

Exploring the Adulthood Transition through the Eyes of Adults Living with Autism
Spectrum Disorder: A Phenomenological Study of Their Expectations, Perceptions,
Experiences, and Goals regarding Adulthood

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Abstract

Autism spectrum disorder (ASD) is a prevalent developmental disorder that makes daily, independent living difficult for many people around the world. Depending on the severity of ASD symptoms, individuals living with ASD rely on various supports to develop everyday skills. However, many of these supports fade away as these individuals transition out of high school into adulthood where they are introduced to an entirely new set of social systems including postsecondary institutions, workplace environments, independent/codependent living arrangements, and mature social relationships. Four emerging adults with ASD were interviewed to gather their expectations, perceptions, experiences, and goals regarding these different domains of adulthood. The participants responded with a wide range of thoughts and emotions, some of which reflect the findings of past research and some of which demonstrate new ways to understand how people with ASD transition to adulthood.

Keywords: autism spectrum disorder, ASD, adulthood, transition

Exploring the Adulthood Transition through the Eyes of Adults Living with Autism Spectrum Disorder: A Phenomenological Study of Their Expectations, Perceptions, Experiences, and Goals regarding Adulthood

The *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013) defines autism spectrum disorder (ASD) as a neurodevelopmental disorder that causes significant impairments and limitations for everyday living. ASD symptoms are present from early childhood, and they typically persist throughout adulthood; however, affected individuals can learn to manage their symptoms and live a healthy, productive life. Social interaction and communication deficits constitute a core diagnostic criterion for ASD. Common examples of these deficits include a lack of responsiveness, minimal social reciprocity, reduced interest in others, and difficulty taking on different perspectives. Individuals living with ASD have more difficulty speaking and understanding speech than those without ASD, and their communication generally reflects the disconnection between their experiences and their emotions. Their thought patterns, behaviors, interests, and activities tend to be rigid and repetitive to such an extent that they are aversive to change. ASD is classified as a spectrum disorder because symptom manifestations vary greatly depending on the severity of the autistic condition, combined with the individual's age, developmental level, and environment.

People with ASD often experience one or more comorbid conditions such as anxiety, depression, intellectual disability, physical disorders, and hypersensitivity/hyposensitivity to various stimuli. Both children and adults with high-functioning ASD were found to have higher rates of anxiety than those with low-

functioning ASD, an intellectual disability, or no neurodevelopmental disability altogether (e.g. Gotham, Brunwasser, & Lord, 2015; Lugnegård, Hallerbäck, & Gillberg, 2011; White, Oswald, Ollendick, & Scahill, 2009). The impact of anxiety on one's life can greatly vary, but common themes include difficulty functioning at work, reduced sense of being able to live a meaningful life, and reduced enjoyment from, or avoidance of, pleasurable activities (Robertson et al., 2018). In addition, patterns of atypical sensory processing commonly found among people with ASD further disrupts their ability to manage their environment, thus producing anxious feelings of uncertainty. Sensory processing plays a significant role in attention, learning, emotional regulation, and social functioning (Chang et al., 2014), so sensory processing dysfunction may produce negative, pervasive effects in these areas of functioning. Tactile sensitivity, for example, can make personal hygiene and grooming activities much more difficult for people with ASD to tolerate (Tomchek & Dunn, 2007). The prevalence of ASD and the current state of transitional support for emerging adults with ASD provide context for some of the common outcomes found throughout literature for people with ASD as they transition to adulthood.

Prevalence of ASD

The prevalence of ASD appears to be increasing around the world. Matson and Kozlowski (2011) reviewed early studies of autism prevalence in the 1960s which reported about 4–5 diagnoses per 10,000 children. Since then, the means by which researchers measure the prevalence of ASD have become more precise, and the estimated rates have been increasing substantially. Baio et al. (2018) reviewed the findings of the Autism and Developmental Disabilities Monitoring (ADDM) Network which consists of

surveillance programs funded by the Centers for Disease Control and Prevention that estimate the number of people living with ASD across the United States. The ADDM's most current prevalence estimate is 16.8 ASD diagnoses per 1,000 eight-year-olds in the U.S.; therefore, 1 in 59 U.S. children is diagnosed with ASD which demonstrates an increase of 150% in cases diagnosed since the launch of the ADDM in 2000. The prevalence of ASD diagnoses, however, varies based on geographical area, sex, race, and ethnicity. One of the most notable distinctions is the significantly higher prevalence rate among boys, who are 4 times more likely to be identified with ASD than girls. Caucasian children were found to have higher prevalence rates of ASD compared to African-American or Hispanic children. Forty-four percent of children with ASD scored in the range of average to above average IQ (>85), 31% scored in a range less than 70 and were classified as intellectually disabled, and the remaining 25% scored in the borderline range between 71 and 85.

Several explanations for the increase in the prevalence of ASD include the expanding diagnostic and assessment criteria of ASD, inaccurate diagnoses, variations among research methodologies, environmental components, cultural factors, and society's general increase of ASD awareness. Regardless of what caused this increase, there remains a large population that has been diagnosed with ASD who require individualized training and support to lead successful lives throughout adulthood (Matson & Kozlowski, 2011).

Transitional Supports and Services for Adults with ASD

Despite the often-overwhelming symptoms that accompany people living with ASD, Wehman et al. (2014) stressed that this population has substantial untapped

potential, and the support services that are available to them should reflect this notion.

However, once individuals exit the public education system, the level of support provided to them decreases dramatically in the domains of employment, education, social development, and independent living. Both caregivers and adults with ASD described the current state of transitional supports as frustrating and underwhelming, resulting in a difficult, awkward transition to adulthood (e.g. Anderson, Stephenson, & Carter, 2017; Cheak-Zamora, Teti, & First, 2015). Parents also expressed a concern that supports were more difficult to obtain for higher-functioning individuals with ASD because their symptoms were less intrusive (e.g. Anderson et al., 2017; Wehman et al., 2014).

Furthermore, adults with ASD who continue to live with their parents may be at risk of losing their strongest support to old age, and there is a concern that older parents are not fit to properly support their children (Howlin, Moss, Savage, & Rutter, 2013).

Zeedyk, Tipton, and Blacher (2016) reviewed 12 studies about the pathway to college for high-functioning youth with ASD and the practical, educational, and social supports that have been established. They concluded that these supports are lacking and the research on their success is lacking as well. Jackson, Hart, Brown, and Volkmar (2018) found that college students with ASD use about 2–3 different support services that are designed to facilitate learning in school, but 30% of their sample expressed a desire for their institution to provide more and better support services. According to Anderson, McDonald, Edsall, Smith, and Taylor (2016), high school students would appreciate transitional supports that focus on daily living skills. Moreover, educators should prepare these individuals for the uncertainties of adulthood and the fact that the transition can be a long process.

Transition planning is a process by which students demonstrate self-determination and control in their lives in meaningful ways by making choices about their future, reviewing these choices, experiencing the consequences, and making new choices. Part of this process involves developing and committing to goals regarding post high school outcomes, including postsecondary school and vocation (Agran & Hughes, 2008). Wei, Wagner, Hudson, Yu, and Javitz (2016) utilized the NLTS2 and found that both participation in transition planning meetings and goal-setting were associated with higher levels of postsecondary enrollment among youth with ASD. However, Wagner, Newman, Cameto, Levine, and Marder (2007) discovered that less than a quarter of their sample of youth with ASD included higher education goals in their transition plans even though 84.4% expected to attend postsecondary school.

Quality of Life for Adults with ASD

Quality of life, as defined by the World Health Organization (n.d.), refers to people's "perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (para. 2). Studies show that both children and adolescents living with ASD have a lower quality of life compared to neurotypical children and adolescents (Kamp-Becker et al., 2011; Potvin, Snider, Prelock, Wood-Dauphinee, & Kehayia, 2015). Eaves and Ho (2008) conducted a study in which parents reported on the quality of life for their young adults with ASD. Parents collectively expressed a wealth of unmet needs for their adult children in the domains of social programs/social outlets, friends, work, and education. Additionally, Anderson et al. (2017) conducted a scoping review of 17 qualitative studies on the relationship between emerging adults with ASD and different

domains of adulthood. Stakeholders described a theme of poor person-environment fit in which there was a disconnection between the developmental needs of adults with ASD and their environments, including the workplace, postsecondary schools, and community service systems.

In Germany, Roy and Dillo (2018) administered a quality of life questionnaire to 32 adults with ASD (22–50 years old) to measure if their perceived quality of life differs from their neurotypical counterparts. The researchers discovered highly significant differences between the two groups; the ASD group exhibited a lower quality of life in the domains of vitality, bodily pain, general health perception, physical role functioning, emotional role functioning, social role functioning, and mental health. Reduced functioning in some of these domains may be directly related or attributable to ASD symptoms. For example, individuals with ASD may perceive more instances of bodily pain due to dysfunctional processing of certain stimuli. However, perceptions of reduced functioning in domains like physical, emotional, and social role functioning may be more generally impacted by the perceived discrepancies among one's expectations, perceptions, experiences, and goals regarding adulthood.

Expectations and Perceptions of Adulthood

Holmes, Kirby, Strassberg, and Himle (2018) measured the impact of parents' expectations of adulthood outcomes for their sons and daughters with ASD. A sample of 298 parents rated the likelihood of 25 adulthood outcomes across various domains such as vocation, postsecondary education, independent living, citizenship, and financial independence. Below-average IQ and more severe ASD symptoms predicted lower expectations among parents for their youth. Also, gender differences were noted as lower

expectations were more likely to be associated with parents of daughters. The parents' expectations predicted their level of engagement in transition-preparation activities, such as coordinating volunteer opportunities or providing household chores, for their emerging adults. Other studies have found parent expectations to be significant predictors of academic achievement (Yamamoto & Holloway, 2010) and gainful employment (Doren, Gau, & Lindstrom, 2012). Holmes et al. (2018) suggested that when parents have higher expectations of their youth, the parents will arrange for transitional supports that are more designed for these desirable outcomes in adulthood.

Anderson et al. (2016) performed a thematic analysis among the expectations of 31 high school students with ASD regarding higher education, employment, friendships, and living arrangements. Approximately 90% of their sample expected to attend more schooling after high school. Sixty-two percent expected to work after high school, and the remaining participants were not sure what to expect regarding employment; however, no students expected not to work after high school. These students characterized their ideal professions as stress-free and enjoyable, differentiating them from unspecialized, low paying, part-time jobs. About 70% expected to maintain their current friendships or develop new friendships after high school. There were only two individuals who did not expect to have friends after high school. The sample's expectations regarding living arrangements were evenly divided into either continuing to reside with parents or leaving the parental home to live independently or semi-independently. Participants acknowledged that these domains are interdependent, and many believed that college was a catalyst for success in areas of employment, independent living, and social connectedness.

Cheak-Zamora et al. (2015) discovered a divergence between the expectations of young adults with ASD and their caregivers. Young adults with ASD emphasized the value of social relationships and desired more opportunities to build friendships. However, caregivers authorized caution as their young adults approached romantic relationships, and caregivers were wary of society's generally negative perceptions of people living with ASD. Most caregivers wanted their youth to go to college, but not all youth expressed the same desire. Youth expressed insecurities about their ability to succeed at a college level, and some were unsure of how to negotiate their interests considering their caregivers' expectations. Therefore, they shared a general reluctance to express their thoughts and fears regarding employment and adulthood to their caregivers, especially when the caregivers' expectations were made known. Youth aspired to obtain interesting, high quality jobs, such as computer programming, but employers would often underestimate the youth's ability and delegate mundane, cleaning jobs to these individuals.

Additionally, Anderson and colleagues (2016) described the ways in which their participants defined adulthood. All but one participant cited individualistic criteria such as financial independence and independent living skills as important in their definitions. Independent household skills (e.g. laundry, washing dishes, making meals) were linked to ideas of personal survival and taking care of oneself. Two thirds of the sample described character qualities such as responsibility and maturity in their definitions. Lastly, about 40% linked different chronological ages with typical developmental events in adulthood such as buying a house and being independent.

Cheak-Zamora et al. (2015) gathered the perspectives of adolescents with ASD ranging from 15–22 years of age on the general issues and unmet needs that they have encountered prior to the adulthood transition and compared them to those of their caregivers. Overall, the young adults with ASD expressed a lack of confidence regarding their future as adults, presenting significant concerns coupled with anxious, overwhelming thoughts and emotions. Caregivers were aware of this lack of confidence, and some firmly believed that their child/client was not ready for the adult world. Many emerging adults with ASD expected their transition to be linear in trajectory (i.e. in ordered/sequenced stages), but the research shows that the trajectory is often nonlinear, and many fall in and out of employment and postsecondary school (e.g. Taylor, Henninger, & Mailick, 2015; Wei, Wagner, Hudson, Yu, & Shattuck, 2015).

Experiences of the Transition to Adulthood

Tracing the typical outcomes for adults with ASD has been a difficult task for researchers due to the heterogeneity of ASD symptoms and their impact on one's life (Howlin et al., 2013); therefore, results may not accurately represent the entire population of adults with ASD. Cheak-Zamora, Teti, and Maurer-Batjer (2018) conducted individual and group interviews with 11 young adults with ASD and had them capture their experiences of the transition to adulthood using a digital camera. When participants described the adulthood transition, they expressed thoughts and feelings of worrying, nervousness, and sadness. The entire sample reported anxious feelings regarding higher education and employment as well as other aspects of independent living, such as driving a car or using an oven. Participants also expressed difficulty in making new friends as an adult because they had fewer opportunities for social interaction compared to when they

were in high school where social interactions frequently occurred. Making new friends was described as anxiety-inducing because participants found it difficult to recognize social cues and follow social rules. Many expressed feelings of sadness, jealousy, and anger when comparing their abilities to those of their friends and family. However, they also expressed love and admiration for their friends and family, recognizing that family support has had a significant impact on their growth and development. Furthermore, animals were identified as a significant coping mechanism for the participants. Many reported developing a strong companionship with the animals which they found difficult to develop with another human.

Howlin et al. (2013) measured the social outcomes of 60 adults with ASD and average IQ, and most of their sample experienced poor social outcomes across a variety of domains throughout adulthood. Over time, their sample showed improvements in IQ assessments, language, and ASD symptomatology; however, their current social outcomes were poorer than in early adulthood. Sixty percent of this sample experienced and rated their social outcomes in adulthood as poor or very poor. Seventy-two percent of the sample did not complete any formal education after high school; 72% were either unemployed or only able to obtain a volunteer position; and 73% lived in a supported residential situation (e.g. parents' home, residential home, hospital) due to limited independent living skills. Seventy-seven percent stated that they had no specific friendships and only made limited contact with peers in group situations. Eighty-four percent never shared or only briefly shared a close, reciprocal relationship that involved personal contact and shared feelings/activities.

Transitional Pathways after Exiting High School. Studies are virtually unanimous in reporting that meaningful employment and postsecondary rates among emerging adults with ASD are low, and that the current transitional supports are not effectively connecting this population with employment or postsecondary enrollment (e.g. Farley et al., 2018; Taylor et al., 2015). Wei et al. (2015) tracked the transitional pathways of a sample of 120 emerging adults with ASD, using employment and postsecondary enrollment rates from the National Longitudinal Transition Study-2 (NLTS2), a comprehensive data set of the experiences of youth with disabilities as they transitioned from high school, at three points in time over a 6-year period following high school. In the period of up to 2 years after exiting high school, the most common outcome for these individuals involved unemployment and no enrollment in postsecondary school (34.7%). The size of this category decreased to 21.3% in the span of 2–4 years after high school, and then it increased to 30.6% in the span of 4–6 years. In addition to this finding, the researchers organized their sample into 3 transitional clusters. The largest cluster (57.4%) was primarily focused on postsecondary education, and enrollment rates within this cluster peaked during the 2–4-year period at 59.2%. The second largest cluster (29%) was continuously or increasingly disengaged in which neither employment nor enrollment was obtained, and 100% of the sample was disengaged for at least 2 years within the 6-year period following high school. The third and smallest cluster (22.4%) was primarily focused on employment. Within this cluster, employment rates peaked at 52.3% over the 6-year period, but only 4% of participants gained full-time employment. Also, many adults with ASD found it difficult to become employed within the first 2 years after high school.

Research indicates that emerging adults with ASD struggle to obtain gainful employment and postsecondary enrollment after exiting high school, and it appears to be just as difficult, if not more, to maintain employment or enrollment over time. Taylor et al. (2015) tracked the patterns of employment and postsecondary school enrollment among 73 adults with ASD and average-range IQ over three points in a 12-year period following high school. Less than one quarter of their sample (24.7%) was consistently engaged in competitive employment or postsecondary education throughout this period. None of the 15 women in this sample were classified as consistently engaged, which could be attributed to the lower expectations of the parents (Holmes et al., 2018). A cluster of their sample (42.5%) was engaged in competitive employment or postsecondary enrollment at one point in the study, but these participants also experienced at least one point during which they were not employed or enrolled in postsecondary school. Over half of those who did earn a postsecondary degree within this cluster never gained competitive employment, and none of them were employed for more than 10 hours/week. The last cluster (32.9%) never gained competitive employment or postsecondary enrollment over the course of the study, and nearly half never gained any form of supported employment. Less than 10% of the entire sample was consistently engaged in competitive employment for more than 30 hours/week, which can be starkly contrasted by the general population's rate of 90–96.2%. Even when adults with ASD successfully complete their postsecondary programs, research shows that it may not lead to employment, and it is even less likely to lead to competitive, meaningful employment related to their field of study (Taylor et al., 2015).

Employment. Farley et al. (2018) surveyed a sample of 162 adults with ASD from Utah (mean age of 35.5) regarding a variety of mid-life variables including employment, social functioning, and independent living. Using the available employment data for 153 of these individuals, 20% were found to be unemployed. Alternatively, 80% were engaged in some form of daily occupation, which took the form of day programs (33%), sheltered workshops (14%), full-time, unsupported employment (12%), part-time, unsupported employment (12%), supported employment (7%), and volunteer work (2%). Cognitive ability, however, did not appear to influence participants' employment status as both employed and unemployed populations represented the full range of cognitive ability levels. Rather, informants reported the following factors as possible reasons for limited employment outcomes: difficulty understanding abstract/novel experiences and staying on task, poor judgment of social situations and lack of interviewing skills, chronic health problems, and requiring more supervision. About 65% of participants received support from long term supports and services, and 14% had accessed vocational rehabilitation services.

Furthermore, the meaningfulness of the employment obtained by adults with ASD is questionable because these individuals work only an average of 5 hours per week (Eaves & Ho, 2008). Both parents and the individuals with ASD perceived a mismatch between the individuals' skills and the employers' work demands, describing their employment as underpaid, mundane, and unrelated to their college degrees (Anderson et al., 2017). In fact, less than half of adults with ASD who earned postsecondary degrees were working in a field relevant to their degree (Taylor et al., 2015).

Higher Education. Jackson et al. (2018) collected self-reported data from 56 postsecondary students with ASD on their academic and social experiences within college as well as their mental well-being. Nearly half of the students reported feeling slightly to very comfortable with their academic workload, and 21.4% felt slightly to very uncomfortable, with the remaining participants falling somewhere in between. Nearly 40% of participants reported having no close friends, but 50% stated that they were slightly to very satisfied with the number of friends they had. Over 75% of the sample reported feeling left out, isolated, or lacking companionship often or sometimes. The rate of loneliness correlated with the number of close friends one had and his/her satisfaction with that amount.

Over half of the sample received a comorbid psychiatric diagnosis while attending school, and the most common diagnoses were depression (35.7%), generalized anxiety disorder (33.9%), social anxiety disorder (26.8%), and attention deficit hyperactivity disorder (23.2%). The sample averaged extremely severe symptom levels of depression and anxiety as well as severe levels of stress. Nearly 75% of the sample reported some form of suicidal behavior in their lifetime, and 53.6% reported having suicidal thoughts within the past year. Suicidal behavior was significantly associated with ASD symptom severity ($r = .40$), number of friends ($r = -.31$), loneliness ($r = .36$), academic comfort ($r = -.30$), depression ($r = .56$), anxiety ($r = .40$), and stress ($r = .39$).

Independent Living. Farley et al. (2018) surveyed the participants' living arrangements, which appeared to reflect their social functioning ratings as only 9% lived in their own home or apartment. Forty-seven percent lived with their family of origin, 27% lived in a group home, 9% lived in an institution, 6% lived in a supported apartment,

and 2% lived with a professional parent, who essentially serves as a foster parent for youth with disabilities. Farley et al. (2018) also took note of the participants' method(s) of transportation, which could very well impact their ability to gain/maintain employment, attend postsecondary school, and engage in social interactions. Sixty-two percent of participants depended on family or support service staff to provide transportation while the remaining 38% traveled independently via public transit or a personal vehicle. Only 7% of participants had their own driver's license. Taylor et al. (2015) also found that adults who were consistently engaged in employment or higher education developed better independent living skills related to meal-preparation than those who were never engaged in these environments.

Social Engagement and Social Functioning. Farley et al. (2018) measured their sample's level of social engagement, and nearly two thirds were involved in at least one organized group; however, 47% of participants reported that they spend little or no time with their peers. Twenty percent spent 1–10 hours per week with their peers, 13% spent 11–40 hours with peers, and 20% spent 41 hours or more with their peers (these individuals were typically involved in community living situations or day programs). The researchers amassed social functioning ratings for their sample, and 10% were classified as very independent, 34% were fair, 41% were limited, and 5% were very limited. According to Cheak-Zamora et al. (2015), young adults with ASD are comforted when they develop relationships with other individuals with ASD.

Research Questions

Farley et al. (2018) concluded that much remains to be understood about the qualitative experience of the men and women living with ASD. They suggested that

future research on the adult population should investigate the extent to which they are satisfied with their current state of living, using methods that include the voices of adults with ASD and proxies for those who are unable to articulate their own values. The paucity of qualitative research on people with ASD and the adulthood transition led to the following research questions: What expectations and perceptions do emerging adults with ASD hold regarding adulthood, what have emerging adults experienced as they transition to adulthood, and what goals do emerging adults have for their future in adulthood? Due to the expansive nature of these research questions, a phenomenological research design provides an appropriate framework from which key cognitive representations held by emerging adults with ASD can be explored, including their expectations, perceptions, experiences, and goals regarding adulthood (Creswell & Poth, 2018). The answers to these questions will provide a glimpse of what the transition to adulthood is like for people with ASD, allowing for the development of more effective transitional supports and services.

Method

Participants

This research was approved by the university's Institutional Review Board, and informed consent was obtained from all participants in this study. Criterion sampling was used throughout November and December 2018 to recruit participants who had an ASD diagnosis, were 18 years of age or older, and had graduated from high school. The researcher partnered with two organizations that provide support services for adults with ASD in southern Ontario to forward recruitment flyers and emails to eligible clientele. Four individuals responded to the recruitment email, and all were interested in

participating in the study. All four participants had previously been diagnosed with ASD as confirmed by either the parents of the participant or the organization that referred the participant. Participants were aged from 23–29 and had graduated from the secondary school system with some variation of a high school diploma or certificate of accomplishment. The sample consisted of two males and two females, and 100% of the sample was Caucasian. All four participants were employed in some manner, and all four lived with their parents. Participation was voluntary, and no compensation was provided.

These participants will be introduced and referred to using pseudonyms. Jessica is a 23-year-old female from southern Ontario. She works one shift every other week at a bakery. She lives in her parents' home, and she spends some of her free time volunteering at a church or playing instruments. Charlie is a 23-year-old male from southern Ontario. He lives in his parents' home, and he spends most of his time volunteering at a senior living community and a mental health organization. Alison is a 29-year-old female from Ontario. She lives in her parents' home, and she is attending postsecondary school to earn her postgraduate certificate in behavioral sciences. Noah is a 23-year-old male from southern Ontario. He lives in his parents' home, and he works at a fast-food restaurant every weekend. He also spends much of his time volunteering with several different daycare centers.

Materials

A semi-structured interview guide that consisted of seven open-response items was used to evoke the participants' expectations, perceptions, experiences, and goals of adulthood (See Appendix). The items were crafted in response to themes in past research that have not been explicitly addressed by adults with ASD who have firsthand

experience in the adulthood transition. The style of this interview guide was inspired by Sites' (2008) interview guide. Open-ended questions allowed participants the freedom to provide as much information as they felt comfortable sharing. However, numerous prompts were utilized to guide participants and to mitigate any anxiety they may experience from not knowing what to share.

Procedure

Upon receiving signed informed consent forms from each participant, the researcher coordinated a time and location to interview each participant separately. Participants were encouraged to pick a preferred time and a location that made them feel comfortable, such as their own home. Two of the four interviews were conducted in-person, one was conducted over Skype, and one was conducted over the phone. The interviews lasted 30–60 minutes. A cellphone was used to record the audio from the in-person interviews, and a computer recording program was used to record the audio from the Skype and phone interviews. The interview recordings were transcribed verbatim, and the data were imported into NVivo 12 Plus to be analyzed.

Data Analysis

The data were analyzed using Robertson and colleagues' (2018) six stages of thematic analysis: familiarization with the data, initial coding, search for themes, review of themes, description of themes, and production of the results report. The researcher listened to the audio and read the transcript of each interview multiple times to immerse himself in the data. The transcripts were coded by topic, and these codes were organized and combined into themes. The researcher did not attempt to extract further meaning from the participants' responses than what was provided at a semantic level. The

participants were emailed the results section, and they verified the trustworthiness of the data.

Results

Multiple themes were found among the participants' responses, which were organized into the following categories: expectations and perceptions of adulthood, experiences in adulthood, feelings about adulthood, and goals for adulthood.

Expectations and Perceptions of Adulthood

Independence. All four participants associated adulthood with ideas and actions related to independence. For example, Alison stated:

Being an adult comes with a lot of nice things. You get a lot more freedom to do a lot of stuff and learn a bunch of self-confidence-boosting things, and you can spend some of your money how you want.

However, she noted that this freedom was limited by societal complications such as taxes, car payments, travel for work, and having to maintain contact with friends and remember social events. She also pondered the idea that she might have had more freedom as a child in the sense of not having to worry as much as she does now. Both Charlie and Noah referenced different independent living skills such as making bank transactions, grocery shopping, cooking/making meals, washing dishes, and doing laundry. Jessica highlighted financial independence skills such as opening a bank account, depositing paychecks, and using a debit card, all of which she has learned since gaining employment. She also mentioned, "I used to have a hard time focusing on work at school, but now I do it independently." Noah has become increasingly involved in

scheduling his transportation through taxi services and Uber, which has given him more independence.

Maturity and Responsibility. Two of the four participants associated adulthood with concepts of maturity and responsibility. Alison stated, “You don’t go to play in a park or whatever. You go out to eat, and you go for a coffee or a tea or something.”

Alison identified different events in adulthood that require a great deal of maturity and responsibility such as moving out, getting a job, starting a family, or returning to school.

Charlie said:

When I’m out at places I got to learn what I can say and what I can’t say, you know. That I’m an adult, and I got to learn that I got to make right choices instead of making the wrong choices.

Charlie alluded to some of the poor choices that he made during high school. He stated that he has learned from his mistakes, and he recognized that making mistakes is a normal element of development.

Experiences in Adulthood

Lack of Understanding from Others. Two of the four participants regularly experienced a lack of understanding from others. Alison stated, “There’s a lot more that goes into just functioning daily, and this is for, I think, anybody on the spectrum. There’s a lot more things that go into getting up, getting dressed, and making food.” She illustrated her daily energy expenditure using a water bottle: half of the bottle is reserved for everyday tasks, one quarter is used to cope with change and other stressors, and the remaining quarter must be dispersed across every other aspect of life. “It’s not shown,” she stated, “and it’s not necessarily realized [by others] the amount that actually is taken

out of you.” She likened her difficulty with daily functioning to a computer that operates strenuously due to the many processes that run in the background. These background processes, though taxing, are necessary for the computer to operate. Similarly, she equips herself with many conscious filters that are necessary to appear functional; however, they generate stress and fatigue, and they can lead to overwhelming feelings and meltdowns. For example, she stated that “some days my clothes drive me absolutely nuts, and I have to try and block that, or I have to change 12 times.” Jessica also expressed the difficulty of having to manage her hypersensitivity to loud noises.

Charlie stated that he often encountered situations in which he was misunderstood by others, sometimes to the extent that they became frustrated with him. He stated that if he is misunderstood, “I have to kind of figure out how I can un-confuse them where I kind of have them relate to things that I’m going through because, with my disability, it’s hard for people to understand me.” He stated that this struggle has become hard for him in adulthood as people continue to misunderstand how ASD affects him. Additionally, both Alison and Charlie acknowledged that they have trouble understanding other people as well.

Involvement in Volunteer Work. All four participants were either actively volunteering or were hoping to volunteer in the future. Charlie described two of his volunteer positions: the first involved visiting residents at a senior living community and making sure they are well, and the second consisted of raising awareness and promoting resources for people who struggle with anxiety and depression. Initially, Charlie was uncomfortable in his volunteer role at the senior living community until he voiced his need for support and had the opportunity to shadow other employees. Now, he feels much

more comfortable and less stressed in his current volunteer position than at his old job.

He said that his volunteer position at the senior living community has potential to become a full-time job. Noah volunteers at two daycare centers, one of which is for children with ASD, as well as a pregnancy center. His responsibilities include reading with the children, helping them make crafts, and playing with them. Jessica volunteers at a church to organize food and hygiene products for those in need, and Alison stated that she would like “to give back” to the community in the future. The three participants with volunteer positions agreed that their volunteer work has provided them with opportunities for social growth.

Coping Mechanisms. Charlie began volunteering with a mental health organization after they helped him learn coping strategies to deal with the effects of bullying and his ASD. Both Charlie and Jessica stated that breathing exercises (i.e. yoga breaths and deep breaths), help calm them when they feel upset. In addition, Charlie said that he would go for walks and listen to relatable music to tune out his surrounding environment and focus on himself and his breathing. Jessica’s calming strategies included taking breaks to use her phone before returning to a task, playing instruments, and listening to music. Charlie also recognized the importance of reaching out to others for support to cope with his anxiety.

Transitional Supports. All four participants discussed the impact of the support they received during the transition to adulthood. Some of the supports and services that were referenced include parents, camp/youth leaders, coworkers, employment readiness programs, employment support coordinators, community living services, ASD support centers, mental health organizations, and online training resources. However, three

participants highlighted difficulties in obtaining these supports, stating that “there's less support as an adult,” and “it's harder when you're an adult to get those [supports] or navigate them.” One participant appreciated the trouble that parents endure to obtain support for their children.

Obtaining Employment. Charlie reported difficulties finding new employment and transportation after having left a job due to being treated poorly: “With my autism, I have trouble finding a job, and I even have trouble finding transportation because I don't have a car, and I don't have a license, so transportation's been a big issue for me.” Noah also cited his search for employment, his job, and his volunteer positions as making adulthood more difficult. Additionally, Alison was apprehensive about the current job/economic climate, not just because of the implications of her ASD, but for her whole generation. Alison believed that her options for employment were less likely to be unionized and offer job security benefits (i.e. health benefits and pensions), and they were more likely to generate feelings of dissatisfaction.

Attending Higher Education. Charlie promptly left college after encountering dreadful living arrangements and unpleasant roommates. He also stated that the online application process for college was stressful, and he found it difficult to process all the information. Noah considered an integrated co-op program at a postsecondary school but decided against it due to the distance from home, uncomfortable feelings surrounding college residency, and changing qualifications for admission.

Feelings about Adulthood

Noah expressed a sense of uncertainty and anxiety about his future and independent living skills such as grocery shopping and financial transactions; however,

he stated that he feels more comfortable about his future now than when he was in high school and did not know where he was headed in life. Alternatively, Alison stated that the freedom to do different things in adulthood increased her self-confidence. She said that she is confronting adulthood one step at a time to avoid confusion and overwhelming feelings; however, she sometimes found herself feeling frustrated and disheartened when she compared her position in life to those of people around her.

Alison described herself as living with high-functioning ASD, which may be unrecognizable by most people, and she outlined several distressing elements of adulthood. She stated that stress could ensue in adulthood because “when you’re an adult, [it’s] even worse because as you get older people expect more from you.” She described these expectations as frustrating and depressing. She also expressed how frustrating it can be to lose support because she appears to function without any need for support, and then “the next month maybe you’ll have a panic attack and break down because there’s no support!” Alison stated that another frustrating and depressing element of adulthood is that her desire for autonomy is impeded by her overwhelming feelings in response to complex governmental and social systems (e.g. taxes, filling out forms, politics) even though she understands them and why she struggles with them.

Feelings about Moving Out. Alison, who is in the process of moving into her own independent basement apartment, expressed feelings of relief as more of her belongings are moved down. When Noah considered higher education, the process of moving into college residency was cited as a source of uncomfortable feelings. Also, Charlie experienced severe anxiety when he moved out of his home into college

residency: “I couldn't handle it, so I broke down, and I was like, ‘I need to go home; I don't feel comfortable here.’”

Feelings about Social Relationships. Alison stated that she felt relatively comfortable sharing with others that she is on the spectrum; however, she felt uneasy about disclosing her ASD to employers because of a concern that employers may be reluctant to hire someone with ASD. She has encountered social situations in which disclosing her ASD has worked against her, so she is more careful about sharing it now. She described herself as “a deer in headlights” when she encounters social interactions that she has not prepared herself for or is expectant of, and she may come away from those interactions feeling like she misinterpreted someone and said the wrong thing. She stated that social skills and understanding social scripts and rules are necessary for success, but these social systems overwhelmed her at times. Charlie said that he has missed a lot of friendships since leaving high school and that it has been difficult to maintain them. He expressed fears of these relationships ending and anxiety about what past friends may think of him.

Feeling Proud in Adulthood. Alison identified a successful moment in adulthood in which she received her college diploma in the mail and showed it to her mom and friends: “That was just a great feeling: just getting it in the mail. It was just wonderful, opening it and seeing it there. That was just great!” The diploma represented all her hard work and her mother’s support, which paid off in the face of adversity. Charlie felt successful when he was able to “figure out pieces and put things together” to accomplish different activities that his camp leaders encouraged him to try like lawn bowling. Jessica felt very proud of herself when she sang the national anthem at multiple

prominent sporting events, and both Noah and Jessica expressed a sense of achievement after gaining employment.

Goals for Adulthood

Employment Goals. Alison expressed a desire for a stable job that is related to her field of study, behavioral sciences, and is more fulfilling than entry-level jobs. She would like her future employment to have good benefits that cover medication and dental costs, or an adequate salary so that she could cover the costs herself. She stated that she would like to work with people with higher-functioning ASD “so that I can teach them the skills that I had to learn more brutally, so they don’t have to learn them brutally, so it’ll be easier for them.” However, she stated that she does not want a job in which she would have to provide personal care for others. Charlie expressed a desire to gain meaningful employment where he fits in and feels accepted: “I’m just kind of looking for places that I think might accept me for me because I’ve had a lot of struggles with different places, and I just want to find a place where I fit in.” He did not have a specific job in mind but hoped to work somewhere in his hometown where he feels safe and comfortable. Jessica stated that her goal is to gain full-time employment at the bakery she currently works at, and Noah stated that his goals include finding more job opportunities and working with kids.

Higher Education Goals. Both Charlie and Noah have no current goals for any form of higher education, but Jessica would like to enroll in a cake decorating course, which is relevant to her current job. Alison is nearing the end of her postsecondary studies, and it is her goal to earn a postgraduate certificate in the behavioral sciences, which will help her achieve her employment goals.

Independent Living Goals. All four participants currently live in their parents' home, but each expressed a desire to live independently, and most wanted to get their driver's license. Noah stated that he would rather live on his own than in a community living arrangement. Alison's independent living goals were financially oriented, and since moving out is so expensive, she is converting the basement of her parent's home into her own apartment. In addition to moving out, Charlie mentioned that he would like to improve his cooking skills.

Social Engagement and Social Functioning Goals. Alison said that once she has achieved her postsecondary education, employment, and independent living goals, she will have enough energy to start looking for a significant other. She was also interested in finding a social group, possibly even online, to play tabletop roleplaying games with. Jessica desired more social connection, stating, "I really, really want to be social with friends and things like that," and she identified many activities that she would like to do with friends such as going to the movies and eating dinner together.

Charlie expressed a strong desire to be understood by others:

I just want people to realize that autistic people aren't different than anyone else, that we all are loving and caring, and that we just need someone to be there for us and to have friends and to be loved and to be appreciated. That's all that we ask for is to be accepted by people.

It is one of his goals to spread ASD awareness and "show people that we're all the same."

Alison also expressed the need for greater ASD awareness, and she hoped to improve her understanding of social situations by practicing social skills and learning social scripts.

Charlie stated that he would like to promote mutual understanding in his social

interactions by having both parties explain their perspectives. He stated that bringing a trusted, mutual friend to mediate the conversation may help facilitate effective, meaningful communication.

Discussion

As participants described their expectations and perceptions of adulthood, all four referred to a variety of actions that demonstrate their ability to live independently. Two out of the four developed this theme of independence, suggesting that expectations of maturity and responsibility influence how they wield their independence in adulthood. The concepts that these participants associated with adulthood mirror those of the sample from Anderson and colleagues' (2016) study.

This sample reflects the least popular transitional pathway from the study of Wei and colleagues (2015) as three out of the four participants were primarily focused on their employment goals and expressed little to no interest in pursuing higher education. However, one participant was focused on her postsecondary education goals which, in a linear fashion, are essential to achieve her employment goals (Anderson et al., 2016). It should be noted that all but one participant was engaged with multiple forms of volunteer work, which may be a by-product of the low rates of full-time employment opportunities described by Farley et al. (2018) and Taylor et al. (2015). Fortunately, these volunteer positions placed participants in an environment that fostered interpersonal relationships.

Participants acknowledged the impact of various supports during their transition, but they strongly echoed the widespread concern for the lack of transitional supports that was reported throughout the literature (e.g. Anderson et al., 2017; Cheak-Zamora et al., 2015; Jackson et al., 2018). Unfortunately, participants expressed a range of negative

emotions, like those from the study of Cheak-Zamora and colleagues (2018), about having to confront different domains in adulthood including employment, independent living skills, moving away from their parents, and social situations. This anxiety surrounding adulthood may reflect the participants' uncertainty toward the current lack of transitional supports and their ability to propel the participants into successful adulthood outcomes. Nonetheless, they all felt proud of their achievements in employment, higher education, and social activities, and each of them held similar goals of living independently, obtaining meaningful employment to support their independence, and increasing and improving their social relationships.

Lastly, two of the four participants experienced a lack of understanding from others to such an extent that one of them made it his goal to spread ASD awareness and improve society's understanding of ASD. Cheak-Zamora et al. (2018) found that emerging adults with ASD ultimately want others to understand that just because they are different, it does not mean that they should be looked down on or rejected. Sadly, the public's misperceptions of ASD can be discouraging for both caregivers and people with ASD (Cheak-Zamora et al., 2015). Thus, society should strive for more inclusion among adults with ASD within higher education and the workplace to increase their neurotypical counterparts' positive attitudes toward individuals with disabilities (Wei et al., 2015).

Limitations

These findings cannot be generalized to the entire population of adults living with ASD because this study only included the expectations, perceptions, experiences, and goals of four adults with ASD. It would not be appropriate to generalize these findings to all adults with ASD because this sample cannot represent the full range of physical,

psychological, and economical differences of the study population. Individual interviews provided participants with an opportunity to freely express themselves; however, some participants were less inclined to express their thoughts and emotions. Also, the researcher may not have probed the participants' responses effectively to encourage the elaboration of their responses. One of the four interviews was performed over the phone, so the researcher was unable to gather rich observations of the participant's nonverbal communication. Two of the four interviews were completed with one of the parents present which may have biased the participants' responses.

Recommendations for Future Research

There is still much to be explored as adults living with ASD seek bigger and better opportunities. It may be worthwhile to replicate this study with more effective techniques to acquire deeper insight from emerging adults with ASD about their emotional states and cognitions regarding different domains of adulthood. Field observations of these adults in different environments could also help explain this transitional phenomenon, and findings could be compared to the participants' responses. By continuing and improving upon research in this field, researchers and stakeholders will improve their understanding of how people with ASD transition to adulthood and how this transition can be facilitated to increase their quality of life.

References

- Agran, M., & Hughes, C. (2008). Students' opinions regarding their individualized education program involvement. *Career Development for Exceptional Individuals, 31*(2), 69–76. doi:10.1177/0885728808317657
- American Psychiatric Association. (2013). Neurodevelopmental disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.
- Anderson, A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders, 39*, 33–53. doi:10.1016/j.rasd.2017.04.002
- Anderson, K. A., McDonald, T. A., Edsall, D., Smith, L. E., & Taylor, J. L. (2016). Postsecondary expectations of high-school students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 31*(1), 16–26. doi:10.1177/1088357615610107
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summaries, 67*(6), 1–23. doi:10.15585/mmwr.ss6706a1
- Chang, Y. S., Owen, J. P., Desai, S. S., Hill, S. S., Arnett, A. B., Harris, J., . . . Mukherjee, P. (2014). Autism and sensory processing disorders: Shared white matter disruption in sensory pathways but divergent connectivity in social-emotional pathways. *PLoS ONE, 9*(7), 1–17. doi:10.1371/journal.pone.0103038

- Cheak-Zamora, N. C., Teti, M., & First, J. (2015). "Transitions are scary for our kids, and they're scary for us": Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 548–560. doi:10.1111/jar.12150
- Cheak-Zamora, N. C., Teti, M., & Maurer-Batjer, A. (2018). Capturing experiences of youth with ASD via photo exploration: Challenges and resources becoming an adult. *Journal of Adolescent Research*, 33(1), 117–145.
doi:10.1177/0743558416653218
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). Washington, DC: Sage.
- Doren, B., Gau, J. M., & Lindstrom, L. E. (2012). The relationship between parent expectations and postschool outcomes of adolescents with disabilities. *Exceptional Children*, 79(1), 7–23. doi:10.1177/001440291207900101
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(4), 739–747.
doi:10.1007/s10803-007-0441-x
- Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research*, 11(1), 142–152. doi:10.1002/aur.1897
- Gotham, K., Brunwasser, S. M., & Lord, C. (2015). Depressive and anxiety symptom trajectories from school-age through young adulthood in samples with autism spectrum disorder and developmental delay. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(5), 369–376. doi:10.1016/j.jaac.2015.02.005

- Holmes, L. G., Kirby, A. V., Strassberg, D. S., & Himle, M. B. (2018). Parent expectations and preparatory activities as adolescents with ASD transition to adulthood. *Journal of Autism and Developmental Disorders, 48*(9), 2925–2937. doi:10.1007/s10803-018-3545-6
- Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572–581.e1. doi:10.1016/j.jaac.2013.02.017
- Jackson, S. L. J., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(3), 643–650. doi:10.1007/s10803-017-3315-x
- Kamp-Becker, I., Schröder, J., Muehlan, H., Remschmidt, H., Becker, K., & Bachmann, C. J. (2011). Health-related quality of life in children and adolescents with autism spectrum disorder. *Zeitschrift für Kinder- und Jugendpsychiatrie und Psychotherapie, 39*(2), 123–131. doi:10.1024/1422-4917/a000098
- Lugnegård, T., Hallerbäck, M. U., & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities, 32*(5), 1910–1917. doi:10.1016/j.ridd.2011.03.025
- Matson, J. L., & Kozlowski, A. M. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 418–425. doi:10.1016/j.rasd.2010.06.004

- Potvin, M.-C., Snider, L., Prelock, P. A., Wood-Dauphinee, S., & Kehayia, E. (2015). Health-related quality of life in children with high-functioning autism. *Autism, 19*(1), 14–19. doi:10.1177/1362361313509730
- Robertson, A. E., Stanfield, A. C., Watt, J., Barry, F., Day, M., Cormack, M., & Melville, C. (2018). The experience and impact of anxiety in autistic adults: A thematic analysis. *Research in Autism Spectrum Disorders, 46*, 8–18. doi:10.1016/j.rasd.2017.11.006
- Roy, M., & Dillo, W. (2018). Quality of life in autism spectrum disorder. *Journal of Autism, 5*(1), 1–6. doi:10.7243/2054-992X-5-2
- Sites, E. C. (2008). *Separate threads or a single woven piece? A phenomenology of the integration of faith and learning* (Doctoral dissertation). Retrieved from <https://digitalcommons.liberty.edu/doctoral/100>
- Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism, 19*(7), 785–793. doi:10.1177/1362361315585643
- Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the short sensory profile. *American Journal of Occupational Therapy, 61*(2), 190–200. doi:10.5014/ajot.61.2.190
- Wagner, M., Newman, L., Cameto, R., Levine, P., & Marder, C. (2007). Perceptions and expectations of youth with disabilities. A special topic report on findings from the National Longitudinal Study-2 (NLTS2): Chapter 6--Youth's expectations for the future. *Journal for Vocational Special Needs Education, 30*(1), 18–27. Retrieved from <https://eric.ed.gov/>

- Wehman, P., Schall, C., Carr, S., Targett, P., West, M., & Cifu, G. (2014). Transition from school to adulthood for youth with autism spectrum disorder: What we know and what we need to know. *Journal of Disability Policy Studies, 25*(1), 30–40.
doi:10.1177/1044207313518071
- Wei, X., Wagner, M., Hudson, L., Yu, J. W., & Javitz, H. (2016). The effect of transition planning participation and goal-setting on college enrollment among youth with autism spectrum disorders. *Remedial and Special Education, 37*(1), 3–14.
doi:10.1177/0741932515581495
- Wei, X., Wagner, M., Hudson, L., Yu, J. W., & Shattuck, P. (2015). Transition to adulthood: Employment, education, and disengagement in individuals with autism spectrum disorders. *Emerging Adulthood, 3*(1), 37–45.
doi:10.1177/2167696814534417
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review, 29*(3), 216–229. doi:10.1016/j.cpr.2009.01.003
- World Health Organization. (n.d.). WHOQOL: Measuring quality of life. Retrieved from <https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>
- Yamamoto, Y., & Holloway, S. D. (2010). Parental expectations and children's academic performance in sociocultural context. *Educational Psychology Review, 22*(3), 189–214. doi:10.1007/s10648-010-9121-z

Zeedyk, S. M., Tipton, L. A., & Blacher, J. (2016). Educational supports for high functioning youth with ASD: The postsecondary pathway to college. *Focus on Autism and Other Developmental Disabilities, 31*(1), 37–48.
doi:10.1177/1088357614525435

Appendix

Interview Guide

Directions: The purpose of this interview is to gather information about your expectations, perceptions, experiences, and goals regarding your transition into adulthood. Feel free to refuse to answer any question that causes you to feel uncomfortable. However, I would encourage you to answer each question to the best of your ability. Let me know if you would like me to repeat a question or if any question is unclear. Feel free to request a break at any point during the interview.

1. Please tell me about yourself.
 - A. What does a typical day look like for you?
 - B. How do you like to spend your free time? Do you have any interests/hobbies?
2. How are you different today than when you were as a teenager?
3. Describe your understanding of adulthood and how you came to this understanding.
 - A. Prompts:
 - I. Synonyms, phrases, closely related concepts
 - II. Thoughts, ideas, concepts, expectations, and experiences that come to mind
4. What has been your experience of adulthood?
 - A. Prompts:
 - I. Postsecondary Education (e.g. application process, moving out, campus life, school relationships)

- II. Employment (e.g. application process, work environment, work relationships)
 - III. Independent Living (e.g. different living arrangements, mental/physical well-being maintenance, cooking, cleaning, transportation, financial matters)
 - IV. Social Life (e.g. developing new friendships, maintaining old friendships, new interests/hobbies)
- B. Describe for me a time when you felt successful.
- C. What challenges have you encountered?
5. What has helped you transition into adulthood?
- A. Have you been involved in any training/support services?
 - B. How have your relationships with other people supported/interrupted this process?
6. What are your goals for the future?
- A. Prompts:
 - I. Postsecondary Education (e.g. school and program type, grades, involvement in clubs, sports, and research)
 - II. Employment (e.g. job responsibilities, work hours, job location, financial compensation, characteristics of the work environment)
 - III. Independent Living (e.g. autonomy, moving out of parents' home, mental/physical well-being, cooking skills, cleaning skills, financial matters)

IV. Social Life (e.g. number of friends, types of friends, romantic relationships, family relationships, frequency of meeting friends, shared activities with friends)

7. (If not addressed in previous questions): How would you describe the impact of autism on your life?

Closer

Thank you for your meaningful responses. The information you shared has greatly increased my understanding of how individuals living with ASD navigate their transition into adulthood. Your responses will help researchers develop effective forms of support to help people living with ASD transition into adulthood and achieve their goals. Is there anything else you would like to share before we conclude the interview? Do you have any questions for me? Wonderful! That is everything, then. Thank you for participating in this study, and I hope you have a great rest of your day.