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TITLE Improving Healthcare Transition Planning and Health-Related Independence for Youth with ASD and their Families

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CONTRACTING ORGANIZATION: University of Missouri System
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14. ABSTRACT There is a critical need for health care transition (HCT) services and health-related independence (HRI) for youth with ASD. Existing HCT measurement tools fail to address youth and caregiver perspectives and no existing measurement tools examine HRI among youth with ASD. In Aim 1 of this study we explored HCT and HRI experiences and needs of youth with ASD and their caregivers utilizing qualitative methods. We recruited 61 caregivers and 43 young adults to participate and completed focus groups with 39 caregivers and individual interviews with 27 young adults. We identified major themes from the qualitative data including: caregiver stress, relationships, adulthood, health challenges, guardianship, financial, resources/suggestions, safety, work/school, health success, appointments, medication or illness management, transition to adult doctor, and self-care. Aim 2a of the study is currently underway. Within this aim we will utilize the themes from Aim 1, findings from previous literature, and experts in the field to develop an ASD-specific HRI outcome measure. The HRI measure and individual items will then be evaluated and revised based on finds from cognitive interviewing and full-scale pretesting.					
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1. INTRODUCTION:

Two million people have an Autism Spectrum Disorders (ASD) diagnosis, the vast majority of whom are 18 years of age or younger, signifying an impending “tsunami” of youth with ASD transitioning into adulthood. We must prepare these youth and their caregivers for the changes that come with adulthood and ensure the health care system will be prepared to help. Unfortunately, less than a quarter of youth with ASD receive basic health care transition (HCT) services. Further, no study, to date, has examined how often youth with ASD are taught to manage their health and self-care needs, therefore, achieving health-related independence (HRI). This study will begin to improve HCT and HRI for youth with ASD by examining the factors leading to successful HCT and HRI and positive caregiver wellbeing. Within the first year of this study (**Aim 1**) we utilized qualitative methods, focus groups and individual interviews, to explore HCT and HRI experiences and needs of youth with ASD (ages 16-25) and their caregivers. We **hypothesized** individual interviews with youth with ASD and focus groups with caregivers will identify key themes associated with HRI including but not limited to self-care skills, safety, knowledge about diagnoses, and sexuality.

2. KEYWORDS:

youth with ASD, health-related independence, health care transition, qualitative methods, measure development

3. ACCOMPLISHMENTS:

- What were the major goals of the project?

Table 1. Approved Statement of Work with Year 1 Completion Updates

Specific Aim 1: Explore HCT and Health-related Independence (HRI) experiences and needs of youth with ASD and their caregivers utilizing qualitative methods		
Aim and Task	Targeted timeline	Completed date or %
Major Task 1: Regulatory Review and Start-up	Oct 2014-Jan 2015	Completed November 2014
Major Task 2: Recruit subjects and conduct Focus Groups and Individual Interviews	Jan 2015- May 2015	Completed July 2015
Major Task 3: Qualitative Data Analysis and Findings Dissemination	May 2015- Jan 2016	60%

- **What was accomplished under these goals?**

1. Major Activities and 2. Objectives from Approved Statement of Work

Table 2. Major activities, approved Statement of Work and achievements in Year 1

Specific Aim 1: Explore HCT and Health-related Independence (HRI) experiences and needs of youth with ASD and their caregivers utilizing qualitative methods
Major Task 1: Regulatory Review and Start-up
Objective 1: Develop interview and focus group survey materials • Caregiver and young adult background and demographic surveys (Appendix 1 and 2, respectively) • Recruitment flyer • Health-related independence priority measure survey (Appendix 3) • Caregiver waiver of documentation of consent form • Young adult consent form
Objective 2: Develop and update University of Missouri IRB materials and application • Consent form for young adults and waiver of documentation of consent for caregivers changed to more accurately reflect the length of focus groups and interviews would be (2 hours and 1 hour respectively) • Similar changes to protocol and recruitment flyer • Caregiver and young adult background and demographic surveys updated • Recruitment flyer changed to include topics covered in focus groups and individual interviews • HRI measure added • Consent for youth and waiver of documentation of consent for caregivers changed to indicate specific background survey and HRI measure to be completed • Protocol updated to include these surveys specifically
Objective 3: HRPO/ACURO • Completed HRPO and ACURO application • Submitted and received approval for study protocol and all study material.
Objective 4: Recruit & Hire staff • 1 research assistant hired • 3 part-time Thompson Center staff recruited • 2 research assistant (volunteers) recruited
Objective 5: Develop and test focus group & individual interview guide; train staff on protocol and procedures • Caregiver and young adults interview guide developed • Review and test interview guide with caregiver and young adult volunteers along with experts in the field • 7 staff members trained
Milestone Achieved: IRB/IACUC & HRPO/ACURO Approval Guides developed and staff trained

Major Task 2: Recruit subjects and conduct Focus Groups and Individual Interviews

Objective 1: Participant Recruitment Screening

- Columbia, MO focus group and individual interview session (Dec 6, 2014)
 - o Contacted 157 potential participants via email and/or mail
 - o Screened 78 potential participants
 - o 17 caregivers scheduled for focus groups
 - o 12 young adults scheduled for individual interviews
- Columbia, MO focus group and individual interview session (Columbia, MO (Jan 17, 2015))
 - o Contacted 98 potential participants via email and/or mail
 - o Screened 16 potential participants
 - o 9 caregivers scheduled for focus groups
 - o 7 young adults scheduled for individual interviews
- Kansas City, MO focus groups and individual interview sessions (Jan 31, 2015)
 - o Developed and distributed flyers and recruitment letters to 75 organizations
 - o Contacted 245 potential participants via email and/or mail
 - o Screened 30 potential participants
 - o 12 caregivers scheduled for focus groups
 - o 11 young adults scheduled for individual interviews
- Hannibal, MO focus groups and individual interview sessions (May 2, 2015)
 - o Developed and distributed flyers and recruitment letters to 14 organizations
 - o Contacted 56 participants via email and/or mail
 - o Screened 25 potential participants
 - o 13 caregivers scheduled for focus groups
 - o 9 young adults scheduled for individual interviews
- Columbia, MO focus group and individual interview sessions (July 11, 2015)
 - o Contacted 103 potential participants via email and/or mail
 - o Screened 22 potential participants
 - o 10 caregivers scheduled for focus groups
 - o 4 young adults scheduled for individual interviews

Objective 2: Conduct focus group with caregivers and Individual Interviews with young adults

- Columbia, MO (Dec 6, 2014)
 - o Conducted 1 focus group (4 participants)
 - o Conducted 2 individual interviews
- Columbia, MO (Jan 17, 2015)
 - o Conducted 1 focus group (3 participants)
 - o Conducted 1 individual interview
- Kansas City, MO (Jan 31, 2015)
 - o Conducted 2 focus groups (13 participants)
 - o Conducted 11 individual interviews
- Hannibal, MO (May 2, 2015)
 - o Conducted 2 focus groups (9 participants)
 - o Conducted 7 individual interviews
- Columbia, MO (July 11, 2015)
 - o Conducted 2 focus groups (10 participants)
 - o Conducted 4 individual interviews

Milestone(s) Achieved:

Recruited 39 caregivers and 27 young adults for qualitative research

Conducted all focus groups (minimum of 2 groups per site) & individual interviews (minimum of 7 per site)

Major Task 3: Qualitative Data Analysis and Findings Dissemination
Objective 1: Clean & code data • Transcribed qualitative data for 8 focus group and 27 individual interviews (all sites) • Developed draft code guide/book for focus groups and individual interviews • Coded all transcribed data based on current code guide/book
Objective 2: Conduct statistical analysis of qualitative data & identify core concepts for the development of the HRI measure • Analyzed data using theme analysis methods in the qualitative software analysis package Atlas ti. • Two staff members were used to confirm coders separately and together to check for agreement • The final codes and code matrix (described in methods section) were matched with quotations from caregivers and youth with ASD.
Objective 3: Prepare results for publication • “Relationship interest, knowledge and experiences among adolescents with autism” ◦ Manuscript under review at <i>Autism: The International Journal of Research and Practice</i> ◦ See Appendix 6 • “Financial health and knowledge of youth with ASD” ◦ Manuscript in preparation for submission to <i>Journal of Financial Management</i> • Abstracts are being prepared for submission to the 2016 International Society for Autism Research Conference and 2016 American Pediatric Societies Conference.
Milestone(s) Achieved: Documentation of key concepts for HRI as identified by caregivers and youth One manuscript under review and one manuscript in preparation for submission Abstracts submitted to national and international conferences to disseminate results

3. Significant results and key outcomes

- The young adult demographic table (Appendix 4) was developed to show the demographic characteristics and condition specific variables for our population (n=27) of young adults with ASD (ages 16-25) with an average age of 19.19 (2.83). The majority of young adult participants were males (74.1%) and a majority of participants were white (96.3%). Sixty-one percent of participants had a high school degree, while 19.2% had some or completed vocational program, and 3.8% had a Bachelor’s degree. Forty-six percent of participants were currently employed. A majority (77.8%) live/ grew up with a two parent household structure. Current diagnoses of participants included autism/ autistic disorder (33.3%), Asperger syndrome (40.7%), PPDNOS (7.4%), and Autism Spectrum Disorder (7.4%). Eleven percent of participants had more than one of these diagnoses. A majority of self-reported severity of ASD was mild (75.0%), followed by a few moderate (21.4%) and no reported severe level of ASD. Finally, half of the young

adults believed that their diagnosis limited their abilities compared to their peers, while 28.6% did not think their abilities were limited and 17.9% did not know.

- The caregiver demographic table (Appendix 5) was developed to show the demographic characteristics for our study population (n=39) of caregivers of young adults with ASD. A majority of caregivers participating in the study were the young adult's biological mother or father (91.2%) and were also married or had a domestic partner (67.6%). Caregiver education level seemed to be higher in mothers than fathers; there were 41.1% of mothers with a Bachelor's degree or higher compared to 33.3% of fathers. Employment status of caregivers in the young adult's home had a majority of dual income homes (53.1%) with single income homes closely following (40.6%). Household incomes varied between families: 5.9% of households made under \$15,000 per year; 32.4% made between \$25,000 and \$49,999 per year; 44.1% made between \$50,000 and \$99,999 per year; and 14.7% made over \$100,000 per year.

Table 3. Young Adult and Caregiver themes generated from interviews and focus groups

Young Adult Themes	Caregiver Themes
Sexual Relationships	Sexual Relationships
Adulthood	Adulthood
Health Challenges	Health Challenges
Health Successes	Health Successes
Financial	Financial
Resources	Resources/ Suggestions
Safety	Safety
Work/ School	Work/ School
Appointments	Appointments
Medication or Illness Management	Medication or Illness Management
Self-care	Self-care
Transition to Adult Doctor	Transition to Adult Doctor
	Caregiver Stress
	Guardianship

4. Other achievements

- Nothing else to report

5. Stated goals not met:

- The grant proposal anticipated conducting individual interviews on 30 young adults with ASD. After completing and analyzing data for 27 individual interviews with young adults, we determined that data saturation had been met and the current sample size was sufficient. The protocol and sample is supported by previous research including Charmaz (2006), Cheak-Zamora, Teti and First (2014) and Cheak-Zamora (2015). In summary the goal of interviewing 30 youth with ASD was not met, but data saturation and appropriate sample size for this study was achieved.

6. Methodology:

Major ASD treatment and support agencies in three cities in the Midwest United States recruited youth and caregiver participants for this study. Study fliers were provided to agency staff for distribution to patients and their families. Interested participants contacted the research team to complete a screening questionnaire. Eligibility criteria for caregivers included having a youth with ASD between the ages of 16 and 25 years and be able to read and speak English; for youth included being between 16 and 25 years of age; having an ASD diagnosis; able to read and speak English; and capable of engaging in required study activities, as measured by youth- and caregiver-reported functional ability. The final sample included 27 youth and 39 caregivers.

A qualitative design using two modalities was utilized to identify *new* concepts related to HCT and HRI for youth with ASD. The first modality assessed caregiver perspectives on health-related transitioning using focus groups. The second modality included individual interviews with youth with ASD. The focus groups lasted approximately 2 hours and individual interviews lasted approximately 1 hour. All participants also complete two surveys to document general demographic and background information and how they rate (importance of) several health-related independence topics.

Data was analyzed using methods of theme analysis, including initial and axial coding, analytical memos, and organizational matrices and reports. The authors generated codes for analysis by consulting the existing literature on issues of independence in youth with

ASD, and inductively, with data provided from the youth themselves. Themes were generated through iterative process and utilizing qualitative software (atlas ti). Additional information regarding coding and data analysis can be found within the methods section of Appendix 6.

- **What opportunities for training and professional development has the project provided?**

- o *Training*

- All staff (n=7) that assisted with this project and additional Thompson Center staff (n=2) were trained by the Co-Investigator in qualitative data collection methods particularly how to conduct focus groups and individual interviews. Training included a presentation on qualitative methods and workshop about how to ask questions, practicing, things to be aware of, and emergency procedures. After each focus groups and individual interview session, the PI, Co-Investigator and staff had a debriefing session to continue learning about qualitative data collection methods. These training activities helped staff to attain greater proficiency in qualitative methods.
- The Co-Investigator also trained two graduate research assistants in how to code qualitative data. This provided extensive training to attain greater proficiency in conducting qualitative data collection and analyzing data, and preparing data for distribution.
- Graduate research assistants were also trained in translational research in which student learned about and assisted in the translation of research data and findings into manuscripts for publication, posters of conference presentations, and PowerPoint presentations for clinical and caregiver audiences.

- o *Professional Development*

- The PI, *Dr. Nancy Cheak-Zamora*, presented seminars on 1) utilizing qualitative methods to understand the needs of youth with ASD and their caregivers, 2) the importance of health care transition and health related independence, and 3) preliminary finds from the this project at:
 - o Healthcare Transition Research Consortium. Houston, TX, 2015

- o Thompson Center Colloquium Research Form, Columbia, MO, 2015 and 2014.
 - o Population, Education and Health (PEH) Seminar Series, University of Missouri, Columbia, MO, 2014.
 - o School of Health Professions, University of Missouri, Columbia, MO, 2014.
 - o Glennon foundation and Saint Louis University Grand Rounds Lecture Series, Saint Louis, MO, 2014.
- **How were the results disseminated to communities of interest?**
 - o Nothing to Report- Year 1 results are being prepared for dissemination.
- **What do you plan to do during the next reporting period to accomplish the goals?**
 - o In the next year, the team plans to:
 - 1) Develop an initial set of items that reflect key concepts identified in aim 1 and previous literature to create a preliminary version of a HRI outcome measure by:
 - Examining key concepts identified in qualitative data and match them with previously developed measures when possible
 - Developing items for all other concepts and match with response options/ scores
 - Combining previously developed items with new items and evaluate measurement tool for clarity, readability, ease of use & content validity; revising if necessary
 - 2) Evaluate and Pre-test HRI measure and revise (if necessary) to complete and test the HRI outcome measure by:
 - Administering measure to a small sample of caregivers of youth with ASD in cognitive interview
 - Revising text of items and/or scoring options based on caregiver feedback; reiterating process if necessary
 - Pre-testing the measure to a small sample of caregivers of youth with ASD (10 caregivers)

- Revising text of items and/or scoring options based on caregiver feedback; reiterating process if necessary

4. **IMPACT:**

- **What was the impact on the development of the principal discipline(s) of the project?**
 - o Findings from this study increased our understanding of how youth with ASD feel about their sexuality and romantic relationships, what challenges they face when trying to develop and maintain romantic relationships, what they want in future relationships, and who they talk to about these issues. This information will be used to educate health care providers, practitioners and researchers in the field of ASD, caregivers and youth with ASD in how to teach youth about sexuality and relationship building and how to help youth achieve their relationship goals, promote healthy and safe experiences and improve their quality of life.
 - o Our findings on what health-related independence topics are important to caregivers and youth with ASD will be of great importance to practitioners and researchers in the field of Health Care Transition and care for people with ASD.
- **What was the impact on other disciplines?**
 - o To our knowledge there is no research on *youth* with ASD's ability to manage their finances, financial knowledge or desire to manage their own finances in adulthood. Findings from this study provide youth perspective on these topics. This information will have a positive impact on various providers working with youth, young adults and adults with ASD. These findings will also be useful to the National Disability Institute, U.S. Department of Labor, Office of Disability and Consumer Financial Protection Bureau as these entire agencies and organizations fund and/or publish on Financial Literacy for People with Disabilities.
- **What was the impact on technology transfer?**
 - o Nothing to Report
- **What was the impact on society beyond science and technology?**
 - o Information gained from year 1 of this study will be shared with health care providers, Autism Specialists, Educators, family member and youth with ASD to

increased their understanding of the needs of young adults with ASD, train providers working with youth and young adults with ASD to promote independence and address their specific needs and increase youth ability to advocate for themselves.

- o The health-related independence measure that will be based on year 1 data will be the first to specifically measure independence in youth with ASD as well as identify specific areas in which clinicians and ASD specialists should focus to improve independence.
- o Findings related to the sexual and financial health concerns of youth with ASD and their caregivers can be used to create training sessions for providers and caregivers and education and skill building classes for youth and young adults with ASD.

5. CHANGES/PROBLEMS:

- **Changes in approach and reasons for change**

- o Nothing to Report

- **Actual or anticipated problems or delays and actions or plans to resolve them**

- o Our original plan was to conduct focus groups and interviews at Southeast Missouri State University in Cape Girardeau, MO. We had low enrollment rates leading up to the scheduled date due to numerous autism-related and disability-related events occurring on and around the original date. We had similar results when attempting to schedule other dates and times for conducting the focus groups and interviews. To resolve this issue the project team reached out to other facilities (Marion County Services for the Developmentally Disabled in Hannibal, MO) to assess availability and community interest. We received approval for this change in venue from the University of Missouri IRB on April 8, 2015 and the DOD HRPO on May 29, 2015. Recruitment and data collection were successful at the Hannibal, MO location.
 - o Similarly the first two sessions of focus groups and interviews in Columbia, MO at the Thompson Center had low turnouts, likely due to holiday activities and poor weather/travel conditions (sessions conducted in December and January). To get closer to our original goals of 36-48 caregivers and 30 young adult, we conducted a third session in Columbia, MO with two focus groups with 10

caregivers and 4 individual interviews for a total of 17 caregivers and 9 young adults participating in the Columbia, MO area.

- **Changes that had a significant impact on expenditures**

- o The project was able to reduce costs in year 1 by only making day trips to data collection locations. Participants requested Saturday day sessions only so the project team conducted all focus groups and interviews in Kansas City, MO and Hannibal, MO in one day each thus eliminating the need for overnight hotel accommodations and additional travel expenses.
- o The new location for our third data collection site (Hannibal, MO) was closer to the Thompson Center than the original location (Southeast Missouri State University in Cape Girardeau, MO), again reducing some travel costs.
- o The research core payroll was less than expected because we had a set per subject cost estimate for recruitment, and we were able to reach the target enrollment faster than we expected.

- **Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents**

- o Nothing to Report

- **Significant changes in use or care of human subjects**

- o Nothing to Report

- **Significant changes in use or care of vertebrate animals.**

- o N/A

- **Significant changes in use of biohazards and/or select agents**

- o N/A

6. PRODUCTS:

- **Publications, conference papers, and presentations**

- o **Journal publications.**

- Cheak-Zamora, N. & Teti, M.; Relationship interest, knowledge and experiences among adolescents with autism; *Autism: The International Journal of Research and Practice*; Under Review; Acknowledgement of federal support: yes.

- Cheak-Zamora, N. & Teti, M.; Financial health and knowledge of youth with ASD; Journal of Financial Management; In preparation; Acknowledgement of federal support: yes.
- o **Books or other non-periodical, one-time publications.**
 - A resource guide was compiled and was given to each participant and parent after focus group and individual interview sessions. This material was for one-time use and was not published. Acknowledgement of federal support was provided. The guides included:
 - o A “Transition Toolkit” by Autism Speaks;
 - o A pamphlet on Vocational Rehab in Missouri by the Missouri Department of Elementary and Secondary Education;
 - o Charting the Life Course Guide by the Missouri Family to Family Resource Center;
 - o And a Missouri Centers for Independent Living Coverage by County map by the Missouri Department of Health and Senior Services
- o **Other publications, conference papers, and presentations.**
 - Nothing new to report
- o **Website(s) or other Internet site(s)**
 - The following websites are the PI’s University of Missouri research page. These contain information about Dr. Cheak-Zamora’s funding, publications, and conference presentations
 - o <https://nancycheakzamora.wordpress.com/>
 - o <http://healthprofessions.missouri.edu/hs/viewProfile.php?facultyName=cheak-zamora-nancy-c>
- o **Technologies or techniques**
 - Nothing to Report
- o **Inventions, patent applications, and/or licenses**
 - Nothing to Report
- o **Other Products**
 - Nothing to Report

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

- What individuals have worked on the project?

Name:	Nancy Cheak-Zamora
Project Role:	Principal Investigator
Researcher Identifier (ORCID ID):	0000-0003-3645-3469
Nearest person month worked:	3
Contribution to Project:	Ms. Cheak-Zamora performed work in ensuring recruitment goals were met; training staff that assisted with qualitative data collection; overseeing focus groups and conducting half of the individual interviews with young adults; and identifying themes within the data that can be used to guide the HRI scale development.
Funding Support:	N/A

Name:	Michelle Teti
Project Role:	Co-Investigator
Researcher Identifier (ORCID ID):	0000-0002-3943-3810
Nearest person month worked:	1
Contribution to Project:	Ms. Teti performed work in training staff that assisted with qualitative data collection; designing, implementing, and analyzing qualitative data; and identifying themes within the data that can be used to guide the HRI scale development
Funding Support:	N/A

Name:	Katie Regan
Project Role:	Graduate Research Assistant
Researcher Identifier (ORCID ID):	N/A
Nearest person	4

month worked:	
Contribution to Project:	Ms. Regan assisted in recruiting caregiver and young adult participants; coordinating focus groups and interviews; conducting interviews; coding qualitative data; and developing reports and presentations.
Funding Support:	N/A

- **Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**

- o Nothing to Report

- **What other organizations were involved as partners?**

Collaborative organization 1

- o **Organization Name:** Autism Works
 - Autism Works is a non-profit organization serving individuals and families who are affected by Autism Spectrum Disorders. They believe that great resources, information and support should be available to everyone in the community.
- o **Location of Organization:** Kansas City, MO
- o **Partner's contribution to the project**
 - **Financial support:** none
 - **In-kind support:** none
 - **Facilities:** Autism Works' provided the facilities for one day to conduct focus groups and individual interviews.
 - **Collaboration:** The Autism Works' staff distributed research flyers and assisted in recruiting participants.
 - **Personnel exchanges:** none
 - **Other:** none

Collaborative organization 2

- o **Organization Name:** Marion County Services for the Developmentally Disabled
 - Marion County Services for the Developmentally Disabled provides services to individuals in their community who cannot be totally self-reliant, including early intervention services for an infant to transportation assistance and

independent living. Their goal is to provide services that enable individuals with disabilities the opportunity to live full lives and contribute back to the communities in which they live.

- o **Location of Organization:** Hannibal, MO
- o **Partner's contribution to the project**
 - **Financial support:** none
 - **In-kind support:** none
 - **Facilities:** Marion County Services for the Developmentally Disabled's provided the facilities for one day to conduct focus groups and individual interviews.
 - **Collaboration:** Marion County Services for the Developmentally Disabled's staff distributed research flyers and assisted in recruiting participants.
 - **Personnel exchanges:** none
 - **Other:** none

8. SPECIAL REPORTING REQUIREMENTS

- **COLLABORATIVE AWARDS**

- o N/A

- **QUAD CHARTS**

- o N/A

9. APPENDICES:

Appendix 1. Caregiver Demographic Survey

Thank you for participating and helping people learn about the needs and opinions of young adults with ASD and their caregivers. The following questions will be about you and your young adult.

Unless instructions specify otherwise, please mark X by the answer choice (only one) which MOST CLOSELY fits you or your young adult:

1) What is your relation to the young adult with ASD?

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Other (please specify): _____

2) Young Adult's Age (in years): _____

3) Young Adult's Gender: ☐ Female ☐ Male

4) Young Adult's Ethnicity:

- ☐ Hispanic or Latino ☐ Unknown
- ☐ Not Hispanic or Latino ☐ Not Reported

5) Young Adult's Race:

- ☐ American Indian or Alaska Native ☐ White
- ☐ Asian ☐ Unknown
- ☐ Black or African-American ☐ Not Reported
- ☐ Native Hawaiian or Other Pacific Islander

6) What is your young adult's highest level of education?

- ☐ Some high school
- ☐ High school
- ☐ Some trade or vocational school
- ☐ Associate's degree in vocational or technical program
- ☐ Bachelor's degree

7) Is your young adult currently attending school, such as high school, vocational or trade school, or college?

- ☐ Yes
- ☐ No

8) Does your young adult currently have paid employment?

- ☐ Yes
- ☐ No

9) If young adult works (paid or volunteer), on average, how many hours per week do they work?

- ☐ 0
- ☐ 1-9
- ☐ 10-19
- ☐ 20-29
- ☐ 30 or more

10) What is your young adult's current diagnosis?

- ☐ Autism or Autistic Disorder
- ☐ Asperger's Disorder (If they were diagnosed before the DSM 5 change)
- ☐ Pervasive Developmental Disorder (PDD NOS)
- ☐ Autism Spectrum Disorder

11) Who gave this diagnosis? Check any/all that may apply to the best of your ability.

- ☐ Primary care physician or pediatrician
- ☐ Developmental pediatrician
- ☐ Psychiatrist
- ☐ Psychologist or Neuropsychologist
- ☐ Team of healthcare professionals
- ☐ Professionals in a school system

12) How would you describe your young adult's ASD?

- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Don't know

13) During the past 12 months, how often has your young adult's ASD affected his/her ability to do things other young adults his/her age do? Would you say:

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Don't know

14) Is your young adult limited or prevented in any way in his/her/their ability to do the things most young adults of the same age can do?

- ☐ Yes
- ☐ No
- ☐ Don't know

15) Please rate your young adult's level of independence:

- ☐ Mostly or completely independent
- ☐ Good self-care skills but still needs some help
- ☐ Some self-care skills but needs a lot of help
- ☐ Few self-care skills, depend on others

16) Please rate your young adult's level of communication:

- ☐ Excellent verbal skills
- ☐ Good verbal skills
- ☐ Some verbal skills
- ☐ Few or no verbal skills

17) What is the current insurance coverage for your young adult?

- ☐ Public
- ☐ Private
- ☐ Both Public and Private
- ☐ Uninsured
- ☐ Other (please specify): _____

18) What other chronic condition(s) does your young adult have? Check all that apply.

- ☐ None
- ☐ Allergies
- ☐ Anxiety and mood disorders (such as social phobia, panic disorder, etc.)
- ☐ Asthma
- ☐ Attention-deficit hyperactivity disorder (ADHD)
- ☐ Behavior or conduct disorder
- ☐ Bipolar disorder
- ☐ Depression (such as major depressive disorder, seasonal affective disorder, etc.)
- ☐ Diabetes
- ☐ Epilepsy or Seizure disorder

- ☐ Gastrointestinal issues (such as chronic diarrhea, nausea, vomiting, acid reflux, etc.)
- ☐ Hearing problems
- ☐ Intellectual disability
- ☐ Obsessive Compulsive Disorder (OCD)
- ☐ Schizophrenia
- ☐ Skin conditions (such as psoriasis or eczema)
- ☐ Sleep disorders (such as problems getting to sleep or staying asleep)
- ☐ Other (please specify): _____

19) Parents Marital/Partner status:

- | | |
|---|------------------------------------|
| ☐ Never Married | ☐ Separated |
| ☐ Married | ☐ Divorced |
| ☐ Domestic Partnership | ☐ Widowed |

20) Mother's Education level: (select highest level attained)

- | | |
|--|--|
| ☐ 1 st through 12 th grade (no diploma) | ☐ Bachelor's degree |
| ☐ High School graduate | ☐ Master's degree |
| ☐ GED or equivalent | ☐ Professional school degree (MD, DDS, DVM, JD) |
| ☐ Some college, no degree | ☐ Doctoral degree (e.g., PhD, EdD) |
| ☐ Associate degree | ☐ Unknown |

21) Father's Education level: (select highest level attained)

- | | |
|--|--|
| ☐ 1 st through 12 th grade (no diploma) | ☐ Bachelor's degree |
| ☐ High School graduate | ☐ Master's degree |
| ☐ GED or equivalent | ☐ Professional school degree (MD, DDS, DVM, JD) |
| ☐ Some college, no degree | ☐ Doctoral degree (e.g., PhD, EdD) |
| ☐ Associate degree | ☐ Unknown |

22) Who is living in your young adult's primary residence? (check all that apply)

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Stepmother
- ☐ Stepfather
- ☐ Adoptive Mother
- ☐ Adoptive Father
- ☐ Siblings

Please note the ages of other siblings in the home and any diagnoses that they may have:

- ☐ Other (please specify): _____

23) What is your family's household income?

- | | |
|---|---|
| ☐ Under \$15,000 | ☐ \$50,000 to \$74,999 |
| ☐ \$15,000 to \$24,999 | ☐ \$75,000 to \$99,999 |
| ☐ \$25,000 to \$34,999 | ☐ \$100,000 and over |
| ☐ \$35,000 to \$49,999 | |

24) What is the employment status of the adults in your home?

- ☐ All adults employed/ dual-income
- ☐ One adult employed/ single-income
- ☐ Adults in household are currently unemployed
- ☐ Other (please specify): _____

Appendix 2. Young Adult Demographic Survey

Thank you for participating and helping people learn about the needs and opinions of young adults with ASD. The following questions will be about you and your background. Unless instructions specify otherwise, please mark X by the answer choice (only one) which MOST CLOSELY fits you:

1) Your Age (in years): _____

2) Your Gender: ☐ Female ☐ Male

3) Your Ethnicity:

☐ Hispanic or Latino ☐ Unknown
☐ Not Hispanic or Latino ☐ Not Reported

4) Your Race:

☐ American Indian or Alaska Native ☐ White
☐ Asian ☐ Unknown
☐ Black or African-American ☐ Not Reported
☐ Native Hawaiian or Other Pacific Islander

5) What is your current diagnosis?

☐ Autism or Autistic Disorder
☐ Asperger's Disorder
☐ Pervasive Developmental Disorder (PDD NOS)
☐ Autism Spectrum Disorder

6) Who gave this diagnosis?

☐ Primary care physician or pediatrician
☐ Developmental pediatrician
☐ Psychiatrist
☐ Psychologist or Neuropsychologist
☐ Team of healthcare professionals
☐ Professionals in a school system

7) Would you describe your ASD as mild, moderate, or severe?

☐ Mild
☐ Moderate
☐ Severe
☐ Don't know

8) During the past 12 months, how often has your ASD affected your ability to do things other young adults your age do? Would you say:

☐ Never
☐ Sometimes
☐ Usually
☐ Always
☐ Don't know

9) Are you limited or prevented in any way in your ability to do the things most young adults of the same age can do?

- ☐ Yes
- ☐ No
- ☐ Don't know

10) Please rate your level of independence:

- ☐ Mostly or completely independent
- ☐ Good self-care skills but still needs some help
- ☐ Some self-care skills but needs a lot of help
- ☐ Few self-care skills, depend on others

11) Please rate your level of communication:

- ☐ Excellent verbal skills
- ☐ Good verbal skills
- ☐ Some verbal skills
- ☐ Few or no verbal skills

12) Describe your use of spoken language:

- ☐ Language use is completely typical
- ☐ There are difficulties with "pragmatic" or social language
- ☐ There is difficulty expressing needs using spoken language
- ☐ Other (please specify): _____

13) What is your current insurance coverage?

- ☐ Public (i.e. Medicaid, Medicare, CHIP, or other government insurance)
- ☐ Private
- ☐ Both Public and Private
- ☐ Uninsured
- ☐ Other (please specify): _____

14) What other chronic condition(s) do you have? Check all that apply.

- ☐ None
- ☐ Allergies
- ☐ Anxiety and mood disorders (such as social phobia, panic disorder, etc.)
- ☐ Asthma
- ☐ Attention-deficit hyperactivity disorder
- ☐ Behavior or conduct disorder
- ☐ Bipolar disorder
- ☐ Depression (such as major depressive disorder, seasonal affective disorder, etc.)
- ☐ Diabetes
- ☐ Epilepsy or Seizure disorder
- ☐ Gastrointestinal issues (such as chronic diarrhea, nausea, vomiting, acid reflux, etc.)
- ☐ Hearing problems
- ☐ Intellectual disability
- ☐ Oppositional Defiant Disorder (ODD)
- ☐ Obsessive Compulsive Disorder (OCD)
- ☐ Schizophrenia
- ☐ Skin conditions (such as psoriasis or eczema)
- ☐ Sleep disorders (such as problems getting to sleep or staying asleep)

☐ Other (please specify): _____

15) With whom do you live? (check all that apply)

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Stepmother
- ☐ Stepfather
- ☐ Adoptive Mother
- ☐ Adoptive Father
- ☐ Siblings

Please note the ages of other siblings in the home and any diagnoses that they may have:

☐ Other (please specify): _____

16) What is the employment status of the adults in your home?

- ☐ All adults employed/ dual-income
- ☐ One adult employed/ single-income
- ☐ Adults in household are currently unemployed

☐ Other (please specify): _____

17) What is your highest level of education?

- ☐ Some high school
- ☐ High school
- ☐ Some trade or vocational school
- ☐ Associate's degree in vocational or technical program
- ☐ Bachelor's degree

18) Are you currently attending school, such as high school, vocational or trade school, or college?

- ☐ Yes
- ☐ No

19) Do you currently have paid employment?

- ☐ Yes
- ☐ No

20) If you work (paid or volunteer), on average, how many hours per week do you work?

- ☐ 0
- ☐ 1-9
- ☐ 10-19
- ☐ 20-29
- ☐ 30 or more

Appendix 3. Health-Related Independence Priority Measure Survey

We are trying to better understand what health-related challenges young adults with ASD and their families experience as they transition into adulthood. To help us decide which topics to study first, we are asking you to rate the importance of 11 general topics that are common issues for young adults during this transition.

1. How important is research on access to health transition resources for young adults with ASD?

This research will answer questions about what health care transition resources are available for young adults with ASD and how useful these resources are in assisting in a successful health care transition.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

2. How important is research on what motivates young adults with ASD and/or their family members to move to from a pediatric health care provider to an adult provider?

This research will answer questions about why some young adults and families transition to an adult provider while others do not.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

3. How important is research on the expectations that young adults with ASD and family members have for the young adults' future?

This research will answer questions about specific expectations and hopes that young adults with ASD and families have for their future.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

4. How important is research on how young adults with ASD develop their expectation/goals for the future and how the young adults and their families develop plans for achieving those expectations/goals?

This research will answer questions about what young adults with ASD and their families are doing (and can do) to achieve their goals and expectations as they become adults.

- ☐ Extremely high priority

- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

5. How important is research on the meaning of independence/adulthood for young adults with ASD?

This research will answer questions about what independence and adulthood means and how young adults and their caregivers view this concept.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

6. How important is research on the meaning of health-related independence for young adults with ASD?

This research will answer questions about what independence in health-related activities (such as medication self-management and self-care) means and how young adults and their caregivers view this concept.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

7. How important is research on ways that caregivers can promote health-related independence for young adults with ASD?

This research will answer questions about how caregivers can encourage and promote greater independence in health-related activities.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

8. How important is research on what young adults with ASD need to learn to gain independence in health-related activities?

This research will answer questions about what resources or trainings should be provided to young adults with ASD to help them be as independent as possible.

- ☐ Extremely high priority
- ☐ High priority

- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

9. How important is research on young adults' self-management skills?

This research will answer questions about young adults with ASD and their knowledge and ability to care for their medical and health care needs.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

10. How important is research on safety concerns for young adults with ASD?

This research will answer questions about young adult's knowledge about safety, and the young adult and family's safety concerns.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

11. How important is research on young adults' need for sexuality education?

This research will answer questions about what young adults need to know about their sexuality, what resources are needed to provide this knowledge and what young adults want related to intimate relationships as they enter adulthood.

- ☐ Extremely high priority
- ☐ High priority
- ☐ Medium priority
- ☐ Low priority
- ☐ Not a priority

12. Please list any other topics that are important to young adults with ASD and their caregivers.

Appendix 4

Table 1 Young Adult Demographic Characteristics and Condition Specific Variables ($n = 27$)

Variable	Percent
<i>Demographic variables</i>	
Gender	
Male	74.1
Race	
White	96.3
Highest level of education	
Some high school	15.4
High school	61.5
Some or vocational program	19.2
Bachelor's Degree	3.8
Current Employment	
Yes	46.2
Hours worked or volunteered weekly	
Not working	42.3
1-19 hours	30.8
20 or more hours	26.9
Household structure	
One Parent	18.5
Two Parent	77.8
Live on my own	3.7
Household Income	
Under \$15,000	7.7
\$25,000 - \$49,999	30.8
\$50,000 - \$99,999	42.3
\$100,000 and over	19.2
<i>Condition specific variables</i>	
Current diagnosis	
Autism/ Autistic disorder	33.3
Asperger Syndrome	40.7
PDDNOS	7.4
Autism Spectrum Disorder	7.4
More than 1 of these	11.1
Severity of ASD	
Mild	75.0
Moderate	21.4
Severe	0
Limited abilities compared to peers	
Yes	50.0
No	28.6

Appendix 5

Table 2 Caregiver Demographic Characteristics
(*n* = 39)

Variable	Percent
<i>Demographic variables</i>	
Relationship to Youth with ASD	
Biological Mother	76.5
Biological Father	5.9
Both Biological Mother and Biological Father	8.8
Other	8.8
Marital/Partner Status	
Never married	5.9
Married/Domestic Partner	67.6
Separated/Divorced/Widowed	26.5
Mother's Education Level	
HS graduate or GED	14.7
Some college o Associate's degree	44.1
Bachelor's degree	29.4
Master's degree	8.8
Professional school degree	2.9
Father's Education Level	
HS graduate or GED	33.3
Some college o Associate's degree	24.3
Bachelor's degree	21.2
Master's degree	12.1
Employment Status	
All adults employed/ dual-income	53.1
One adult employed/ single-income	40.6
Adults in household are currently unemployed	3.1
Other	3.1
Household Income	
Under \$15,000	5.9
\$25,000 - \$49,999	32.4
\$50,000 - \$99,999	44.1
\$100,000 and over	14.7

****The following pages contain proprietary information****

Appendix 6. "Relationship interest, knowledge and experiences among adolescents with autism"

Relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder

Journal:	<i>Autism</i>
Manuscript ID	Draft
Manuscript Type:	Original Article
Keywords:	Adolescents, Autism spectrum disorders, Qualitative research
Abstract:	A dearth of research exists to describe sexual and romantic relationships among young adults with Autism Spectrum Disorder (YA-ASD) from the perspectives of YA-ASD themselves. Sexuality and intimacy are important parts of development and influence health and quality of life. We conducted semi-structured interviews with 27 YA-ASD to explore these topics. Using theme analysis we uncovered four thematic categories defining YA-ASD's sexual and romantic relationship experiences and perspectives including: interest in relationships, imagined ideal partners, reality of relationships, and seeking advice. Although many YA-ASD expressed wanting to be in a relationship, few reported having partners. Among those that did, their actual relationships rarely met their ideals. YA-ASD talked with parents and friends but not health care providers. The need for additional sexuality and relationship education was expressed. Although all young adults likely struggle with sexuality and intimacy, YA-ASD possess additional risk factors that complicate these components of their lives. Sexual education should be introduced early and include social/relationship skills-building and courtship modeling. Caregivers, educators and providers must initiate discussions about sexual health with YA-ASD including concepts of sexual self-hood and risk. Future research should examine issues of sexuality from the young adult's perspective.

Relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder

Introduction

Sexuality is a normative aspect of development for all adolescents with or without disabilities. The last decade of research on sexuality of adolescents and adults with Autism Spectrum Disorder (ASD) have debunked previous notions of asexuality, lack of sexual experience, and high rates of sexual dysfunction. A slowly growing body of research indicates that persons with ASD have the same sexual interests and desires as neurotypical individuals (Gilmour et al., 2012; Dewinter et al., 2014; Dewinter et al., 2013; Gilmour et al., 2014). Unfortunately, the lack of social awareness and communication difficulties associated with an ASD diagnosis makes developing and maintaining sexual relationships challenging for this group. As a result, inappropriate or unsolicited sexual behavior toward others and sexual exploitation occurs in young adults with ASD more frequently than their typically developing peers (Mehzabin and Stokes, 2011; Dozier et al., 2011; Coskun and Mukaddes, 2008). Likewise, the symptoms of their disability make it difficult for young adults with ASD to have fulfilling sexual relationships that meet their needs and desires for the future (Mehzabin and Stokes, 2011; Sperry and Mesibov, 2005). In addition to a public and personal safety issue, understanding and addressing the desires, needs and experiences of young adults with ASD is a *quality of life* issue.

The vast majority of what we know about sexual and relationship health among young adults with ASD has been taken from caregiver and health provider reports (Kellaher, 2015; Dewinter et al., 2014). Although this body of work provided a preliminary understanding of sexual health for young adults with ASD there is a large gap in understanding the mental and emotional aspect of sexuality experienced by young adults themselves (Gilmour et al., 2012). Further, sexual behaviors may be greatly misreported due to the private nature of sexual

1
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3 expression and heightened vigilance towards deviant behavior among young adults with ASD
4
5 (Coskun and Mukaddes, 2008; Dozier et al., 2011). This gap in the literature has been partially
6
7 filled by an insurgence of researchers examining sexuality and sexual behavior of high-
8
9 functioning *adults* with ASD through quantitative surveys.
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11

12
13 Several of these quantitative studies include comparative analyses of sexual experiences
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15 reported by adults with ASD and their typically developing peers (Gilmour et al., 2012; Brown-
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17 Lavoie et al., 2014; Dewinter et al., 2014; Mehzabin and Stokes, 2011). Only one of these
18
19 comparative analyses included young adults with ASD and this study included only males with
20
21 high functioning autism (Dewinter et al., 2014). Results from these studies consistently show
22
23 that both adults with ASD and those without ASD had equal relationship and sexual desires,
24
25 similar knowledge about privacy, appropriate sexual behavior, and overall sexual health. On the
26
27 other hand, comparative studies provide conflicting evidence on the number of sexual
28
29 experiences persons with high-functioning ASD report, compared to their typically developing
30
31 peers (Dewinter et al., 2014; Mehzabin and Stokes, 2011; Gilmour et al., 2012). While several
32
33 studies found the prevalence of dating and intercourse to be similar between groups, others
34
35 studies uncovered that adults with ASD were significantly less likely to have as many sexual
36
37 experiences as their peers. Multiple studies have shown that rates of masturbation are similar
38
39 between groups (Dewinter et al., 2014; Byers et al., 2013).
40
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46
47 Adults with ASD report higher levels of anxiety about relationships and sex, compared to
48
49 adults without ASD. Levels of anxiety are reduced when the person becomes involved in a
50
51 relationship or has some experience with relationships (Byers et al., 2013; Byers et al., 2012).
52
53 Although previous reports indicated that persons with ASD were more likely to be sexually
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55 victimized or participate in sexual deviant behaviors, most of the current research shows that
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these experiences are infrequent and in some cases equivalent to their typically developing peers (Dewinter et al., 2014; Byers et al., 2013; Brown-Lavoie et al., 2014).

While survey-based studies have been useful in understanding the amount and types of sexual experiences had by adults with ASD, more information is needed on the individual’s experiences and perspectives. Because these studies are limited to adults, little is known about the experiences or perspectives of young adults with ASD. A small number of qualitative studies – whose methods are well-suited to explore sexuality more in-depth – offer important insight into caregivers’ perspectives and concerns about their children’s sexuality, but do not highlight young adults’ responses (Cridland et al., 2014; Kellaher, 2015; Gilmour et al., 2014). Two qualitative studies that included young adults with ASD revealed a need for more sexual education and skill-building to promote relationship development and appropriate behavior (Sperry and Mesibov, 2005; Hatton and Tector, 2010). Individuals with ASD reported a lack of self-awareness of their sexuality and believed that more opportunities to explore these ideas would have led to major changes in their lives including developing and maintaining appropriate relationships and avoiding abuse and exploitation (Hatton and Tector, 2010). Given the relative lack of research on relationships and sexuality among *young adults* with ASD, a lack of information from *young adult*’s perspectives, and the importance of understanding sexuality to promote health and quality of life, we aimed to explore sexuality and relationships among young adults with ASD through semi-structured interviews.

Method

Recruitment and eligibility

Young adults with ASD in partnership with three different major ASD treatment and support agencies in three cities in the Midwest United States were recruited for this study. Study

1
2
3 fliers were provided to agency staff for distribution to clients and patients. Interested participants
4
5 contacted the research team to complete a screening questionnaire. Eligibility criteria included
6
7 being between the ages of 16 and 25 years; having an ASD diagnosis; able to read and speak
8
9 English; and capable of engaging in required study activities, as measured by young adults - and
10
11 caregiver-reported functional ability. The final sample included 27 young adults, a sample size
12
13 determined to be sufficient for data saturation in previous analyses with young adults with ASD
14
15 (Cheak-Zamora et al., 2015; Cheak-Zamora and Teti, 2014).
16
17
18

19 *Project Procedures*

20
21
22 Participants took part in 30-60 minute semi-structured interviews. This analysis is part of
23
24 a larger study on health-related independence among young adults with ASD. The interview
25
26 guide was developed based on the authors' previous experience conducting qualitative research
27
28 with young adults with ASD (Cheak-Zamora et al., 2015), the health-related independence
29
30 literature (Cheak-Zamora et al., 2014), and feedback from ASD practitioners, researchers, and
31
32 parents of young adults with ASD. The guide included 12 questions with open and closed
33
34 prompts, preparatory multiple choice reflection questions, and the use of a white board, to
35
36 support young adult's communication. The questions covered various areas including health
37
38 management, social experiences, future aspirations and expected challenges. The majority of
39
40 data for this analysis come from the following questions: "Tell me about your relationship with
41
42 your boyfriend or girlfriend."; "What would your ideal partner or relationship to be like?";
43
44 "What kind of relationship advice do you seek from others?"; "What does it mean to be an
45
46 adult?"
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52 *Data Analysis*

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Data was analyzed using methods of theme analysis (Charmaz, 2006), including initial and axial coding, analytical memos, and organizational matrices and reports. The authors generated codes for analysis by consulting the existing literature on issues of independence in young adults with ASD, and inductively, with data provided from the young adults themselves (Charmaz, 2006). The analysis was framed around the intent to gain information on a general set of important concepts in the literature such as “experiences with the health care system” and “the meaning of independence.” As a first step, however, the second and third author reviewed all of the transcripts and created a codebook (i.e., a list of defined codes to guide the analysis and generation of themes) that combined the items in the literature with examples and language from young adults. The final codebook was comprised of ten items, including codes for “health challenges,” “relationships,” and “readiness for health independence,” among others.

Next the second and third author entered the transcripts into Atlas ti, a qualitative software analysis package (Scientific Software Development, 2011), and using the codebook, matched text excerpts to codes. Initial coding was conducted by reviewing the transcripts line by line to identify how participants’ experienced matched codes. Both coders started the analysis by coding 25% of the data independently and then meeting to calculate coder agreement. After the first 25% of coding was complete, agreement was only 60%. The coders clarified the code definitions, and coded another 25% section of data. After the second round of coding, coder agreement was 90%, so the coders completed the analysis on all 21 transcripts – meeting weekly to discuss coding, preliminary findings, and analysis memos.

Then the coders reviewed the initial coding analysis and conducted axial coding to consolidate, clarify and expand the codes and identify final themes. Finally, a matrix was created that outlined and defined each of the final themes and a report that listed example quotes under

each theme, to organize the data for the results section. The first author, who conducted many of the interviews, reviewed the matrix and report to ensure that the data appropriately reflected the content of the interviews. This analysis focuses mostly on one theme, “relationships” and its subthemes, which are outlined in the results.

Results

Participants

Demographic and condition specific characteristics of young adults (n=27) are presented in Table 1. Young adult participant's ranged in age from 16 to 25 years old ($\bar{x} = 19.19$ (SD=2.83)). The majority of the sample was non-Hispanic white and male (Table 1). Most youth within our study described themselves as having Asperger's Syndrome (40.7%) or Autism/Autistic Disorder (33.3%). While the majority of young adults rated their ASD symptoms as mildly severe (75%), with none stating but stating they had severe symptomology, half said their ASD limited their activity compared to their peers.

Summary of results

Young adult's provided extensive dialogue within individual interviews much of which focused on intimate relationships and sexuality. These topics fell into four thematic categories: interest in relationships, ideal partnerships, relationship reality, and where young adults went for relationship advice. This manuscript will elaborate on these themes utilizing pseudonyms to replace participant's names.

Interest in Relationships

When asked to define adulthood or independence, young adults readily included marriage and family in their responses. Discussing current relationships was part of a more complex conversation. Many young adults (n=22/27) said that they were not in a relationship. The

majority of these participants (n=19/27), however, expressed clear interest in *being in a relationship*. Two young adults expressed curiosity and tentative interest, five said directly that they did *not want* a relationship, and one young adult did not comment on his interest. Among the young adults who were interested in being in a relationship but did not have one, many were confused, sad, and/or frustrated by their lack of relationship success and generally lacked relationship confidence.

For instance, Rick, an 18 year old male, lamented with frustration that he did not understand why he was never asked to his school’s Sadie Hawkins dance because “I’m nice to them [girls]. I make jokes. I try to be the nicest person I can.” He even admitted that at times he “goes to school on a daily basis thinking ‘OK, is somebody going to ask me today?’” He even problem-solved his transportation barriers saying, “Even though I can’t drive doesn’t mean I can’t pick [a date] up. My mom and I can.” As a result he said he feels more comfortable with a computer, which “understands me...I can tweak it. I can enter code into it. I can make it do certain things...The computer understands me more than people do.” Rick was not alone. Similarly, Emma, a 22 year old female said she “would love to love somebody” but was “not optimistic about her chances.” Justin described some of his “awkward” relationship experiences and concluded “I’m autistic. I – we, shouldn’t have to deal with romance,” although when asked, he also said that he *did want* to be in a relationship.

Reasons for non-interest in relationships varied but centered on resistance to intimacy and the fact that relationships could bring “trouble.” A few young adults were simply uncomfortable talking about relationships and requested to move on to other topics before explaining their relationship ideas or experiences. For instance, Mark, a 19 year old male, explained that the subject was hard to discuss and said “I don't really think about sensitive stuff like this because I

1
2
3 never have had a relationship before, so I have to find a way to [express myself about this
4 topic].” Other participants were more direct. Sam said he did not want a relationship because he
5 did not want children. Amber, a 25 year old female participant explained, “No [I do not want a
6 boyfriend]. I’m just not that kind of person. I just say, ‘don’t touch me at all.’ I think that is
7 normal though.” Similarly, Emily, a 25 year old female, expressed discomfort with physical
8 touching, saying, “Not a chance in the world [that I’d have a boyfriend or girlfriend]. That is
9 gross. They kiss. I don’t want to kiss anybody.”

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11
12 Amy, a 20 year old female said “relationships are just too much trouble right now,”
13 although these sentiments may have stemmed from her ongoing reflections on her own sexuality.
14 She recently discovered she was “different” than her peers, which in her words meant that she
15 had “a lot on her plate” in regards to relationships.

16
17
18 I turned fifteen and I wasn’t really interested in guys. I was like, “Well, this is kind of
19 weird, all of my other friends already have boyfriends, and I’m not interested”...I had a
20 friend who was a lesbian, I had her take me down to Kansas City, and they had a group
21 for gays, transsexuals, lesbians, all the others. I was like, “Holy cr*p, I’m bisexual.” It
22 clicked, and I was like, “Okay, so, how do I tell my parents this?”

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24
25 Derek, a 17 year old male also said that relationships were a bit frustrating, but for different
26 reasons. He was worried about being taken advantage of – “[I’m not in a relationship] because
27 every time I want a girlfriend, it’s usually 15 or 14 or 16 year olds. I’m like ‘You know what?
28 You’re not mature and all you want is money and jewelry...I’m done with this.’” Overall, a few
29 young adults expressed outright disinterest in emotional and physical intimate relationships with
30 others. The majority of participants, however, reported wanting intimacy and companionship.

Fear of rejection, relationship anxiety, and a lack of self-confidence, particularly related to living with ASD, complicated their relationship desires.

Ideal Partners

The majority of young adults had ideas about their ideal partner. Caring, kind, smart, romantic, and funny were part of most young adult’s descriptions. As Justin put it, he wanted “somebody that can make me my best.” Understanding autism was also important. Austin, a 19 year old male commented:

Loyalty - so, not cheating on me, but really caring and understanding of my autism. I would tell them that before we get in a relationship, and hopefully that doesn’t break us up. I would say, “Does that change your view of me?” If they said no, then we’re good. Like many other male participants, Austin also wanted a girlfriend who was physically attractive. Alex – a 24 year old male, noted though, that it was not helpful to get too caught up on looks:

I used to get depressed a lot when I was a teenager, because I was not very self-confident. I wanted a girlfriend but my standards, I was aiming too high. I have a girlfriend right now, I’ve been together with her about a year and she’s great and I love her. And, that kind of taught me not everything's on looks.

When describing their ideal relationship goals, many participants’ responses were similar to those of all teens. One notable difference was the desire for a partner that understands ASD. Yet overall, young adults wanted acceptance and kindness in partners.

The Reality of Young adult’s Relationships

Young adult’s descriptions of their actual relationships sometimes differed from their ideal. As Alex noted above, his relationship was “great” and he loved his girlfriend. Yet many relationships were unclear or even seemingly unhealthy. For instance Zarah, 17 years old, said

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3 she had a boyfriend but then when she was asked about the details of the relationship she added,
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5 “Well... sometimes I barely even see him. He’ll go out of town. Right now, he lives in
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7 California. But sometimes he’ll come down here and meet me and see me.” Similarly, David –
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9 an 17 year old male, said he had a girlfriend but spoke fairly negatively about her, saying she had
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11 “little going for her.” When asked how long he was in the relationship he said he did not know,
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13 but clarified that it had been a while, “longer than a week,” elaborating that dating her was hard
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15 because “she kind of lives in the country so it takes a little bit of planning and precision.”
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19 Several young adults gave examples of relationships that were defined by drama –
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21 including confusion, cheating, and mistreatment. For instance, Amy described her first girlfriend:
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24 We had Algebra together, and then the problem was, I found out she cheated on me with
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26 a guy. And she said she was a lesbian, but yet she doesn’t believe in bisexuality, and then
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28 now, like, the next time I dated her, she left me again for another guy, and got pregnant
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30 on me.”
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34 Austin wanted to ask a girl to the prom, but he said his friends were trying to stop him because
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36 they said the girl was rude to him. “I don’t see it,” he admitted:
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39 She bossed me around, but I, like, kind of let her say stuff because I don’t want to make
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41 her mad, I want her to be happy. So, if she tells me to, like, go buy her something, I’ll
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43 buy her something. Not like a watch, but, like, candy or whatever.
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46 Alex said his relationship formed when he helped his friend with a break up. He was not
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48 particularly happy, and unenthusiastically labeled the relationship, “alright,” elaborating that
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50 “She’s had a rough life... I mean, she didn’t know about her real mom until she was like, 13.
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52 And, well, she’s younger than me. She’s 19 and I’m 24... And, basically, she might have self-
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esteem problems.” Derek, described a frustrating situation in which a girl asked him to go to a dance but when he showed up, she had another date. He explained his reaction:

Well, if you didn't want to dance with me, you should have said, “Hey, I already have a date, instead of me wasting my gas all the way to come to see your pretty little face.” So, I'm done with this. I broke up with her. And the rest is history.

Although a few young adults reported positive relationship experiences, many young adult’s relationships were defined by confusion or stress. Young adults were not sure of the status of their relationships or described being hurt or taken advantage of.

Relationship Advice

None of the participants disclosed that they were engaging in sexual activity – although many avoided the question altogether. Amy said directly that she had not had sex. It was an interest among some, however. Alex said he thought so many people were “doing it, nowadays.” He elaborated, “I remember back then people were like, ‘You can't have sex before marriage. Now, but, you know...if I feel like [it's] right...” Emily said she did not want to be in a relationship but she did directly express wanting more information about both sex and relationships.

Sex education is really important, you know? I hear nothing about sex, but I was really concerned at a lot of the noises I heard in the dorms...I thought people were hurt. [In high school] sex education was all about “Don't have sex,” which is fine if you don't care like me, but I feel like you should know more about it, recognizing good and bad in relationships in general.

Many young adults (n=24/27) did say they had someone to talk to about sex and relationships but many were also tentative in their responses and the content of those conversations was not

1
2
3 always clear. The conversations were often described as vague and about future plans like
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5 parents' encouragement of marriage or acceptance of young adult's disinterest in marriage.
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8 Many said that they talked or could talk to parents, siblings, and less often, friends. For example,
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10 Justin said that asking his friends for relationship advice was like "asking a plumber advice on
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12 how to run a country." We asked participants specific questions related to conversations they had
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14 with health care providers about puberty, sexual health and sexual risk. Only four participants
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16 said clearly that their doctors attempted to talk to them about sex and relationships in the context
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18 of their adolescent health appointments. Young adults wanted information about sex and
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20 relationships. Although they expressed having support persons in place to confide in about sex,
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22 the content of the actual conversations was unclear and young adults health care providers did
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24 not provide support
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29 **Discussion**

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31 Research to date has shown the importance of sexuality and sexual relationships of adults
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33 with ASD, yet the experiences of young adults with ASD continue to be an unexplored area.
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35 This study used qualitative methods to explore sexuality and relationships from the perspectives
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37 of young adults themselves versus those of their caregivers or in researcher-defined
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39 questionnaires.
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43 Our research shows that young adults with ASD are generally interested in sharing their
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45 experiences and desires for romantic relationships when asked. Most young adults within our
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47 study were very interested in pursuing romantic relationships, getting married, and having a
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49 family. While they reported a basic understanding of sex and relationships they had little
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51 knowledge of how to develop or manage a romantic relationship. This intersection of high desire
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53 but low applicable knowledge signals a deficit in these young adults ability to meet their life
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goals and achieve fundamental adult milestones. Helping young adults with ASD work to have appropriate romantic relationships will increase their ability to lead more fulfilling lives and aid in their ability to be independent and achieve their view of successful adulthood.

Previous research is conflicted on whether young adults have similar sexual experiences compared to their typically developing peers. While Dewinters and colleagues showed that young adult males with ASD had similar dating, partnered and masturbation experiences, adults within Mehzabin’s study indicated fewer sexual experiences and behaviors (Dewinter et al., 2014; Mehzabin and Stokes, 2011). Other studies show relatively low frequency of current or past relationships/sexual experiences among adults with ASD, but did not include a comparison group (Byers et al., 2013). Our study supports later findings as few participants reported previous sexual or romantic relationship experience.

Similarly previous studies concurred that adults and likely young adults with ASD desired romantic relationships and sexual experiences and these desires were similar to their typically developing peers. The majority of young adults with ASD in this study had the desire to be in a fulfilling romantic relationship. Unfortunately most young adults that we talked to were unable to find and develop such relationships. Most of the young adults within our study described specific challenges initiating and maintaining relationships. Many of the issues the participants discussed were age appropriate such as not knowing how to talk to the opposite sex, feeling nervous about rejection, and lack of experience.

Participants also described other issues that seemed more related to their disability such as the desire for a partner who understood ASD, ability to maintain eye contact, difficulty talking to new people, and sensory issues that resulted in avoiding physical contacts. Previous research has also documented that adults with ASD have difficulty engaging in sexual activity due to

1 sensory issues and the need to control and predict the situation (Hatton and Tector, 2010).
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3 Research suggests that being in a relationship has a positive effect on managing some of these
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5 anxieties and increasing sexual satisfaction in adults with ASD (Byers et al., 2013; Byers et al.,
6
7 2012). This provide strong support for the need to help people with ASD navigate the world of
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9 adult relationships while they are in adolescence and young adulthood as these initial
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11 experiences may lead to more profound and healthy relationships in adulthood. Youth and
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13 young adults need sexual education curriculum that start early and include social and relationship
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15 skill building. Young adults with ASD need training in effective communication and perspective
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17 taking as well as modeling of relationship initiation and dating.
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21 Other than the benefits of previous experience, to our knowledge, no other research has
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23 examined what characteristics lead to successful or unsuccessful sexual relationships among
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25 young adults with ASD. Our findings have identified challenges that young adults with ASD
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27 face while perusing romantic relationships. While understanding challenges is imperative for
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29 developing helpful support systems, identifying young adult's strengths would also contribute to
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31 research and practice (McCrimmon and Montgomery, 2014). Research documenting young
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33 adult's reports of positive and healthy relationships, positive relationship communication, and
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35 other relationship success stories could help researchers and practitioners build relationship
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37 programs and conversations and guide future research.
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41 This study found a distinct difference between the young adult's description of an ideal
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43 partner and their actual partners. Participants spoke clearly about how their ideal partner would
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45 treat them: "kind," "loving," "loyal, "nice," and "won't take advantage of me." Most young
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47 adults described partners as someone with whom they could enjoy sharing their life and
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49 described healthy relationships that they likely saw at home or on television. Some young adults
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described striving to find the perfect partner or only being attracted to the “prom queen” but even in these instances most young adults recognized that these desires were not realistic. Unfortunately these expectations did not closely match their current or previous relationship/partner. Most young adults described their relationships in negative terms by talking about their partner’s problems, feeling taken advantage of, or rarely seeing or talking to their boyfriend/girlfriend. The lack of previous literature on this subject makes it difficult to determine if these issues are common among adolescents and young adults’ lives or if they need to be addressed with specific interventions and training. Further examination of how young adults with ASD seek relationships and deal with relationship issues and how this varies by gender will be important in future research.

Young adults within our study struggled with how to initiate a relationship and how to improve or maintain relationships. Similarly, two previous studies on adults sexual education needs revealed a lack of knowledge and skills in relationship development, struggles with understanding differences between appropriate and inappropriate behavior around the opposite sex and low self-awareness about their sexuality (Hatton and Tector, 2010; Sperry and Mesibov, 2005). Many of these participants stated they wished relationship building was taught at school and that the deficiency of this understanding has “lead to major life challenges” (Hatton and Tector, 2010).

Similarly participants within this study said they wanted more information about how to be in a relationship but did not know who to talk to. Several participants described not being able to talk to their parents or doctor about sexuality and relationships and not trusting that their friends had accurate information. Research suggests that compared to typically developing adults, adults with ASD were less likely to get information from social sources such as health

care providers, parents and peers and more likely to use non-social sources such as the television, internet, brochures and pornography (Brown-Lavoie et al., 2014). This is troubling as the accuracy of this information is questionable at best. Further this form of information gathering hinders the young adult's support systems from understanding the young adults needs and may increase the likelihood of sexual victimization (Brown-Lavoie et al., 2014). Caregivers, educators and health care providers should be empowered to have discussions about sexual health with young adults with ASD. If these groups lack knowledge, comfort, or self-efficacy to have these conversations, trainings are also needed to help people have conversations about intimacy and relationships with youth. Further when sexual education courses are taught in school it is important to ensure that young adults with ASD attend and that information is presented in multiple formats and in ways they can understand. Post-program interviews with youth can shed light on what youth learn in these programs as well as answer youth's remaining questions.

Learning dating etiquette and about the emotional and safety rules are also important and challenging. Young adults with ASD may not pick up on unspoken social rules about privacy, personal space or sexual forwardness. They may lack information about sexually transmitted infections and how to have safe sex. As Amy explained, young adults may have questions about sexual self-hood including sexual orientation and gender identity. Sexual selfhood is a concept that most young adults and adults struggle with but can be increasingly illusive for young adults with ASD, due to lack of information and limited self-awareness. Caregivers and schools may not understand the importance of teaching these lessons, may dismiss these issues based on assumptions about young adult's sexuality, or may not have the needed resources or skills. Young adults understanding of their sexual selfhood will help them create a positive self-image

and sexual self-view as well as reduce the likelihood of abuse and sexual exploitation (Byers et al., 2013; Brown-Lavoie et al., 2014).

Limitations

Our study was qualitative study; as such we did not aim to collect generalizable data but to explore the experiences of specific young adults in detail. Our study might not capture the experiences of young adults who differ from our study population (e.g., participants from urban areas, racial/ethnic minorities). The individual interviews were effective for many but not all of the participants. Combining focus groups with individual interviews may have provided more opportunity for individual reflection and may have increased comfort and participation among young adults with more extreme communication challenges. Asking additional detailed and direct questions about sexual behavior may have resulted in more information about specific sexual acts and practices.

Conclusion

This study collected qualitative data from young adults with ASD, which is a new but much needed area of study (Kaehne and O'Connell, 2010). We found that young adults with ASD are interested in romantic and sexual relationships but are relatively unprepared to develop or sustain them. Finding and maintaining relationships is important for young adult's health and quality of life. Although educational programs and research on sexual health of young adults with ASD have been established, these efforts may be missing the mark by not including young adults in the development of the programs, such as selecting topics to be included and the method for providing the information. Our research provides greater insight into how young adults perceive romantic relations, their experiences and desires for the future. These findings are important because they not only improve our understanding of sexuality of young adults with

ASD, but also demonstrate a sound methodological procedure (individual interviews) to facilitate input from young adults with ASD. Looking ahead, parents, educators and health care providers will need data like this to understand young adult sexual health and safety, before they can develop better practices to support them.

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Table 1 Participant Demographic Characteristics and Condition Specific Variables
(*n* = 27)

Variable	Frequency	Percent
<i>Demographic variables</i>		
Gender		
Male	20	74.1
Race		
White	26	96.3
Highest level of education		
Some high school	4	15.4
High school	16	61.5
Some or vocational program	5	19.2
Bachelor’s Degree	1	3.8
Current Employment		
Yes	12	46.2
Hours worked or volunteered weekly		
Not working	11	42.3
1-19 hours	8	30.8
20 or more hours	7	26.9
Household structure		
One Parent	5	18.5
Two Parent	21	77.8
Live on my own	1	3.7
Household Income		
Under \$15,000	2	7.7
\$25,000 - \$49,999	8	30.8
\$50,000 - \$99,999	11	42.3
\$100,000 and over	5	19.2
<i>Condition specific variables</i>		
Current diagnosis		
Autism/ Autistic disorder	9	33.3
Asperger Syndrome	11	40.7
PDDNOS	2	7.4
Autism Spectrum Disorder	2	7.4
More than 1 of these	3	11.1
Severity of ASD		
Mild	21	75.0
Moderate	6	21.4
Severe	0	0
Limited abilities compared to peers		
Yes	14	50.0
No	8	28.6
Don’t Know	5	17.9