



Navigating the Transition to Adulthood: Perspectives of Autistic Individuals

Samara M. Wolpe, Ph.D.

01 ✨ Introduction ✨

Transitioning into Adulthood for Autistic Individuals



Language Statement

The identity-first language 'autistic' is used throughout this presentation when referring to individuals on the autism spectrum to respect and utilize the language preferred by the majority of autistic individuals.



The transition into adulthood is a notoriously difficult stage of life for autistic individuals.

Services Cliff

- ★ 97% of autistic teens receive services in high school, while 75% receive services in their early 20s

Entering Higher Education/Employment

- ★ 33% of autistic adults are never employed or continue higher education after high school, in comparison to only 8% of peers with learning disabilities or speech-language impairments

Poor Outcomes

- ★ Majority of studies find poor to very poor outcomes in independent living, rate of employment, and friendship quality and quantity, although these poor outcomes may be more closely tied to characteristics of the individual.



02 ✨ Literature Review ✨





How Do We Measure ‘Success’?

- ★ Majority of research in outcomes in autistic adults found ‘poor’ to ‘very poor’ outcomes
- ★ Outcomes conform to neurotypical standards of ‘success’ and measures vary between studies
- ★ Overall Outcome Rating (OOR Scale): commonly used outcome measure
- ★ Autistic individuals may define success along different axes
- ★ Only a subset of autism outcome research demonstrates high methodological quality

Qualitative exploration of autistic adults’ experiences and priorities is warranted

Employment

Employment Rates

Autistic adults have low rates of employment even compared to individuals with other developmental disabilities.

Workforce

- 20-55% employed

55% never employed

Employer Prejudices

Prejudice in hiring may play a role

- **Autistic Strengths**

- ★ Tolerant of repetitive work
- ★ Dependability & adherence to rules

Higher Education

- ★ Majority of autistic adults do not attend higher education
- ★ 11% of autistic adults attended 4-year college
- ★ 42% received accommodations
- ★ College is a prerequisite for high-paying jobs
- ★ Difficulties in obtaining accommodations with poor executive functioning (EF)
- ★ Poor mental and physical health rates→ difficulty navigating college requirements



Intersectional Identities

Race/Ethnicity

- ★ Non-white autistic students identified ½ the rate of white students
- ★ Non-white autistic students less likely to receive healthcare services
- ★ Non-white & low-SES autistic adults less likely to be successful in adulthood

Gender

- ★ Female/gender non-conforming individuals unlikely to be identified
- ★ Girls better at 'masking' behaviors
- ★ Understudied in autism research
- ★ Gender diverse/LGBTQ+ experience poor health outcomes in adulthood



Theoretical Framework

Medical Model of Disability

Disability as pathology

Unhealthy deviation from aspirational standard

'Normal' vs. 'deviant'

Social Model of Disability

Examines disability through lens of inclusion/exclusion

Focus on structures that promote ableism

Increasingly adapted into academia

Neurodiversity

Neurological differences part of range of human development

Autism as a natural state of being vs. a disorder/disability

'Nothing about us, without us'



03 ✨ Current Study ✨





Current Study

- ★ Only 3.5% of published research on autism focuses on adults
- ★ There is a critical need to examine the transition into adulthood and to center autistic individuals and their experiences.
- ★ **Current study:** focuses on the experiences of autistic young adults transitioning out of high school and into adulthood.
- ★ **Goal:** understanding invisible barriers, gain a greater understanding of how autistic individuals measure success and their own quality of life.

Research Questions

1. What are the barriers autistic individuals encounter in the transition to adult life?
 - a. What barriers did autistic individuals experience in higher education?
 - b. What barriers did autistic individuals experience in employment?
2. What resources do autistic individuals find most helpful in navigating this transition?
3. What could families, organizations, employers, and educators do to support autistic adults transitioning into adulthood?
4. What strategies for success do participants recommend to autistic emerging youth to navigate the transition into adulthood?
5. What does success mean to autistic individuals in their own lives?



Positionality





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Methods



Participants

- ★ 18 autistic adults (1 excluded, total 17) ages 18+
- ★ Recruitment took place through social media and organization contacts
- ★ Initial google survey to determine eligibility + demographic info
- ★ Zoom interview between 30-60 mins



The flyer has a light purple background with a faint mountain range. At the top left is a blue and white lily-like flower, and at the top right is a green leafy branch. The text is centered and reads: 'Do you identify as an autistic adult?' in a large, bold, black serif font. Below this is 'We want to hear your voice!' in a smaller, black serif font. Then, 'We are looking for autistic adults to participate in a 30-60 min interview on transitioning into adulthood for a voluntary UCLA research study.' in a black serif font. Below that is 'Contact communityautismresearch@gmail.com if you are interested!' in a black serif font. At the bottom left is the 'Ucla' logo in blue. To its right are the names 'SAMARA WOLPE, M.A.' and 'JEFFREY WOOD, PH.D.' in a small, black, sans-serif font. To the right of the names is a colorful infinity symbol logo. At the very bottom, in small black text, is 'Protocol ID: RB423-000412 · UCLA IRB Approved · Approval Date: 6/28/2023 · Committee: North General IRB'.

Do you identify as an autistic adult?

We want to hear your voice!

We are looking for autistic adults to participate in a 30-60 min interview on transitioning into adulthood for a voluntary UCLA research study.

Contact communityautismresearch@gmail.com if you are interested!

Ucla

SAMARA WOLPE, M.A.
JEFFREY WOOD, PH.D.

Protocol ID: RB423-000412 · UCLA IRB Approved · Approval Date: 6/28/2023 · Committee: North General IRB

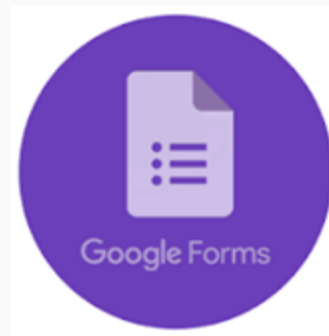
Participant ID	Pseudonym	Gender	Age	High School Type	Racial/Ethnic Identity	Primary Spoken Language	Diagnosis
P_01	Jamie	Nonbinary	26	Mainstream	Mexican'- 'American	English	Autism
P_02	Arlo	Male	28	Mainstream	White/Latino	English	Autism
P_03	Ben	Male	31	Mainstream	White	English	Autism
P_04	Kayden	Male	28	Mainstream	White	English	Autism
P_05	Kiki	Female	19	Mainstream and Special Education	White	English	Autism
P_06	Alex	Nonbinary	23	Special Education	White	English	Autism
P_07	Kyle	Male	22	Mainstream	Hispanic/Latino and White, Multiracial	English, French, Spanish	Autism
P_08	Jane	Female	35	Mainstream	Middle eastern/Caucasian	English	Autism

P_09	Zach	Male	32	Mainstream	White	English	Autism
P_10	Sam	Nonbinary	28	Mainstream	Indigenous Native American	English	Autism
P_11	Rose	Female	22	Mainstream	White	English	Autism
P_12	Sarah	Female	36	Mainstream	White	English	Autism
P_13	Katherine	Female	24	Mainstream	White, Non-'Hispanic	English	Autism
P_14	Rebecca	Female	25	Mainstream	Hispanic	English	Autism
P_15	Nina	Female	25	Mainstream	White	English	Autism
P_16	Maddie	Female	22	Mainstream	biracial (black and white)	English	Self-'identify as autistic
P_17	Emily	Female	29	Mainstream	Hispanic/White	English	Autism



Materials

- ★ Interview Questions
- ★ Demographic Google Survey
- ★ Zoom Interviews
- ★ Google Survey follow-up





Procedures

- ★ Interview protocol developed to ascertain experiences of autistic individuals transitioning into adulthood
- ★ Interviews conducted through Zoom
- ★ Participants provided with study protocol and consent form prior to interview
- ★ Verbal consent was obtained before recording began
- ★ Member checking was done before publicizing the results
- ★ Recordings + transcripts stored on secure, password-protected server



Data Analysis

Thematic Analysis

Iterative and inductive approach to thematic analysis

Created codebook: dynamic, evolving document

Synoptic chart: capture frequencies of code occurrence

Systematic Coding Consensus

PI and RA coded transcripts separately

Discussion were held to come to consensus

Iterative process allowed PI and RA to achieve agreement

Interrater Reliability

RA coded 100% of transcripts separately

Assess fidelity

Compare codes/discuss discrepancies until consensus is reached (minimum of 80% agreement)



05



Results





Educational/Vocational Experiences	Barriers to Success	What Works	Recommendations
Accommodation Experiences in Higher Education Accommodation Experiences in Employment Routines/Change Masking	Finances Underestimated/Infantilized Ignorance and Indifference Low Support Needs Social Interactions: School Social Interactions: Work Burnout/Meltdown Executive Functioning (EF) Disclosure	Acceptance/Unlearning Finding Community Individualized Attention/Mentorship Finding Your Passions/Strengths Alternative Pathways	High School Recommendations College Recommendations Job Recommendations Family Recommendations Young Adult Recommendations



Educational/Vocational Experiences

★ Accommodation Experiences in Higher Education

→ Navigating disability offices

→ Barriers and variability in experiences

“The process of some of the accommodations... is a lot of steps and it's daunting...I don't want to have to do all those steps and I might not remember to do them within that time frame. So **I feel like there's still barriers even when you have accommodations.**” (Rebecca)

★ Accommodation Experiences in Employment

→ Employers forgetting accommodations

“**[Listen] to my needs**, like what kind of clients I needed because... I even get overstimulated if the kids [are] going wild. Okay, they're not listening to me... **I'm going to get burnt out.**” (Nina)



Educational/Vocational Experiences

★ Routines/Change

→ Moving away from established routines

→ Dealing with change

★ Masking

→ Important social strategy

→ Mentally taxing

“Generally, it’s very difficult... to adjust to new areas, even if it’s just the same city... I do try to be open, which is another thing that is often not very easy to do as someone on the spectrum.”
(Arlo)

“My family’s Mexican.. I grew up not knowing the most about mental health... it’s not something that was talked about or really understood. We had to do well in school, that was our responsibility. And so when I started to struggle... **I knew if I was struggling I wasn’t going to get help. I was going to get reprimanded... or hit.**” (Sam)



Barriers to Success

★ Finances

- lack of financial literacy
- keeping and maintaining a job

★ Underestimated/Infantilized

- perceived as children, given adult responsibilities
- stigma-free support

★ Ignorance and Indifference

- invisible disabilities ignored

“Suddenly, I have to [do] the paperwork. **Suddenly, I'm financially responsible.**” (Alex)

“**Presume competence**...they assume, because I look serious and I'm quiet that I don't know what I'm talking about or I don't know what's going on or I'm incapable...**Just because I don't present as a neurotypical person would, doesn't mean I'm not competent.**” (Jane)

“Sometimes I get overwhelmed and I need a minute. And they were the type of employer that was like, okay, but that's all an excuse... you're being lazy... **they were of the mind that if your disability was not a physical one, then you didn't have one.**” (Maddie)



Barriers to Success, Cont.

★ Low Support Needs

→ difficulty finding appropriate support

"I was able to mask so well that... **I was able to just place myself out of special education services because I could blend in like a neurotypical person.** But then...I'm realizing, I need some... accommodations." (Kyle)

★ Social Interactions at School

→ sensory overwhelm, masking

→ social rule violations

"**Socially, I felt like I wasn't picking up on cues...**I would sit down with my friend and it seemed like they didn't want me to be there. Or I wasn't invited to a party and stuff and **I just felt like people were leaving me out and I felt like I was being annoying to them**" (Nina).

★ Social Interactions at Work

→ unwritten workplace social rules

→ suspicious/hostile coworkers

"**People... just automatically know there's something off about you,** that you're a little weird and that you do things very rigidly, and they're like, hmm, she's weird... **And they kind of backhandedly bully you.**" (Emily)



Barriers to Success, Cont.

★ Burnout/Meltdown

- barrier to consistent employment
- struggles with self-care

"I've had a complete breakdown, burnout... where I just became someone completely different which led to me **getting fired multiple times...** it's just like you're not even you anymore at that moment. **It's a very scary place to be.**" (Emily)

★ Executive Functioning (EF)

- trouble keeping up

"It's like, you're on this road and you have no map. And everyone else seems to have a map in their hands or in their head, and they're doing fine. And you're still at the beginning of the road, like, what's happening? Which way do I go? I can't move forward." (Jane)

★ Disclosure

- sharing autistic identity
- repeated explanation

"I wanted to start on a fresh page and not be known as the weird autistic kid. I wanted to be known as just, hey, that kid does good monologues. That kid's not a half-bad singer." (Alex)



What Works

★ Acceptance/Unlearning

→ self-acceptance, internalized ableism

→ unmasking

★ Finding Community

→ neurodivergent friendships

→ autism advocacy

★ Individualized Attention/Mentorship

→ understanding and compassionate mentors

“Autism doesn’t make you different in the sense of, oh, you’re living in an entirely different universe and you don’t know what’s going on...You’re living in the same world as everyone else. **Your mind just works a little differently and innovation, invention, and progress requires people who think differently.**” (Maddie)

“[Autistic social support groups] are valuable to me because they understand my little quirks and sometimes I’ll make little joy noises and jokes and they’ll just be like haha, like I get you, I understand why you’re doing that...**I feel very judged by society, but having my neurodivergent friends, it’s fun.**” (Nina)

“I had a teacher whose son was autistic... She was very accommodating. **She introduced new methods of learning to me.**” (Maddie)



What Works

★ Finding Your Passions/Strengths

→ special interests

→ sustainable career paths

"Talk about your special interest. Go on and on about how much you love whatever you love." (Jamie)

★ Alternative Pathways

→ community college, gap years

"Not every single person is going to be able to go directly from high school to college and finish college within four years. Sometimes just **having the real life experiences, and learning through failures too, is crucial for someone who is a hands-on experience type of learner.**" (Sarah)



Recommendations

★ High School Recommendations

→ teach finances, study strategies

★ College Recommendations

→ UDL classroom design

→ menu options of accommodations

★ Job Recommendations

→ listening to accommodations

→ Neurodiversity education

“Have a place on school websites that direct parents toward the research, so they could learn more about neurodiversity and autism and be connected with... the neurodivergent communities.” (Kyle)

“Here’s an example of your schedule. **How are you gonna manage your time? Do you need a timer? Do you need to make a list?** Those types of things. That would have been really helpful,” (Jane)

“All the jobs that I’ve had... **I had different ways of doing things and allowing me to do them the way I needed to do them in order to get the same result.** And sometimes, I would figure out ways to save money for the companies I worked for but they were like, no. **Do it the way it’s written.**” (Emily)



Recommendations

★ Family Recommendations

→ education, support, transparency

→ teaching self-acceptance in childhood

“Tell your kids they’re autistic. Be honest and upfront with them. Try to support them. Not trying to make them hide their disability or hide their oddness. And celebrate it, too. Let them know, hey, yeah your brain and world functions differently, but **there’s beauty in that.**” (Jamie)

“If they had done more research... that would have been beneficial in just not feeling defective throughout middle school and high school and into adulthood.” (Emily)

“Be present as a parent and really take into account that your child is an individual, and you’ll have to shift your parenting style.” (Sarah)



Young Adult Recommendations

★ Planning for the Future

→ finding special interests and a mentor

“Find a mentor. Find people that you want to work with and that will support you, because that will make all the difference.” (Kyle)

★ Finding Friendship and Community in Adulthood

→ common interests and shared identity

“I know people with autism tend to have really deep interests, **join in social clubs based on your interest.** If there’s nothing out there for what you’re interested in, **maybe you can create your own.**” (Katherine)



Young Adult Recommendations

★ Self-Acceptance

→ being patient, not comparing oneself to others

“You’re going to learn to love every aspect of your identity: the good, the bad. **Be patient with yourself.**” (Arlo)

“**[Autism] is not something that is to be feared... you’re still a person deserving of patience, deserving of love.** You’re still somebody who needs a little help now and then and that’s okay.” (Maddie)

“**Don’t compare yourself to people who are not facing the same struggles as you** because that’s not fair to you and it’s also not fair to them, because sometimes **there are things that people with autism can do that people who don’t have autism can’t.**” (Maddie)



06 ✨

Discussion ✨



Implications

- ★ Toll of Masking
 - exploring implications of masking based on context
- ★ Accommodations
 - offering 'open accommodations'
 - examining most useful resources
- ★ Finding Self-Acceptance
 - community education to increase understanding and acceptance
 - building a strong support network





Limitations

1

Generalizability

These interviews cannot be generalized to the autistic community as a whole.

2

Homogeneous Sample

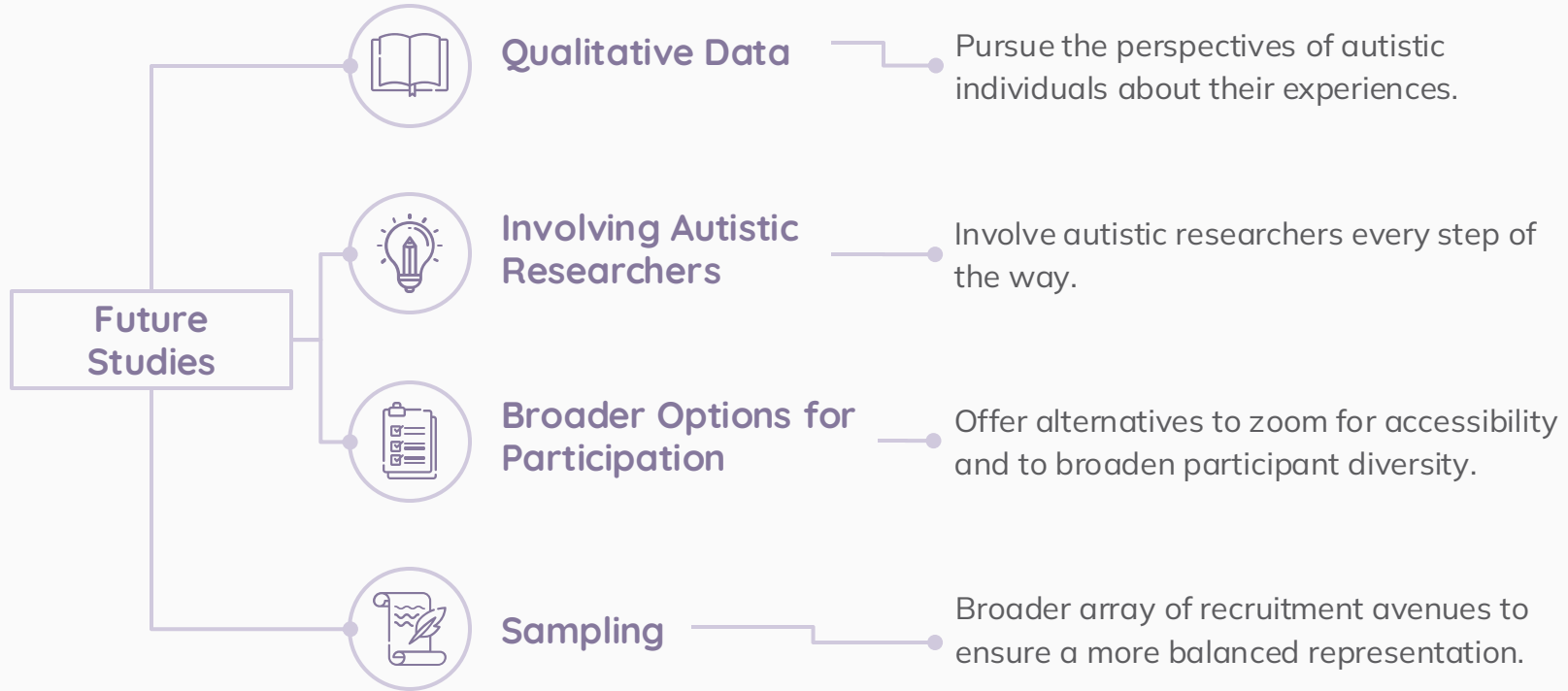
This sample was majority White and highly verbal.

3

Positionality

I am not autistic, and this study was not co-designed with autistic individuals.

Future Research





Conclusions

- ★ The goal of this study is to understand how autistic adults can be better supported in the transition to adult life.
- ★ Represents a jumping-off point for researchers to increase collaboration with the autistic community.
- ★ Center the priorities/desires of autistic community in designing interventions to promote better quality of life in adulthood.



If you want to learn more...



Wolpe, S. M., Tien, I. S., Lee, M. N.,
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“Neurodivergent people just get
each other”: Navigating friendship
and community in the transition to
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**Thank
You!**





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07



Appendix



Table 2. *Code Application Frequency*

	Emily	Maddie	Nina	Rebecca	Katherin	Sarah	Rose	Sam	Zach	Jane	Kyle	Alex	Kiki	Kayden	Ben	Arlo	Jamie	Totals
																		21
Barriers to Success	15	18	11	15	13	13	15	19	6	28	15	10	0	5	7	7	16	3
Burnout/Meltdown	2	4	1	5	1	4	1	1	1	4	0	1	0	1	0	1	4	31
Disclosure	0	1	1	1	0	2	1	0	3	0	4	1	0	2	0	0	0	16
Executive Functioning	2	1	1	5	2	0	2	5	0	7	2	2	0	0	0	0	1	30
Finances	1	1	2	1	5	0	2	1	0	0	4	2	0	0	4	0	0	23
Indifference	2	2	1	0	0	0	0	5	2	5	0	2	0	0	0	0	0	19
Lower Support Needs	0	0	1	0	0	0	4	1	0	0	2	0	0	0	0	0	1	9
Social Skills	2	3	3	0	2	2	1	5	0	8	1	0	0	0	3	2	5	37
Timing of Diagnosis	6	6	0	3	0	5	4	0	0	1	2	0	0	0	0	0	5	32
Underestimated/Infantilized	0	0	1	0	3	0	0	1	0	3	0	2	0	2	0	4	0	16

Educational/Vocational	10																	
Experiences	3	2	11	4	2	6	6	3	5	5	12	4	0	4	3	17	17	4
Accommodation and Special																		
Services Experiences	2	1	5	3	1	1	1	0	1	3	9	2	0	3	1	6	5	44
Masking	1	1	1	0	0	0	2	3	3	0	3	1	0	0	2	0	9	26
Partying/Drugs	0	0	1	0	0	2	1	0	0	2	0	0	0	1	0	5	0	12
Routines and Change	0	0	4	1	1	3	2	0	1	0	0	1	0	0	0	6	3	22
Life Skills Preparation	2	3	2	2	4	1	1	1	2	1	2	7	4	5	3	1	5	46
Constructive Experiences	1	2	2	0	1	1	0	1	2	0	1	3	4	3	3	1	0	25
Lack of Preparation	0	0	0	2	2	0	1	0	0	1	1	2	0	2	0	0	2	13
Unhelpful Experiences	1	1	0	0	1	0	0	0	0	0	0	2	0	0	0	0	3	8
	12																	
Recommendations	7	5	6	8	11	7	7	1	3	6	8	7	5	7	6	7	22	3
College Recommendations	0	0	0	1	1	2	1	0	0	3	1	0	0	1	0	0	5	15
Family Recommendations	1	1	1	1	3	2	1	0	1	1	2	1	1	3	2	0	6	27

High School																		
Recommendations	1	1	1	1	1	1	3	0	1	0	2	1	1	0	0	0	3	17
Job Recommendations	2	1	2	1	2	0	0	1	0	1	0	0	2	0	1	0	0	13
Young Adult																		
Recommendations	3	2	2	4	4	2	2	0	1	1	3	5	1	3	3	7	8	51
<i>Asking for Help</i>	0	0	0	1	0	0	0	0	0	0	1	1	1	0	0	0	1	5
<i>Finding Friendship and</i>																		
<i>Community in Adulthood</i>	0	0	2	0	1	0	0	0	0	1	1	0	0	0	0	0	2	7
<i>Planning for the Future</i>	3	0	0	0	3	1	0	0	0	0	1	2	0	1	3	0	1	15
<i>Self-Acceptance</i>	0	2	0	3	0	1	2	0	1	0	0	1	0	1	0	0	3	14
																		18
What Works	16	10	11	7	9	6	7	15	9	3	31	15	7	10	11	8	12	7
A Different Route	3	1	1	2	0	1	0	0	2	1	1	2	1	0	0	1	0	16
Acceptance/Unlearning	1	4	0	1	0	1	3	6	2	0	8	2	0	1	3	2	2	36
Advocacy	1	0	3	0	0	0	1	0	3	0	3	0	1	1	1	0	5	19
Finding Community	2	1	4	1	2	1	2	2	1	0	13	2	1	1	0	0	3	36

Finding Your																		
Passion/Strengths	5	2	1	2	2	1	1	5	0	0	0	4	0	1	1	0	1	26
Individualized																		
Attention/Mentorship	2	1	2	1	1	2	0	1	1	2	5	4	2	3	4	5	1	37
Starter Jobs	2	1	0	0	4	0	0	1	0	0	1	1	2	3	2	0	0	17
																		13
Totals	50	43	45	42	47	36	41	40	29	46	73	55	21	39	38	41	85	87

Appendix

Young Adult Transition Interview Questions

1. Could you describe what you doing now in your adult life?
 - a. Career/education
 - b. Living situation (dorm life?)
2. Could you tell me what you remember about preparing for adult life/college/next steps in high school?
3. What did you do in high school that you feel best prepared you for *[college, vocational school, internship/job, independent living—ask whichever applies to the participant]*?
4. What was most difficult for you about transitioning from high school to *[next steps fill in here]*?
5. Was there anything about this transition that you remember going well or being easy?
6. What do you think might have helped make that transition easier?
 - a. Things your school could do
 - b. Things your job/college/internship/support staff could do
 - c. Things your family could do
7. Is there any advice you would give to a young autistic adult who is about to graduate from high school?
8. Is there anything else you'd like to share on this topic?

Figure 1. Interview Protocol



80%

Autistic adults find it difficult to visit a practitioner
compared to 35% non-autistic adults

50-58 years

Life expectancy for autistic adults vs. national average
of 76.1 years

Intersectionality

Identity plays a role in understanding physical and
mental healthcare for autistic adults

Social Outcomes

- ★ 1 in 4 autistic adults are socially isolated
- ★ 60% wish they had more friends
- ★ Friendships associated with decreased loneliness, lower depression & anxiety, positive self-esteem

WHY ARE FRIENDSHIPS SO DIFFICULT?

