points to her father as the genetic source of her autism. Unlike Thorsos, Cowhey did not feel loved or nurtured by her father regardless of his disability. Rather, Cowhey’s father was aloof and addicted to alcohol.

My father never showed much affection towards anyone. As I look back at the way my father was, I feel my autism came from him. My
father was an alcoholic. I understood him because I felt he could not stop drinking just like I could not stop rocking (Cowhey, p. 23).

Whereas Mr. Thorsos raises the potential for a parent with autism becoming especially supportive to a daughter with autism, Mr. Cowhey demonstrates how a parent’s undiagnosed autism could add chaos to family life. In Sharon Cowhey’s case, her father’s lack of affection and dependence on alcohol may have negatively impacted Sharon throughout her developmental process. Mr. Cowhey’s alcoholism appears to have led to Sharon’s affinity toward her current husband, another alcoholic. In fact, Cowhey sees parallels between the destructive behaviors exemplified by both her father and husband: “My father being an alcoholic drove drunk. Every time he would do this it worried me. Barry drinks and when he drinks and drives he worries me too.” (Cowhey, p. 61) This passage by Cowhey suggests that feelings she first associated with her father’s drinking resurfaced in connection to her husband’s drinking. At the very least, this suggests that Cowhey was familiar, if not comfortable, with alcoholic behaviors.

Although Cowhey and Thorsos both believe their fathers had many autistic characteristics and may have simply had cases of undiagnosed autism, that is where the similarity ends. Thorsos felt loved and valued by her father, regardless of his own condition. Unlike Thorsos, Cowhey did not feel nurtured by her father, but autism wasn’t the only source of difficulty; alcoholism emotionally affected her psyche and may have prepared her for a future marriage with another alcoholic.

4. **Family shapes attitudes about disability**
The way one’s family understands autism can influence the way girls and women perceive their own disability (Baron-Cohen; Hacking; Hartmann; Plumb). Dawn Prince-Hughes, Deborah Thorsos, and Sharon Cowhey describe ways in which family shaped their attitudes about themselves.

Prince-Hughes has a particularly tender memory of her father attempting to comfort her during hard times at the beginning of adolescence. She remembers “he was trying hard to help me but had to admit that he and my mother had considered finding a hospital for me” (Prince-Hughes, p. 51). Her parents’ fears reinforced her own anxiety about her potential to care for herself in the future.

My parents tried to come to check on me as best they could and bring me things to make my life easier, but I was losing contact with them, moving away from them and into nothingness. I was ashamed that I couldn’t function, and sometimes I avoided them when I knew they were coming. (Prince-Hughes, p. 64)

Her inability to care for herself was a source of insecurity for her and it seems her parents’ low assessment of her life skills reinforced this attitude. Dawn’s parents were concerned about her when she was still a child, but without a diagnosis, Dawn’s issues must have seemed mysterious and unusual. Her parent’s early concern for her future enhanced her own doubts about her ability to care for herself as an adult.

Thorsos worried about her future in terms of becoming a financial burden to her family.

Without a job or any government funds I wouldn’t be able to afford rent on my own. I didn’t want to depend on my parents for rent money or want
my mother and Tom or Bob and Jen to be forced to take me into their homes and become a burden to them if I couldn't make money (Thorsos, p. 186).

Thorsos was driven to find a job and earn money, rather than exploring her interests. In this case, Thorsos is afraid that her family will perceive her in a negative light if she cannot contribute financially. In her youth and adolescence, Thorsos was afraid of becoming a burden to her family; in adulthood; she found work in a cafeteria, even though she was overeducated for that position. The fear of becoming a burden to her family appears to have played a significant role in her transition to adulthood.

Sharon Cowhey also sees autism in ways that are informed by her family's needs and opinions.

I am sure my family has been affected by me in more ways than one. But because I cannot go back in life, I do have some regrets, especially on how I did not hug my mother or comfort my sister Angel’s two children when they were little. If I could be just a little normal I would have been a better daughter to my parents (Cowhey, p. 94).

Cowhey's regrets demonstrate the connection between autism and the social conventions that govern family relationships and responsibilities. In this way, Cowhey reveals how her self-image is informed by the role autism plays within the context of the family unit. Autism does not exist in a vacuum; in other words, it becomes
a limitation when the social environment conflicts with the neurology of individuals with autism.

In this section, Dawn Prince-Hughes, Deborah Thorsos, and Sharon Cowhey consider how family attitudes influenced the ways they viewed themselves throughout the process of development. Dawn’s parents exacerbated her own concerns about her ability to survive as an adult, Deborah’s concern about becoming a burden to her family lead her to take a job far beneath her education, and Sharon’s family bolstered the idea that her disability was an obstacle to fulfilling traditional family roles and obligations.

5. **Family as a conduit to formal systems of support**

Family plays an integral role in the developmental process of women with ASD in direct ways and also as a catalyst for connecting to more formal networks of support (Meadan, Halle, & Ebata; Renty & Roeyers). This was true for Deborah Thorsos, Ericka Hammerschmidt, and Dawn Prince-Hughes.

Deborah Thorsos elaborates on how her family directly provided her with emotional support and also enabled her to make contact with public programs designed for people with disabilities: “They want to help me as much as possible and looked into a highly rated vocational and residential program, community services for autistic adults and children” (Thorsos, p. 189). Thorsos seems to benefit from her family’s supportive roles throughout her life which facilitated a successful transition through childhood, adolescence, and adulthood.

Erika Hammerschmidt credits her parents with providing emotional support throughout the developmental phases of her life. “Much of their help was simply
in trying to understand my differences. From the age of four, I had a psychiatrist; from the age of ten or eleven, I went with my parents to meetings of the Tourette Syndrome Association” (Hammerschmidt, p. 26). Beginning at an early age, Ericka’s parents sought to support her becoming active in support groups for autism and Tourette’s. Hammerschmidt’s parents appear to have set an early precedent for interacting with others who share a common disability. As Hammerschmidt grew older, she continued to reach out to the autism community for friendship and emotional support.

Dawn Prince Hughes felt supported by her parents, but they were uncertain about how best to help her because she was not diagnosed with autism until adulthood. Although her parents did not know she had autism, they were aware that Prince-Hughes was gay and they were very supportive and proactive in response. Her parents made an effort to connect Prince-Hughes with a support group run by members of the gay and lesbian communities. “I think the other people involved cared about me and wanted to be supportive, even if at times they didn't understand me. I know they worried about my drinking as well” (Prince-Hughes, p. 59).

Based on her experiences coming out, had the Prince family known about her autism, they probably would have helped her reach out to other formal systems of support for people with autism. The early support of her parents enabled her to embrace her sexuality from an early age, so it seems logical that they would have supported Prince-Hughes with her autism needs in a similar fashion.

Dawn Prince-Hughes, Ericka Hammerschmidt, and Deborah Thorsos were born in different time periods, but they shared a common experience of having supportive families that helped them reach out to broader systems of support. At the
same time, a supportive family could not offset the difficulties of being undiagnosed until adulthood and the tumultuous adolescence that left Prince-Hughes homeless and addicted to alcohol. Family is important, but it is not the only factor that affects adolescent girls with autism transitioning into women.

6. **Participation in the spiritual life of the family**

   Families that include girls with ASD in spiritual life and religious practice provide opportunities for social integration and generate positive feelings of self-worth (Clancy; Vogel, Polloway, & Smith). In this section, Grandin, Thorsos, Cowhey, and Ronan reflect on their adolescent experiences with organized religion. Grandin and Thorsos had positive experiences with religious institutions that provided opportunities for socialization and participation.

   Temple Grandin was fully involved in the religious life of her family and community, just as she was included in the other activities of daily life in her household. Grandin attributes much of her success to her mother and other family members who essentially provided her with many opportunities to practice typical social interaction.

   I had a proper religious upbringing with prayers every night, church on Sunday, and Sunday school every week. I was raised in the Episcopal Church. . . To my mind, all methods and demonstrations of religious ceremony were all equally valid, and I still hold this belief today (Grandin, p. 222).

   Grandin’s tolerant attitude toward religion may derive, in part, from positive feelings she experienced from being included in religious practice. Additionally,
Grandin’s religious observance seems to be consistent from childhood, through adolescence, and into adulthood.

Although Grandin is Episcopalian and Thorsos identifies as an Ashkenazi Jew, they were both included in the religious customs of their families. Their inclusion in other aspects of family life seems consistent with their participation in religious observance.

In an age before children with disabilities were regularly integrated into schools or other civic domains, Deborah Thorsos was fortunate that her parents advocated for her chance to attend a Jewish day camp in Forest Hills from 1966 until 1967.

My parents felt that since I got along well in the classroom and with typical children in my neighborhood that a summer program with regular children would work out fine for me. . . There were all sorts of activities, arts and crafts, swimming in the pool with group lessons, drama, and weekly cookouts at the Valley Stream Park just outside of Queens in Long Island. I got along with most of the kids, except for a few of the girls who used to tease me a lot. I liked the idea of being with typically developing children, even with some teasing going on. I adjusted to that. I’ve learned to ignore others who made fun of me (Thorsos, p. 39).

In spite of some teasing, Thorsos was thankful for the chance to interact with typically developing peers. The variety of scheduled activities at the day camp gave Thorsos a structured environment in which she could practice the vital skills of social
interaction and conduct. Without the support of her parents, Thorsos would not have had this important opportunity. The combination of family support coupled with participation in religious life benefitted Thorsos and Grandin as the journeyed from childhood and made productive transitions into womanhood.

7. **Exclusion and abuse in religious life**

Families that exclude girls with ASD from participation in religious rites and rituals have the potential to negatively impact their developing self-esteem and sense of value (Pargament & Raiya; Webb-Mitchell). This was the case for Cowhey and Ronan who became disenfranchised by their exclusion and treatment in the Catholic Church.

Cowhey attended Catholic school until she was a junior in high school when she dropped out because she was being physically reprimanded by teachers.

My parents never knew that the nuns would hit the kids, I would never tell them not even about my other thoughts. Mom and Dad never knew anything that I was going through and I am sure at the time they wouldn't have understood if they did (Cowhey, p. 17).

Cowhey’s situation again demonstrates the convergence of two traditional networks of social support, family and religion, in a way that detracted from Sharon Cowhey’s passage into adulthood. Cowhey may have been negatively impacted by the abuse she suffered at school and also the distance in her relationship with her parents. Had her parents been more in tune with her treatment in parochial school, she may have received her high school diploma. This example demonstrates weaknesses in the overall support network surrounding Sharon Cowhey.
Therese Ronan was not fully included in the religious life of her Catholic family. Ronan was consistently restricted from traditional participation in Catholic rituals starting when she was a girl and into adulthood.

My family didn't want me to receive my First Holy Communion in a group, because I have slow motor skills. But I was hoping that I could still dress up like a bride with a veil and walk down the aisle like my cousin Marie at her First Holy Communion. Nevertheless, I wasn't allowed to. I had to settle for a dress without a veil. I don't know why. I don't know if they knew I wanted one (Ronan, p. 32).

This early restriction from an important rite of passage in the Catholic Church set a precedent for the future. Therese was deeply offended that she was not named godmother to her nephew, a high honor in the Catholic tradition.

To this very day, I feel that I would have been just as good a godmother to the little guy. I helped to baptize him. Nevertheless, I still had no choice but to play second fiddle to his mother's sister.

For the longest time, I felt that my sister-in-law was deliberately not fair and overlooked autistic me for her so-called normal sister. Now I know that if something had ever happened to them, I would be just as able to teach him the Catholic faith as her normal sister would be (Ronan, p. 95).

This last passage by Therese Ronan exemplifies the ways in which traditional systems of social support, family and religion, become entwined in a system
that excludes and belittles women with ASD. This example again demonstrates a pattern of exclusion that Therese Ronan experienced in girlhood, when she was kept from the mainstream First Communion ceremony, and continuing into adulthood when she was denied the role of godmother.

This section shows how religious practice is inextricably tied up with family life and perceptions of disability. Grandin and Thorsos routinely recall supportive family structures that extend into the realms of religious participation. On the other hand, Cowhey and Ronan often cite negative interactions with family members that overlap with the rituals and duties of a practicing Catholic woman.

8. **Struggling with friendship**

Girls and women with ASD often report difficulties making and maintaining friendships (APA; Chamberlain, Kasari, & Rotheram-Fuller; Davidson; Jones & Meldal; Laugeson et al.). Deborah Thorsos recognized her social limitations from an early age, but found acceptance with her siblings whom she relied on to socialize throughout her childhood. “Since I wasn’t able to socialize and make friends on my own, I was dependent on my siblings for company.” (Thorsos, p. 13)

The social support her siblings provided during childhood did not offset the difficulties that came with the expanding social terrain of adolescence. Adolescence highlighted Thorsos’ social shortcomings because it became obvious that her peers developed faster than she did. “As I entered adolescence it had become more difficult to make friends, since my autism and a short attention span made it harder to keep up with the maturing of my peers with their increasingly complex socialization” (Thorsos, p. 81).
Thorsos describes how the characteristics of autism, a developmental disability, became more pronounced as she began adolescence. The increasingly complex nature of peer interactions and relationships became a barrier that distressed Thorsos and affected her self-image: “I was aware that I wasn't as social as many of the other teenagers that I knew. I want to become more outgoing. I had difficulty initiating conversation and participating in discussions. I lack spontaneity. Any progress that I made was very slow” (Thorsos, p. 88).

Contrary to many stereotypes of autism, Thorsos was not oblivious or unaware of the increasing social demands brought on by adolescence. Rather, her knowledge of the gaps between Thorsos and her peers was a source of insecurity that undermined her self-esteem.

Unlike Deborah Thorsos, Sharon Cowhey could not rely on her siblings to provide and support a social life. Starting in childhood, Sharon Cowhey struggled to maintain friendships, this trend continued into adulthood. “Friendship never lasted too long for me”, Cowhey admits (p. 19). In the rare instances when Cowhey managed to form friendships, they were short-lived: “For me socializing is out of my league. Freaky normal is the name I give to most of the people I meet” (Cowhey, p. 56).

Without supportive siblings to aid in building social skills, Cowhey had less of a foundation to later build deeper and more meaningful friendships in adolescence and adulthood. Cowhey felt alienated from those she calls “freaky normal” people who demonstrate social fluency and have no difficulty making friends.
Erika Hammerschmidt wanted to form friendships, but had difficulty due to some of the sensory differences associated with autism. Even though Hammerschmidt craved the company of others, she struggled to deal with the strain that interpersonal relations put on her sensory systems.

I would become sensory-defensive. Loud noises, bright lights and strong smells raised my panic to unbearable levels. Although I didn't want to be alone, I couldn't stand being touched, or even having other people close to me. It felt like an invasion, like an attack. Sometimes my skin became so sensitive that physical contact was painful (Hammerschmidt, p. 47).

Hammerschmidt emotionally wanted to connect with others and form friendships, but the physical limitations of her neurology limits her ability to engage in typical social interactions. Hammerschmidt feels that her early sensory defensiveness limited her capacity to make friends during childhood. “Such friends were merciful exceptions to the general rule that I fit in with nobody. I am grateful to them and always will be; without their friendship, my only enjoyable interaction would have been with close family members and a few teachers” (Hammerschmidt, p. 128). Hammerschmidt highlights the point that Thorsos raised, that is, a concern about relying too heavily on family for social stimulation. Although she did not have many friends, Hammerschmidt had the benefit of forming some early friends and peers.

Lianne Willey did not realize that it was autism that made it difficult for her to grasp the unwritten nuances of social life because she did not receive a diagnosis until adulthood. Willey moved through childhood and adolescence without an autism
diagnosis, but she struggled to master abstract social rules that came with adulthood. Willey wrestled with the independence that came with college life, in contrast to the comfort and ease of her high school friends whom she had known since childhood.

I had no way of knowing that AS left me without an intrinsic awareness of what it means to make and keep friends, to fit in and mold, to work cooperatively and effectively with others. Had no way of knowing college students would be so cruel to those who did not fit in the circle of their normal. But as the first semester in college moved on, I seemed to be left behind. I noticed groups forming and all of them without me (Willey, p. 42).

Without the support of her family and community where she was raised, Willey’s social limitations became glaringly obvious. Before she began college, she could rely on a network of friends to overtly tell her what was socially acceptable, but the social environment of the university exposed her social shortcomings that are familiar to others with autism.

In this section, several of the women express frustration with their abilities to initiate and maintain friendships. Deborah Thorsos describes relying on her siblings to provide her with a social life she could not establish on her own. In a similar sense, Lianne Willey benefitted from a supportive neighborhood and childhood friends to guide her at the beginning of her social life. However, Willey’s deficits became apparent when she ventured outside the comfort of her hometown to attend a distant college. Sharon Cowhey felt alienated and distant from neurotypical people beginning at an early age; her term “freaky normal” speaks to this deep discomfort and confusion surrounding
mainstream, neurotypical social behavior. Erika Hammerschmidt was aware of her social limitations beginning in childhood, she was familiar with the overwhelming feelings that resulted from having atypical sensory reactions, and perhaps this early awareness empowered her to build her skill set and diminish sensory overload.

9. **Developing friendships**

Women with ASD report that making friends became easier as they grew older. Ronan and Hammerschmidt expanded their circle of friends in high school by connecting with other students who had disabilities and shared similar interests. Hammerschmidt had the added resource that Internet communities of others with ASD provided and which became an integral part of building a wide network of friends during college.

Therese Ronan utilized her segregated classroom to meet other disabled adolescents and develop social networks based on their similar interests and placement in the education system.

I met several new friends in my high school special education class. I met Jolie on the second day of class. I had brought some movie magazines to school to look at in my spare time. I shared one with Jolie, and we became good friends. I also met Sherry (Ronan, p. 50).

Although they were in the same special ed. program, their common interest in celebrity magazines formed the basis of a strong friendship during adolescence.
Erika developed a friendship with a girl named Ali in high school that also grew out of shared interests and qualities. Both teenage girls enjoyed creating alternate worlds complete with distinct societies and social systems and they enjoyed co-creating and interacting in these imaginary worlds. Like Erika, Ali had been diagnosed with Asperger’s Syndrome, although Ali eventually identified with another diagnosis.

What's important is that she's doing well, has a promising future and is still one of my best friends. She ended up going to the same college I went to. Through her, I've met Marie, my other kindred spirit. In some ways, she may be even more like me (Hammerschmidt, p. 132).

As Hammerschmidt grew older, she continued to connect with others on the Autism Spectrum. The internet became an instrumental method to form friends based on a shared identity and interests. Hammerschmidt’s early connection to others on the autism spectrum appears to have set the stage for an even wider network of friends in adulthood.

Hammerschmidt praises her community of friends on the autism spectrum for their support and fellowship. Hammerschmidt’s comrades in autism further the perspective of not being alone and isolated from each other or the neurotypical human experience.

I'm deeply grateful to have friends who have gone through some of the same difficulties I have: learning the foreign language of human life and teaching others the language of ourselves. My friends and I have come a long way, and with each other’s help and the help of
many other people, we’ve finally made Earth a place that can feel like home to us (Hammerschmidt, p. 134).

Hammerschmidt’s comment above extends beyond the realm of colloquial friendship because she is using the term friends to describe a community of people with autism. Hammerschmidt speaks on behalf of her peers and elevates her personal story to level of political representation.

Whereas Hammerschmidt’s social skills developed as she transitioned into adolescence, Thorsos is proud of the transition she made from adolescence into adulthood. In adulthood, Thorsos no longer feels isolated because of her supportive social network of friends.

Unlike my early adolescent days when I didn't have a good network of friends outside my special school, I had established circles of friends here so I no longer felt isolated. I had the opportunity to show my folks actual proof of how I had matured over the years (Thorsos, p. 283).

Thorsos points to her circle of friends as a source of self-esteem and personal growth because she struggled with friendship since childhood. Thorsos explains she once had to rely on her family to provide a social environment in childhood, but in contrast, she is excited to demonstrate the vast circle of friends she made in adulthood, without the help of her family.

Ronan, Hammerschmidt, and Thorsos agree that making and maintaining friendships became easier as the moved toward adulthood. Connecting with other people with disabilities proved to be an ample source of friends and support. For Ronan,
special education classrooms and mental health support groups helped to counter some of the negative messages she received from her family about her status. Rather than internalizing messages that invalidated her status within the family, like their belief that she couldn’t be a godmother or wife, Ronan recognized the social stigma that surrounded people with disabilities. Hammerschmidt successfully used the Internet to build a wide circle of friends in college that satisfied her need for a social life. Further, Erika met her future husband though her network of friends and stayed in touch with many of these friends after she graduated from college. Thorsos also recognized the potential for a shared disability identity to provide greater opportunities for relationships, she also bonded with her future husband based on shared experiences of disability.

This section explores the impact that families, religious affiliation, and friends have on the developmental processes of girls becoming women with autism. These social networks had the potential to either enrich or detract from the lives of these women.
V. DISCUSSION OF FINDINGS

A. Further Analysis and Discussion

This section synthesizes the results of my research in relation to the existing state of knowledge pertaining to girls with autism becoming women. In particular my research sheds light on the experiences of baby boomer women with ASD because six out of seven authors were born during that era. Baby boomer women with ASD were born soon after the term autism was coined. At that time in history, ideologies about race and disability were put into practice through institutional segregation. Segregation was detrimental to the emotional, social, and academic development of girls with ASD. Baby boomer girls who did not have an ASD diagnosis in childhood still suffered from discrimination, stigma, and social isolation. Although the political climate has shifted significantly since the baby boom, girls and women with ASD still face many of the same issues, including unemployment and poverty. Family support is critical to the success of women with ASD in every generation.

This baby boomer generation of American women with ASD grew up in an era before widespread knowledge about autism (Baron-Cohen; Hacking). This lack of information was exacerbated by the institutional segregation of students with disabilities. Civil rights and access to education were not ensured for baby boomer girls with ASD like Deborah Thorsos, Temple Grandin, Therese Ronan, Sharon Cowhey, Dawn Prince-Hughes, and Lianne Willey. Therese Ronan’s two year exclusion from school represents the experience of 1.75 million disabled students before 1970 who did not have the right to a free and public education (TASH,). These extended absences impeded education and also deprived girls with ASD of critical time spent with peers.
and opportunities for social development (Goodwin, & Staples). The underlying ideologies that justified segregation threatened the social status and self-image of baby boomer girls with autism (Harrower, & Dunlap; Kasari, et al.). Deborah Thorsos illustrates how internalizing Ideologies of ability and able-bodiedness gave rise to feelings of Inferiority and difference (Dubbin; Gabriels; McRuer; Siebers; Taylor and Seltzer; TASH).

Dawn Prince Hughes, Lianne Willey, and Sharon Cowhey avoided segregated education because they were not yet diagnosed with autism during their school years. They may have avoided segregation, but still struggled to form friendships and succeed in school. In an emerging phenomenon, parents of children with ASD often recognize their own autistic traits after their child receives diagnosis. Lianne Willey’s autobiography highlights this process. The autobiography of GRASP founder Michael John Carly also contains a similar description. The growing number of adults receiving ASD diagnoses prompted by the diagnosis of a biological child supports evidence of a genetic link to autism (APA; Hu-Lince et al.; Jamain et al.; Muhle, Trentacoste & Rapin). Furthermore, delayed diagnosis can be very disruptive to girls with ASD transitioning toward womanhood. Prince-Hughes in particular demonstrates how undiagnosed girls and women are susceptible to problems with depression, anxiety, alcohol, relationships, and work (Wylie, Beardon, & Heath). The acquisition of an ASD diagnosis provides more than a label or means to receive services, it opens up avenues to a disability identity that affirms positive meanings of disability, pride, and connection to a wider community (Lasgaard et al.; Portway and Johnson). An ASD diagnosis allows processes of ‘coming home’, ‘coming to feel we belong’, ‘coming together’, and ‘coming
out' to begin (Gill). Regardless of diagnosis, baby boomer girls with ASD faced stigma and discrimination that negatively affected developing concepts of self and society. (Portway & Johnson).

Like the ideologies that structure educational environments, family attitudes also shaped the ways girls and women with ASD conceptualize disability and identity (Baron-Cohen; Hacking; Hartmann; Plumb). Along with an early diagnosis, financial and emotional support from their families helped Grandin and Thorsos graduate from high school and transition to college. The efficacy of early diagnosis and family support are magnified in light of the fact that baby boomer women with ASD grew up during an era of educational segregation (Portway & Johnson; Lasgaard et al.).

The women featured in my dissertation underscore a common issue among women with ASD who have difficulty interpreting the logic and social cues involved in dating and romantic relationships (Gougeon; Mehzabin & Stokes; Tissot). This confusion over romance is compounded by social attitudes, family values, and educational policies that affect the sexual development of girls with ASD (Atwood; Van Pelt). Baby boomer girls with ASD were routinely separated from their peers by segregation and prejudice; therefore, they did not have equal access to sociosexual knowledge. Sociosexual knowledge refers to the information and meaning that children and adolescents learn from interacting with peers. However, baby boomer girls with ASD did not have the same social opportunities as their typically developing peers, so they may not have gained the same type of sociosexual knowledge (Atwood; Griffiths; Henault; Hingsburger). In addition, baby boomer women with autism confronted processes of desexualization and infantilization that limited their sexual self-expression
(Garland Thomson; Gill; Sandahl,). Like other disabled women, Therese Ronan endured efforts by her family and the state to control her sexuality and reproduction.

The socio-political system of segregation began to shift with the landmark Supreme Court ruling in Brown vs. the Board of Education (1954), and civil rights legislation, such as the passage of the Rehabilitation Act of 1973 and IDEA in 1975. The dismantling of segregation and shifting ideologies presented new possibilities for the generation of American women with ASD. Generation X follows the baby boomer generation. Generation X is characterized by the acceptance of social diversity and inclusion of minorities and marginalized groups. Members of generation X are more likely to question authority, disagree with discriminatory or unfair educational policies, and place a higher value on social relationships (Isaksen; Miller).

At the time this research was conducted, there was only one autobiography written by an American woman with autism from Generation X. I am hesitant to draw any generalizations from one autobiography, but Hammerschmidt’s narrative highlights changes in the cultural climate and shifting generational values. For example, members of Generation X who have ASD benefited from the emergence of the Internet. Online communities and forums allow individuals with ASD to interact without the distraction of facial expressions, body gestures, voice modulation, and other forms of nonverbal communication (Robertson). The proliferation of cyber networks of people with autism offers a sense of community and belonging that was not yet available to baby boomer women. In addition, the Internet provides people with autism with more avenues toward self-expression, political mobilization, and advocacy. The role of online social networks in the lives of women with ASD from Generation X is significant because communal
attachment and a positive sense of disability identity can improve self-esteem and counter negative ideologies (Dunn and Burcaw). Although political ideologies and social systems have changed due to legislation and the disability rights movement, unemployment is still an ongoing issue for women with ASD (Gabriels; Taylor and Seltzer, 2010). Hammerschmidt’s narrative reflects how vocational rehabilitation, job training, and prejudice among employers are issues that continue to keep women with ASD from successful employment.

Effective coping techniques are vital to girls with ASD as they transition toward womanhood. My research reveals two unique strategies that helped girls with ASD move toward womanhood. Temple Grandin describes how visual symbols allowed her to feel more comfortable making important transitions in life. By visualizing various doors, Grandin coped with the stress of the unknown. Touchstone perspective is another coping strategy that enabled Hammerschmidt, Prince-Hughes, and Grandin to better comprehend the social norms and practices of neurotypical society by first understanding other constellations of behavior and meaning (alien civilizations, cattle in a stockyard, and captive mountain gorillas).

In closing, the findings reported and discussed here are meant to help fill the gaps in the state of knowledge pertaining to how girls with autism move toward womanhood. Despite their generational differences, the unyielding support of family, financial means, and a diagnosis in childhood appears to help American girls with autism transition toward adulthood.
B. **Limitations**

These authors represent an intelligent, extremely articulate, literate, and communicative cohort of women with ASD at one end of the autism spectrum. One major concern “is the representativeness of these accounts of the experience of the higher functioning group from which they are drawn, and second, of the wider autistic population, the majority of whom would find it difficult or impossible to communicate” (O’Neil and Jones, p. 286). Another major issue is the overall lack of cultural diversity reflected by this list of authors. None of the authors has an ethnic background from Africa, Latin America, or Southeast Asia. Deborah Thorsos represents the most ethnic diversity in this sample because she is Jewish. These ethical concerns are important because this cohort does not reflect the entire spectrum of experience, but does represent the lives of seven American women with ASD. Ian Hacking, however, argues that autobiographies are introducing new phenomena that require new language and discourse. In Autistic Autobiography (2009), Hacking argues that all these narrative texts represent perceptual and sensory experiences that we have yet to articulate.

Another limitation of this research is the focus on published autobiographies of autism. This is problematic because of the “winnowing traditionally done by the gatekeepers of publishing” (Couser, p. 12). Only autobiographies fitting with the publisher’s aesthetic preferences make the cut, so autobiography that does not correspond to cultural scripts of autism may be overlooked.

Despite these limitations, the results still speak to the experiences of seven women who are representative of a small group of women with autism who have the
cognitive abilities and drive to express their life stories in a narrative format. These autobiographies may not reflect the entire autism population, but illustrate some of the key systems of socialization that affect the lives of these seven literate and skilled women.

C. **Future Research**

Education, career aspirations, sexuality, and social networks are four major themes illuminated by my research. However, there were many compelling ideas and examples that are not featured here. The direction and scope of this academic process gravitated toward the overarching social systems that affect the development of these particular women as they grew. Psychological factors, like self-esteem provide another intriguing avenue to explore in future work. Utilizing other qualitative research techniques, like open interviews, could also supplement the current data in the future.

The phenomenon of late or delayed ASD diagnosis is another rich opportunity for future research. Like Bracher points out, there is very little existing research that examines this phenomenon especially in relation to identity formation before diagnosis. Pre-diagnostic identity formation relates to many disabilities beyond ASD so this type of future research could have wide reaching implications for the field of disability studies.

There is a lack of research that focuses on an aging population of women with ASD, an issue that is becoming more apparent as the first generation of women diagnosed with ASD is getting older. The needs and experiences of older women with ASD are not yet adequately understood. In addition to older women with ASD, future research could attempt to uncover more personal narratives of ASD from more diverse sources. The state of knowledge pertaining to minority women with ASD remains
underdeveloped. Another avenue toward future research is a limited, but growing literature that looks at girls with ASD transitioning toward adulthood, while also transitioning toward another gender identity (De Vries, et al.; Jacobs, et al.).

D. **Conclusion**

The autobiographies featured in my dissertation constitute the first wave of cultural self-representations by women with ASD. As such, six out of seven narratives speak to the experiences of the baby boomer generation. Women with ASD from Generation X and Millenial women may not share the same experiences of their predecessors, but a deeper understanding of these first accounts provides a historical yard stick to measure cultural change. My research marks an effort to elaborate the social forces and personal variables that shaped these original autobiographies by women with ASD.
CITED LITERATURE


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Areas of Concentration: Existential Sociology, Civil Rights, Advocacy
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2008
Developed syllabus and overall course structure, utilized a variety of technical equipment and computer applications, and administered all grades.
Teacher’s Assistant to Professors David Mitchell and Sharon Snyder in “Disability in American Film” 2007
Collaborated on curriculum and exam development, coordinated transportation and insured accessibility for disabled professor and students, met with students upon request, administered midterm exam, and graded all written work, including final exam papers.

RELATED EXPERIENCE

Autism Home Support Services Northbrook, IL

Applied Behavior Analysis Therapist 2009–2010

Implemented applied behavior methods to meet the therapeutic needs of children with autism, collaborated with team members for ongoing assessment, analyzed data derived from therapy sessions, and consulted with parents to provide support in the home and community.

Jewish Child and Family Services, Northbrook, IL

Long-term Substitute Teacher 2008

Lead group activities, achieved IEP goals, and delegated team responsibilities with other teachers in a self-contained, early childhood classroom for students with Autism Spectrum Disorders (ASD).

University of Illinois, Chicago, IL

Research Assistant 2002–2007

Supported Professors Snyder and Mitchell in their compilation of the Encyclopedia of Disability (Sage, 2005), investigated property rights and obtained permission to use featured art, performed administrative tasks, prepared course materials, assisted students with academic and accessibility issues.

Keshet, Northbrook, IL

Site Director 2003

Supervised campers with disabilities and associated staff, taught integration techniques and disability awareness, strategized with parents and professionals to implement
campers’ goals, coordinated overall integration of disabled children into typical camp group.

PUBLICATIONS AND PAPERS

“Autism”

“Nano-Politics, Geopolitics, the African Diaspora, and Disability Hegemony: Gilroy’s Theoretical Applications to Black Magazines”.
Paper presented to Society for Disability Studies Conference, Bethesda Maryland 2003

“Ethics of Disability Research”
Paper presented to American Society for Bioethics and Humanities, Chicago, IL 2003

CERTIFICATIONS
Illinois Leadership Education in Neurodevelopmental Disabilities LEND Trainee, Chicago, IL
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