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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 including 3 focus groups with caregivers and individual interviews with 27 youth. We identified major themes including: caregiver stress, relationships, health challenges, financial, safety, work/school, medication management, transition to adult doctor, and self-care. Within Aim 2a of the study we utilized the themes from Aim 1 and experts in the field to develop an ASD-specific HRI outcome measure. The HRI measure covers 8 domains. The individual items and response options were evaluated by experts in the field, caregivers and youth with ASD and revised based on their recommendations. Cognitive interviewing and full-scale pretesting were then conducted to examine the validity, appropriateness, and user-friendliness of the measure. Within Aim 2b, the HRI measure along with established HCT measures were administer to a national sample of 510 caregivers to better understand HCT, HRI, and predictors of success. Exploratory Factor Analysis was conducted to examine the HRI items and develop independent and reflective constructs and a meaningful total score. The final HRI measure included 5 constructs and was shown to be valid.

15. SUBJECT TERMS
youth with ASD, health-related independence, health care transition, qualitative methods, measure development

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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 and thereby 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 year one of this study (Aim 1), we utilized qualitative methods, focus groups and individual interviews, to examine what aspects of the HCT and HRI and most important and needed by youth with ASD (ages 16-25) and their caregivers. Within year two of this study (Aim 2a), we utilized the qualitative data to develop a measure of HRI. The HRI measure was then tested and revised through an iterative process, using expert, caregiver and youth with ASD feedback, and cognitive and pilot testing. Within year 3, we implemented the HRI measure in 5 national clinics to understand the transition experiences of youth with ASD and their caregivers and examine the reliability and validate of the measure. The HRI measure along with established HCT measures were administer to a national sample of 510 caregivers to better understand HCT, HRI, and predictors of success. Exploratory Factor Analysis was conducted to examine the HRI items and develop independent and reflective constructs and a meaningful total score. The final HRI measure included 5 constructs (Knowledge of medical and mental health conditions, Health care visit and medication management, Sexual health knowledge, Safety and Sexual Safety knowledge, and Health Insurance knowledge). All constructs were shown to independently contribute to the HRI total score. The five-factor HRI measure performed well on all convergent and construct validity analysis. This project developed an HRI-scale that is a self-administered measure of health care transition and independence needs of a unique and under-represented population- young adults with ASD. This scale identifies their specific transition needs and will assist in developing tailored-interventions.

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	November 2014
Milestone Achieved: IRB/IACUC & HRPO/ACURO Approval Guides developed and staff trained		
Major Task 2: Recruit subjects and conduct Focus Groups and Individual Interviews	Jan 2015- May 2015	July 2015
Milestone(s) Achieved: Recruit 36 cg and 30 y for qualitative research Conduct all focus groups (2 groups per site) & individual interviews (10 per site)		October 2015
Major Task 3: Qualitative Data Analysis and Findings Dissemination	May 2015- Jan 2016	January 2016
Milestone(s) Achieved: Document of key concepts for HRI as identified by caregivers and youth. Publication of 1-2 papers related to results		December 2016

Table 2. Approved Statement of Work with Year 2 Completion Updates

Specific Aim 2a: Develop and test an ASD-specific HRI outcome measure through an iterative process using qualitative findings from Aim 1 and experts in the field.		
Aim and Task	**Targeted timeline**	**Completed date or %**
Major Task 1: Develop initial set of items that reflect the key concepts identified in Aim 1	Oct 2015-March 2016	April 2016
Milestone(s) Achieved: Preliminary version of a HRI outcome measure		May 2016
Major Task 2: Pilot test HRI measure and revise if necessary	April 2016-Oct 2016	October 2016
Milestone(s) Achieved: Complete and tested HRI outcome measure		February 2017

Table 3. Approved Statement of Work with Year 3 and 4 Completion Updates

Specific Aim 2b: Administer a previously established HCT measure and the ASD-specific HRI outcome measure to a national sample of caregivers to better understand HCT, HRI, and predictors of success.

Aim and Task	Targeted timeline (months)	Completed date or %
Major Task 1: Recruit subjects and distribute survey for completion	September 2016 – February 2017	August 2017
Milestone(s) Achieved: Estimated 500 completed survey		October 2018
Major Task 2: Data inputting, analysis, and publication development	February 2017 – December 2017	October 2018
Milestone(s) Achieved: Publication of 2-4 papers Publication of HRI scale for use in health care and educational settings		90% Completed

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

Specific Aim 1:
Explore HCT and Health-related Independence (HRI) experiences and needs of youth with ASD and their caregivers utilizing qualitative methods

- **Qualitative Research Project Completed**
  - 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)
- **Publications**
  - **Cheak-Zamora N.C.**, Teti M., Maurer-Batjer A.,* & Koegler E.* (2017). Exploration and comparison of adolescents with autism spectrum disorder and their caregiver's perspectives on transitioning to adult health care and adulthood. *Journal of Pediatric Psychology*. Published online May 2017 DOI: 10.1093/jpepsy/jsx075
  - **Cheak-Zamora N.C.**, Teti M., Peters C. & Maurer-Batjer A.* (2017). Financial capabilities among youth with autism spectrum disorder. *Journal of Children and Family Studies*. 26:1210-1317. DOI: 10.1007/s10826-017-0669-9
  - First J.*, **Cheak-Zamora N.C.**, & Teti M. (2016). A qualitative study of stress and coping with transitioning to adulthood with autism spectrum disorder. *Journal of Family Social Work*. Published online 08 June 2016 **DOI:**10.1080/10522158.2016.1185074
- **Aim 1 Regional, national, and international presentation**
  - Cheak-Zamora N.C., Teti M., and Regan, C.* (2016). Relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Poster presentation, Pediatric Academies Societies Annual Meeting. Baltimore, MD. April 30-May 4.
  - Cheak-Zamora N.C., Teti M., and Regan, C.* (2016). Relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Poster presentation, International Meeting for Autism Research (IMFAR). Baltimore, MD. May 11-14.
  - Cheak-Zamora N.C., Teti M., & Regan, C.* (2016). A patient-centered, collaborative approach to creating a measure of health independence among young adults with autism spectrum disorder. Poster session, Health Care Transition Research Consortium Research Symposium. Houston, TX. October 26.
  - Cheak-Zamora N.C., Teti M., and Regan, C.* (2016). Sexual and relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Podium

presentation, Health Care Transition Research Consortium Research Symposium. Houston, TX. October 26.

- Cheak-Zamora N.C., Teti M., and Regan, C. (2016). Sexual and relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Podium presentation, American Public Health Association Annual Meeting. Denver, CO. October 29-November 2.
- Cheak-Zamora N.C., Teti M., and Regan, C. (2016). A patient-centered, collaborative approach to creating a measure of health independence among young adults with Autism Spectrum Disorder. Podium presentation, American Public Health Association Annual Meeting. Denver, CO. October 29-November 2.
- Cheak-Zamora N.C. (2016, October). *Equity, diversity and inclusion in maternal and child health.* Session moderator, American Public Health Association Annual Meeting. Denver, CO.

Specific Aim 2a:
Develop and test an ASD-specific HRI outcome measure through an iterative process using qualitative findings from Aim 1 and experts in the field.

- **Development of Health Related Independence (HRI) and additional survey material**
  - See Appendix 1
- **Qualitative and Quantities Research Project Completed- Cognitive Interviews and HRI Pretest.**
  - Conducted 15 Cognitive Interview with caregivers
  - Conducted 21 pretest surveys with caregivers, completed 12 follow-up phone calls with caregiver participants.
- **Publications**
  - Teti M., **Cheak-Zamora N.C.**, Maurer-Batjer A.,* & Bauerband, L. (2018). A qualitative comparison of caregiver and youth perspectives on sexuality and relationships among youth with autism. Journal of Developmental & Behavioral Pediatrics. Published online ahead of print November 2018. doi: 10.1097/DBP.0000000000000620
- **Publications under review**
  - **Cheak-Zamora, N.C.,** Teti, M., Maurer-Batjer, A., O'Connor, K.V., and Randolph, J.K. "Sexual and relationship interest, knowledge and experiences among adolescents with Autism Spectrum Disorder." Submitted to *Archives of Sexual Behavior* on *12/27/2016* Revisions received *05/31/2017* Resubmitted *08/25/2017*
- **Aim 2a Regional, national, and international presentation**
  - Cheak-Zamora, N.C., Teti, M., and Maurer-Batjer, A. (2017). Development and testing of a Health-Related Independence measure for young adults with Autism Spectrum Disorder. Pediatric Academies Societies 2017 Meeting. San Francisco, CA. May 6-9,
  - Cheak-Zamora, N.C., Teti, M., and Maurer-Batjer, A. (2017). Development and Testing of a Health-Related Independence Measure for Young Adults with Autism Spectrum Disorder. 2017 International Meeting for Autism Research. San Francisco, CA. May 10-13.
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Evaluation of Health-Related Independence Measure – Development and Testing. Poster. Healthcare Transition Research Consortium. Houston, TX. Oct. 4.
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Assessing Mental Health Conditions Prevalence, Knowledge, and Care Seeking Behavior in Youth with Autism Spectrum Disorder 4th Annual Mental Health Transition Collaborative. Houston, TX. Oct. 4.
  - Anna Maurer-Batjer, A., Cheak-Zamora, N.C., and Teti, M. (2017). Transitioning to adult health care and adulthood: Adolescents with Autism Spectrum Disorder and their caregivers' perspectives. Presentation. APHA 2017 Annual Meeting & Expo. Atlanta, GA. Nov. 4 – 8.
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Assessing mental health conditions prevalence, knowledge, and care seeking behavior in youth with Autism Spectrum Disorder. Poster. APHA 2017 Annual Meeting & Expo. Atlanta, GA. Nov. 4 – 8.

Specific Aim 2b:
Administer a previously established HCT measure and the ASD-specific HRI outcome measure to a national sample of caregivers to better understand HCT, HRI, and predictors of success.

- **Quantitative Research Project Completed**
    - 484 completed survey by caregivers of young adults with ASD from 5 clinics across the US (510 partially completed surveys)
    - Conducted factor analysis on HRI scale
- **Publications under review**
    - **Cheak-Zamora N.C.**, Maurer-Batjer A.,* Malow, B. & Coleman A. Self-determination in Young Adults with Autism Spectrum Disorder. Under review at Journal of Autism and Developmental Disabilities.
- **Publications in preparation**
    - **Cheak-Zamora N.C.,** Teti M., Maurer-Batjer, A.* & Petroski, G. Development and testing of a Health Related Independence measure for young adults with Autism Spectrum Disorder.
    - **Cheak-Zamora N.C.,** & Maurer-Batjer, A.* Assessing and Comparing Health-Related Independence for Physical and Mental Health Conditions in Youth with Autism Spectrum Disorder.

- **Aim 2b Regional, national, and international presentations**
    - Cheak-Zamora, N.C. Teti, M. and Maurer-Batjer, A. (2018). Adolescents with Autism Spectrum Disorder and Their Caregiver's Perspectives on the Adolescents' Sexuality and Relationships. International Society for Autism Research (INSAR) 2018 Annual Meeting. Rotterdam, Netherlands. May 9 – 12, 2018.
    - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Assessing and Comparing Health-Related Independence for Physical and Mental Health Conditions in Youth with Autism Spectrum Disorder. International Society for Autism Research (INSAR) 2018 Annual Meeting. Rotterdam, Netherlands. May 9 – 12, 2018. Submitted *10/18/2017*
    - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2018). Mixed method approach to examining sexual and relationship health in adolescents with Autism Spectrum Disorder. American Public Health Associations (APHA) 2018 Annual Meeting & Expo. San Diego, CA. Nov. 10-14.
    - Cheak-Zamora, N.C., Maurer-Batjer, A., and Petroski, G. (2018). Disparities in self-determination in young adults with Autism Spectrum Disorder. APHA 2018 Annual Meeting & Expo. San Diego, CA. Nov. 10-14.

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

Year 1 of Grant:

- **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.

- **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:
        - Healthcare Transition Research Consortium. Houston, TX, 2015
        - Thompson Center Colloquium Research Form, Columbia, MO, 2015 and 2014.
        - Population, Education and Health (PEH) Seminar Series, University of Missouri, Columbia, MO, 2014.
        - School of Health Professions, University of Missouri, Columbia, MO, 2014.
        - Glennon foundation and Saint Louis University Grand Rounds Lecture Series, Saint Louis, MO, 2014.

Year 2 of Grant:

- **Training**
    - Cognitive interview training
        - Developed cognitive interview guide with guidance from Dr. Teti, our Co-I, with qualitative expertise on 4/14/2016
        - Cognitive interview training session was held at the Thompson Center on 4/19/2016 to train study staff on how to effectively conduct a cognitive interview
        - Provided staff with both cognitive interview guide and an editorial report that explained cognitive interviews
    - Pretest follow-up phone call
        - Graduate research assistant developed a protocol for follow-up phone call with feedback from Dr. Teti (Co-I) and trained research staff on phone call etiquette and data collection process
    - REDCap training
        - Graduate research assistant attended REDCap training session in order to learn how to most efficiently and effectively create an electronic survey
        - Graduate research assistant subsequently trained PI and another research assistant on REDCap
- **Professional Development**
    - The PI, *Dr. Nancy Cheak-Zamora*, presented seminars on 1) utilizing collaborative approach to develop scale to measure health-related independence among youth with ASD, 2) the importance of health care transition and health related independence, and 3) preliminary finds from the this project at:
        - Thompson Center Colloquium Research Form, Columbia, MO, Feb. 2016.
        - Cheak-Zamora N.C., Teti M., & Regan, C.* (2016). Sexual and relationship interest, knowledge and experiences among young adults with autism spectrum disorder. Podium presentation, Health Care Transition Research Consortium Research Symposium. Houston, TX. Oct. 26.
        - Cheak-Zamora N.C., Teti M., & Regan, C.* (2016). A Collaborative approach to creating a measure of health independence among young adults with Autism Spectrum Disorder. Poster presentation, Health Care Transition Research Consortium Research Symposium. Houston, TX. Oct. 26.
        - Cheak-Zamora N.C., Teti M., and Regan, C.* (2016). A patient-centered, collaborative approach to creating a measure of health independence among young adults with Autism Spectrum Disorder. Podium presentation, American Public Health Association Annual Meeting. Denver, CO. Oct 29-Nov 2.
        - Cheak-Zamora N.C. (2016). Equity, diversity and inclusion in maternal and child health. Session moderator, American Public Health Association Annual Meeting. Denver, CO. Oct 29-Nov 2.

Year 3 and 4 of Grant:

- Training
  - Online Survey Development Training
    - Use of Google Drive for Young Adult Cognitive Interviews
      - Graduate research assistant developed demographic survey on Google Forms through Google Drive
      - Graduate research assistant developed cognitive interview guide on Google Docs through Google Drive to have in-time online dialogs with participants
      - Graduate research assistant created tutorial to inform other research staff on how to use Google Drive
    - REDCap training
      - Graduate research assistant created REDCap tutorials for collaborating sites
        - General REDCap training
        - Exporting Data
        - How to use “Participant Identifier” feature
        - REDCap- Call questions required
        - REDCap Guide of Missing Choices
        - Inactive REDCap surveys
        - Update Clinical Data on REDCap instructions
        - Update Waiver of Documentation of Consent on REDCap
- Professional Development
    - Dr, Cheak-Zamora has presented and attended training session on Health Care Transition and Adolescent Health Research to several academic and professional groups including: School of Health Professions; Thompson Center for Autism and Neurodevelopmental Disorders, and an international Health Care Transition Research Consortium.

How were the results disseminated to communities of interest?

Year 2 of Grant:

- The PI conducted a presentation of findings at a Panel Discussion and Question and Answer Session for over 70 family members and educators to share information regarding the needs of young adults with autism and their caregivers at Autism: The Teenage Years and Beyond held at the Mercy Health Center in St. Louis, MO 2/22/2016

Year 3 of Grant:

- The results of this project were disseminated to caregivers of young adults with ASD and people with ASD, as they make up the communities of interest. These individuals can access the results through the local paper, newsletters, television, news reports, and community forums. This includes but is not limited to:
  - Presentation at Thompson Center Client Day and Open house
  - Published interview for Autism Speaks Newletter
- For health care providers and researchers in the field please see references conference presentations and publications.

What do you plan to do during the next reporting period to accomplish the goals?

Nothing to Report

4. IMPACT:

- **What was the impact on the development of the principal discipline(s) of the project?**

Year 1 of Grant:

- Findings from this study increased our understanding of how youth with ASD feel about their sexuality and romantic relationships, what challenges they face when tiring 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.
- 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.

Year 2 of Grant:

- Findings from this study increased our understanding of youth with ASD's level of health-related independence (HRI) in regards to: Knowledge about medical and mental health conditions; Self-Care; Medication Management; Health care visits; Safety; Sexual Health; HC Financial Management; and Developing goals for future / goal planning. 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 health skills and how to help youth achieve their health independence goals, promote healthy and safe experiences, and improve their quality of life.
- Our findings on how caregivers interpret HRI topics are important to caregivers and youth with ASD, as well as great importance to practitioners and researchers in the field of Health Care Transition and care for people with ASD. This understanding will help practitioner communicate more effectively with caregiver as well as make communication with youth with ASD a priority during health care appointments.

Year 3 and 4 of Grant:

- *Young Adult Cognitive Interviews*: Our findings on how young adults with ASD interpret HRI topics are important not only to young adults and youth with ASD, but findings also hold great importance to practitioners and researchers in the field of Health Care Transition and care for people with ASD. This understanding will help practitioners communicate more effectively with youth with ASD which should be a priority during health care appointments in order to empower youth and improve health care knowledge.
- *HRI Survey Data:* Findings from this study increased our understanding of youth with ASD's level of health-related independence (HRI) in regards to: Knowledge about medical and mental health conditions; Self-Care; Medication Management; Health care visits; Safety; Sexual Health; Health Care Financial Management; and Developing goals for future / goal planning. This information can be used to educate health care providers, practitioners, researchers, caregivers, and youth with ASD on how to best teach health skills and how to help youth achieve their health independence goals, promote healthy and safe experiences, and improve their quality of life.

- **What was the impact on other disciplines?**

Year 1 of Grant

- 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.

Year 2 of Grant

- Within year 2, findings from Aim 1 and 2a of this study have been presented at discipline at the Principle's Investigators academic discipline conference Public Health (American Public Health Association) as well as discipline specific conferences in: Autism (International Meeting for Autism Research), Pediatric (Pediatric Academies Societies), and Health Care Transition (Health Care Transition Research).
- Understanding what aspects of health and self-care are important to youth with ASD and their caregivers is imperative. To our knowledge, there are currently no measures of a youth with ASD's ability to manage their own health care needs and few for youth with other special health care needs. The HRI measure we developed and pretested can be used by numerous researchers to examine what factors predict independence. Findings from this study will provide youth and caregivers perspectives on these topics. It will also allow practitioners to evaluate what system level improvements are needed to promote independence for youth with ASD. 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 American Public Health Association and Health Care Transition Research Consortium; as well as the following journals: Pediatrics; Journal of Autism and Developmental Disorders; Journal of Adolescent Research; Journal of Developmental and Behavioral Pediatrics; and Autism: The International Journal of Research and Practice.

Year 3 and 4 of Grant

- Within year 3, findings of this study have been presented at the Principle's Investigators academic discipline conference Public Health (American Public Health Association) as well as discipline specific conferences in Autism (International Meeting for Autism Research), Pediatrics (Pediatric Academies Societies), and Health Care Transition (Health Care Transition Research).
- Understanding what aspects of health and self-care are important to youth with ASD and their caregivers is imperative. To our knowledge, there are currently no measures of a youth with ASD's ability to manage their own health care needs and few for youth with other special health care needs. The HRI measure included in the national sample can be used by numerous researchers to examine what factors predict independence. Findings from this study will provide youth and caregivers' perspectives on these topics. It will also allow clinical practitioners to evaluate what system level improvements are needed to promote independence for youth with ASD. 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 American Public Health Association and Health Care Transition Research Consortium; as well as the following journals: Pediatrics; Journal of Autism and Developmental Disorders; Journal of Adolescent Research; Journal of Developmental and

Behavioral Pediatrics; Archives of Sexual Behavior; and Autism: The International Journal of Research and Practice.

- **What was the impact on technology transfer?**
  - We utilized an electronic survey database, REDCap (Research Electronic Data Capture) to create and disseminate our Health-related Independence measure. REDCap is a secure web-based application for survey development and data storage. Through REDCap, results can be easily transferred. Additionally, the created surveys can be shared. The 5 participating clinics will be using the survey we developed on REDCap to recruit and collect data on caregivers within their clinics. Beyond this study, providers, educators, and health care facilities can use the REDCap survey with little adaptation in order to gage the health-related independence of their patients, clients, and students.

  - We prepared the Health Related Independence Survey in an electronic format. It is and has been easily distributed and used online in various clinics to improve clinic care.

- **What was the impact on society beyond science and technology?**

Year 1 of Grant

- 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.
- 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.
- 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.

Year 2 of Grant

- Information gained from year 2 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.
- The developed health-related independence measure based on year 1 data is 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.

Year 3 and 4 of Grant

- Information gained from year 3 of this study has and will be shared with health care providers, autism specialists, educators, family members, and youth/young adults with ASD to increase their understanding of the needs of youth/young adults with ASD. Also, this information can be used to train providers working with youth/young adults with ASD to promote independence and address their specific needs. Further, this training could increase youth's ability to advocate for themselves.

- The health-related independence (HRI) measure developed based on year 1 data is the first to specifically measure independence in youth with ASD as well as identify specific areas in which clinicians, ASD specialists, and caregivers should focus to improve independence. The implementation of the HRI measure in primary care clinics will 1) improve the awareness of caregivers and youth with ASD regarding the youth's level of independence and areas of needed improvement, 2) education health care providers on the need for transition services, and 3) provide a mechanism for tracking progress in the development of medical management, self-care and safety skills.

5. CHANGES/PROBLEMS:

● Changes in approach and reasons for change

- Nothing to Report

● Actual or anticipated problems or delays and actions or plans to resolve them

Year 1

- 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.
- 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.

Year 2

- Developing items for the HRI measure required more iterations than we expected. This has extended our timeline for this phase of our project.

Year 3

- Receiving approval for the third phase of our study, which involved including cooperating sites on our IRB, took longer than we expected. We did not realize we needed to submit a sub-form for approval, thus extending the IRB process. Amendment was approved quickly once sub-from was completed. We adjusted our timeline slightly to stay on track to complete tasks on time. This includes providing additional time for each collaborative site to collect data, preparing analysis plan and data dictionary while data collection is in progress, and shortening the time allotted to the data analysis process.

- **Changes that had a significant impact on expenditures**
  - Nothing to Report
- **Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents**
  - Nothing to Report
- **Significant changes in use or care of human subjects**
  - Nothing to Report
- **Significant changes in use or care of vertebrate animals.**
  - Nothing to Report
- **Significant changes in use of biohazards and/or select agents**
  - Nothing to Report

6. PRODUCTS:

- **Publications, conference papers, and presentations**
  - **Journal publications.**
    - **Published journal articles**
      - First J.[*], **Cheak-Zamora N.C.**, & Teti M. (2016). A qualitative study of stress and coping with transitioning to adulthood with autism spectrum disorder. *Journal of Family Social Work*. Published online 08 June 2016 **DOI:**10.1080/10522158.2016.1185074
      - **Cheak-Zamora N.C.**, Teti M., Maurer-Batjer A.,[*] & Koegler E.[*] (2017). Exploration and comparison of adolescents with autism spectrum disorder and their caregiver's perspectives on transitioning to adult health care and adulthood. *Journal of Pediatric Psychology*. Published online May 2017 DOI: 10.1093/jpepsy/jsx075
      - **Cheak-Zamora N.C.**, Teti M., Peters C. & Maurer-Batjer A.[*] (2017). Financial capabilities among youth with autism spectrum disorder. *Journal of Children and Family Studies*. 26:1210-1317. DOI: 10.1007/s10826-017-0669-9
      - Teti M., **Cheak-Zamora N.C.**, Maurer-Batjer A.,[*] & Bauerband, L. (2018). A qualitative comparison of caregiver and youth perspectives on sexuality and relationships among youth with autism. Journal of Developmental & Behavioral Pediatrics. Published online ahead of print November 2018. doi: 10.1097/DBP.0000000000000620
    - **Manuscripts under review**
      - Cheak-Zamora, N.C., Teti, M., Maurer-Batjer, A., O'Connor, K.V., and Randolph, J.K. "Sexual and relationship interest, knowledge and experiences among adolescents with Autism Spectrum Disorder." Submitted to *Archives of Sexual Behavior* on *12/27/2016* Revisions received *05/31/2017* Resubmitted *08/25/2017*
      - **Cheak-Zamora N.C.**, Maurer-Batjer A.,[*] Malow, B. & Coleman A. Self-determination in Young Adults with Autism Spectrum Disorder. Under review at Journal of Autism and Developmental Disabilities
    - **Manuscript currently being prepared for submission**
      - Cheak-Zamora, N.C., Teti, M., and Maurer-Batjer, A. (2016). "Development and testing of a health-related independence measure for Young Adults with Autism Spectrum Disorder."

        - **Cheak-Zamora N.C.,** & Maurer-Batjer, A.* Assessing and Comparing Health-Related Independence for Physical and Mental Health Conditions in Youth with Autism Spectrum Disorder.

- ### Books or other non-periodical, one-time publications.
    - Teti M., Majee W., Cheak-Zamora N.C., & Maurer-Batjer A.* Understanding health through a different lens: Three applications of Photovoice in public health. In Press, *Research Methods in Health and Social Sciences, Volume 3: Innovative Research Methods in Health Social Science*, Springer Publications.
    - *Assisted with the development and writing of the Chapter 6:* How Can We Meet the Needs of People with ASD as They Progress into and through Adulthood? Of the 2016-2017 *IACC Strategic Plan*.
        - Interagency Autism Coordinating Committee (IACC). 2016-2017 Interagency Autism Coordinating Committee Strategic Plan For Autism Spectrum Disorder. October 2017. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/strategic-plan/2017.

- ### Other publications, conference papers, and presentations.

- **Invited Presentation**
    - **Cheak-Zamora N.C.** (2017, January). *Creating a measure of Health-Related Independence among young adults with Autism Spectrum Disorder*. Podium presentation, Transition Research Consortium Meeting. Teleconference.
    - **Cheak-Zamora N.C.** (2016, February). *Autism: The teenage years and beyon*d. Podium presentation, Thompson Foundation for Autism. Mercy Hospital, Creve Coeur, MO.
    - **Cheak-Zamora N.C.** (2014, May). *Transition of care from pediatric- to adult-centered care*. Podium presentation, Glennon Foundation and Saint Louis University Grand Rounds Lecture Series. Saint Louis, MO.

- **2016 Regional, national, and international presentation**
    - Cheak-Zamora N.C., Teti M., and Regan, C.* (2016). Relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Poster presentation, Pediatric Academies Societies Annual Meeting. Baltimore, MD. April 30-May 4.
    - Cheak-Zamora N.C., Teti M., and Regan, C.* (2016). Relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Poster presentation, International Meeting for Autism Research (IMFAR). Baltimore, MD. May 11-14.
    - **Cheak-Zamora N.C.,** Teti M., & Regan, C.* (2016). A patient-centered, collaborative approach to creating a measure of health independence among young adults with autism spectrum disorder. Poster session, Health Care Transition Research Consortium Research Symposium. Houston, TX. October 26.
    - Cheak-Zamora N.C., Teti M., and Regan, C.* (2016). Sexual and relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Podium presentation, Health Care Transition Research Consortium Research Symposium. Houston, TX. October 26.
    - Cheak-Zamora N.C., Teti M., and Regan, C. (2016). Sexual and relationship interest, knowledge and experiences among young adults with Autism Spectrum Disorder. Podium presentation, American Public Health Association Annual Meeting. Denver, CO. October 29-November 2.

- Cheak-Zamora N.C., Teti M., and Regan, C. (2016). A patient-centered, collaborative approach to creating a measure of health independence among young adults with Autism Spectrum Disorder. Podium presentation, American Public Health Association Annual Meeting. Denver, CO. October 29-November 2.
- **Cheak-Zamora N.C.** (2016, October). *Equity, diversity and inclusion in maternal and child health.* Session moderator, American Public Health Association Annual Meeting. Denver, CO.

- **2017 Regional, national, and international presentation**
  - Cheak-Zamora, N.C., Teti, M., and Maurer-Batjer, A. (2017). Development and testing of a Health-Related Independence measure for young adults with Autism Spectrum Disorder. Pediatric Academies Societies 2017 Meeting. San Francisco, CA. May 6-9.
  - Cheak-Zamora, N.C., Teti, M., and Maurer-Batjer, A. (2017). Development and Testing of a Health-Related Independence Measure for Young Adults with Autism Spectrum Disorder. 2017 International Meeting for Autism Research. San Francisco, CA. May 10-13.
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Evaluation of Health-Related Independence Measure – Development and Testing. Poster. Healthcare Transition Research Consortium. Houston, TX. Oct. 4.
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Assessing Mental Health Conditions Prevalence, Knowledge, and Care Seeking Behavior in Youth with Autism Spectrum Disorder 4th Annual Mental Health Transition Collaborative. Houston, TX. Oct. 4.
  - Anna Maurer-Batjer, A., Cheak-Zamora, N.C., and Teti, M. (2017). Transitioning to adult health care and adulthood: Adolescents with Autism Spectrum Disorder and their caregivers' perspectives. Presentation. APHA 2017 Annual Meeting & Expo. Atlanta, GA. Nov. 4 – 8.
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Assessing mental health conditions prevalence, knowledge, and care seeking behavior in youth with Autism Spectrum Disorder. Poster. APHA 2017 Annual Meeting & Expo. Atlanta, GA. Nov. 4 – 8.

- **2018 Regional, national, and international presentation**
  - Cheak-Zamora, N.C. Teti, M. and Maurer-Batjer, A. (2018). Adolescents with Autism Spectrum Disorder and Their Caregiver's Perspectives on the Adolescents' Sexuality and Relationships. International Society for Autism Research (INSAR) 2018 Annual Meeting. Rotterdam, Netherlands. May 9 – 12, 2018.
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2017). Assessing and Comparing Health-Related Independence for Physical and Mental Health Conditions in Youth with Autism Spectrum Disorder. International Society for Autism Research (INSAR) 2018 Annual Meeting. Rotterdam, Netherlands. May 9 – 12, 2018. Submitted *10/18/2017*
  - Cheak-Zamora, N.C. and Maurer-Batjer, A. (2018). Mixed method approach to examining sexual and relationship health in adolescents with Autism Spectrum Disorder. American Public Health Associations (APHA) 2018 Annual Meeting & Expo. San Diego, CA. Nov. 10-14.
  - Cheak-Zamora, N.C., Maurer-Batjer, A., and Petroski, G. (2018). Disparities in self-determination in young adults with Autism Spectrum Disorder. APHA 2018 Annual Meeting & Expo. San Diego, CA. Nov. 10-14.

- **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
    - https://nancycheakzamora.wordpress.com/
    - http://healthprofessions.missouri.edu/hs/viewProfile.php?facultyName=cheak-zamora-nancy-c

- **Technologies or techniques**
  - During the year 3 of this study, we developed the electronic survey (i.e., demographic survey, HRI measure, Service Utilization/Unmet Need, Health Care Transition Readiness, Healthcare Transition Success, Quality of Care, Self-determination Caregiver Support, and Clinical data [to be entered by study personnel only]) on REDCap (Research Electronic Data Capture). REDCap is a secure web application for building and managing online surveys and databases. We used REDCap to share our survey with the collaborating sites. Then each site disseminated the REDCap surveys via email. Participants completed the survey by selecting the provided link and filling in the electronic survey. Research staff entered clinical data into REDCap as well. Collaborating sites downloaded data and data dictionaries and sent them to PI. Further, REDCap can be used by providers, educators, and health care facilities with little adaptation in the future.

- **Inventions, patent applications, and/or licenses**
  - Nothing to Report
- **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. Dr. Cheak-Zamora performed work in ensuring recruitment goals were met; training staff that assisted with qualitative and quantitative data collection; identifying themes within the data that can be used to guide the HRI scale development; developing HRI scale; and overseeing cognitive interviews and pretesting. Dr. Cheak-Zamora performed work in ensuring recruitment goals were met; training staff that assisted with qualitative and quantitative data collection; identifying themes within the data that can be used to guide the HRI scale development; developing HRI scale; overseeing cognitive interviews and

	pretesting; and collect and analyze large-scale data on the HRI survey and related-measures.
Funding Support:	N/A

Name:	Michelle Teti
Project Role:	Co-Investigator
Researcher Identifier (ORCID ID):	0000-0002-3943-3810
Nearest person month worked:	1 (year 1 and 2 of grant)
Contribution to Project:	Dr. Teti performed work in training staff that assisted with qualitative data collection (i.e., cognitive interviews); 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 month worked:	4 in year 1 and 10 in year 2
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. Ms. Regan assisted in developing cognitive interview guide, conducting cognitive interviews, and creating electronic HRI measure.
Funding Support:	N/A

Name:	Anna Maurer-Batjer
Project Role:	Graduate Research Assistant
Researcher Identifier (ORCID ID):	N/A
Nearest person month worked:	3
Contribution to Project:	Ms. Maurer-Batjer assisted in developing electronic HRI measure, conducing follow-up phone calls, and creating reports and presentations.
Funding Support:	N/A

Name:	David Beversdorf
Project Role:	Graduate Research Assistant

Researcher Identifier (ORCID ID):	N/A
Nearest person month worked:	1
Contribution to Project:	Dr. Beversdorf provided mentorship in the development of the measure and quantitative methodology.
Funding Support:	N/A

Name:	Janet Farmer
Project Role:	Mentor
Researcher Identifier (ORCID ID):	N/A
Nearest person month worked:	1
Contribution to Project:	Dr. Farmer provided mentorship in the development of the measure and quantitative methodology.
Funding Support:	N/A

Name:	Melissa Mahurin
Project Role:	Research Core Coordinator
Researcher Identifier (ORCID ID):	N/A
Nearest person month worked:	1 month in year 3
Contribution to Project:	Ms. Mahurin assisted collecting data at the Thompson Center data collection site and coordinated data collection and data entry at other data collection sites.
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?**
  - Nothing to Report
- **What other organizations were involved as partners?**
  - Nothing to Report

8. SPECIAL REPORTING REQUIREMENTS

- **COLLABORATIVE AWARDS**
  - N/A
- **QUAD CHARTS**
  - N/A

9. APPENDICES:

Appendix 1: National Sample Survey

Thank you for agreeing to participate in this important research. Participation is voluntary and will not affect you or your child's medical care and/or benefits.

All questions have multiple-choice answers and should take no more than 30-45 minutes to complete. Survey questions were designed with an understanding that young adults with ASD differ greatly in their ability to perform certain tasks.

Instructions:

- Please read each question carefully and choose the response that best fits your young adult's ability to complete each specified task.
- You must answer all questions to complete the survey in order to receive your $20 gift card.
- Words with an asterisk (*) near them include examples for your reference. The list of examples is found on pages 30-32.

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 are about you and your young adult. Unless instructed otherwise, please select the answer choice (only one) that MOST CLOSELY fits you or your young adult with ASD.

These are questions about your YOUNG ADULT:

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

☐ Biological Mother
☐ Stepmother
☐ Adoptive Mother
☐ Grandparent
☐ Biological Father
☐ Stepfather
☐ Adoptive Father
☐ Other, please specify: ___________________________

2) What is your young adult's age? (in years) __________

3) What is your young adult's gender?

☐ Female
☐ Transgender Female*
☐ Gender non-conforming*
☐ Male
☐ Transgender Male*

4) What is your young adult's ethnicity?

☐ Not Hispanic or Latino
☐ Hispanic or Latino

5) What is your young adult's race?

☐ White
☐ Black or African-American
☐ Asian
☐ Native Hawaiian or Other Pacific Islander
☐ American Indian or Alaska Native
☐ Unknown

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

☐ Less than 8th grade
☐ 8th through 12th grade (no diploma)
☐ High School graduate
☐ GED or equivalent
☐ Associate degree
☐ Bachelor's degree (e.g., BA, AB, BS, BBA)
☐ Post-baccalaureate*

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

☐ Yes

If yes, what type of school?

- ☐ High school
- ☐ Vocational or trade school
- ☐ College
- ☐ Post-graduate school

☐ No

☐ Other, please specify: ___________________________

8) Does your young adult currently have paid employment?

☐ Yes, full time paid employment

☐ Yes, part time paid employment

☐ No

If yes, what type of employment?

- ☐ Employment with no supports
- ☐ Supported employment
- ☐ Sheltered workshop

9) Does your young adult currently have unpaid employment or volunteer?

☐ Yes

☐ No

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

☐ Autism or Autistic Disorder

☐ Asperger's Disorder

☐ Pervasive Developmental Disorder (PDD NOS)

☐ Autism Spectrum Disorder

☐ Other, please specify: ___________________________

11) What was your young adult's age at time of CURRENT diagnosis? (in years)

____

12) What type of professional first gave this diagnosis?

☐ Primary care physician or pediatrician

☐ Developmental pediatrician

☐ Neurologist

☐ Psychiatrist

☐ Psychologist or Neuropsychologist

☐ Team of healthcare professionals

☐ Professionals in a school system

☐ Other, please specify: ___________________________

13) **How would you describe your young adult’s CURRENT symptoms of ASD?**

☐ Mild
☐ Moderate
☐ Severe

14) **During the past 12 months, how often have symptoms of ASD affected your young adult’s ability to do things that other young adults his/her age do?**

☐ Never
☐ Sometimes
☐ Usually
☐ Always

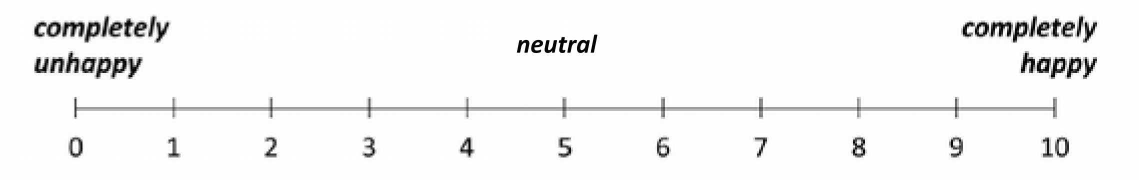
15) **What is your young adult’s level of independence?**

☐ 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 other

16) **What is your young adult’s level of verbal communication skills?**

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

17) **Please draw an X on the scale below to indicate how happy you think your young adult feels at this moment.**



18) **How motivated is your young adult to learn skills* that will enhance his/her ability to live independently or more independently?**

☐ Very motivated
☐ Somewhat motivated
☐ Somewhat unmotivated
☐ Very unmotivated

19) What other chronic condition(s) does your young adult have? (Please check Yes for all items that have been a problem for your young adult now or in the past.)

	No	Yes	Unsure
Allergies (food, medication, environmental)	☐	☐	☐
Anoxia	☐	☐	☐
Anxiety disorders (such as social phobia, panic disorder)	☐	☐	☐
Asthma or other lung problems	☐	☐	☐
Attention-deficit hyperactivity disorder (ADHD)	☐	☐	☐
Bipolar disorder	☐	☐	☐
Dental problems	☐	☐	☐
Depression (such as major depressive disorder, seasonal affective disorder)	☐	☐	☐
Diabetes	☐	☐	☐
Disruptive behavior disorders (such as Conduct disorder or Oppositional Defiant disorder)	☐	☐	☐
Ear, nose, and throat problems	☐	☐	☐
Epilepsy or Seizure disorder	☐	☐	☐
Gastrointestinal issues (such as constipation, chronic diarrhea, nausea, vomiting, acid reflux)	☐	☐	☐
Genetic disorder	☐	☐	☐
Headaches	☐	☐	☐
Hearing problems	☐	☐	☐
Heart conditions	☐	☐	☐
Intellectual disability/disorder (previously called Mental Retardation)	☐	☐	☐
Learning disorder	☐	☐	☐
Loss of skills/regression	☐	☐	☐
Obsessive Compulsive Disorder (OCD)	☐	☐	☐
Schizophrenia	☐	☐	☐
Skin conditions (such as psoriasis or eczema)	☐	☐	☐
Sleep disorders (such as problems getting to sleep or staying asleep)	☐	☐	☐
Tics	☐	☐	☐
Tourette Syndrome	☐	☐	☐
Vision problems	☐	☐	☐

If other health condition(s), please specify: ______________________________

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

☐ Public (such as Medicaid, Medicare, or other government health insurance coverage)
☐ Private
☐ Both Public and Private
☐ Uninsured
☐ Other, please specify: ____

21) Does your young adult take any prescription medications?

☐ Yes
If yes, number of prescription medications: ____________
☐ No
☐ Unsure

22) Does your young adult take any over the counter medications?

☐ Yes
If yes, number of over the counter medications: ___________
☐ No
☐ Unsure

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

☐ Biological Mother
☐ Stepmother
☐ Adoptive Mother
☐ Siblings
☐ Biological Father
☐ Stepfather
☐ Adoptive Father
☐ Other, please specify: __________________________

These are questions about YOU:

24) What is your age? (in years) ________

25) What is your marital/partner status?

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

26) What is your gender?

☐ Female
☐ Transgender Female*
☐ Gender non-conforming*
☐ Male
☐ Transgender Male*

27) What is your ethnicity?

☐ Not Hispanic or Latino
☐ Hispanic or Latino

28) What is your race?

☐ White
☐ Black or African-American
☐ Asian
☐ Native Hawaiian or Other Pacific Islander
☐ American Indian or Alaska Native
☐ Unknown

29) What is the highest level of education you have completed?

☐ Less than 8th grade
☐ 8th through 12th grade (no diploma)
☐ High School graduate
☐ GED or equivalent
☐ Some college, no degree
☐ Associate degree
☐ Bachelor's degree (e.g., BA, AB, BS, BBA)
☐ Post-baccalaureate*

30) What is the highest level of education completed by the second caregiver?

☐ No second caregiver
☐ Less than 8th grade
☐ 8th through 12th grade (no diploma)
☐ High School graduate
☐ GED or equivalent
☐ Associate degree
☐ Bachelor's degree (e.g., BA, AB, BS, BBA)
☐ Post-baccalaureate*

31) What is your family's household income?

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

32) 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: ___________________________

Caregiver Quality of Life

These questions relate to the care you provide for your young adult with ASD and your own personal well-being.

1. **I have fulfillment with carrying out my care tasks for my young adult.**
    ☐None
    ☐Some
    ☐A lot

2. **I have relational problems with my young adult.**
    ☐None
    ☐Some
    ☐A lot

3. **I have problems with my own mental health.**
    ☐None
    ☐Some
    ☐A lot

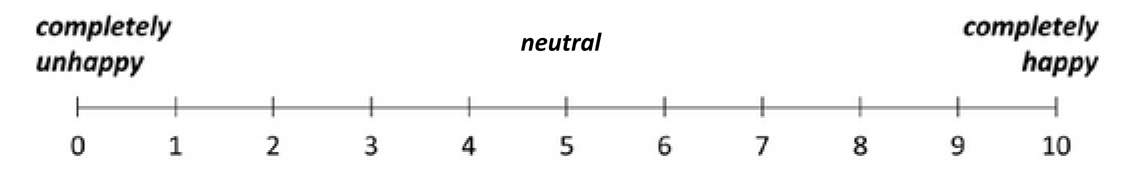
4. **I have problems combining my care tasks with my daily activities.**
    ☐None
    ☐Some
    ☐A lot

5. **I have financial problems because of my care tasks.**
    ☐None
    ☐Some
    ☐A lot

6. **I have support with carrying out my care tasks, when I need it.**
    ☐None
    ☐Some
    ☐A lot

7. **I have problems with my own physical health.**
    ☐None
    ☐Some
    ☐A lot

8. **Please draw an X on the scale below to indicate how happy you feel at this moment.**



Survey questions were designed with an understanding that young adults with ASD differ greatly in their ability to perform some activities of daily living. For some tasks a young

Health-Related Independence

person may not need guidance, while for other tasks it will be necessary for an adult to provide assistance or "take over." For each question, please choose the response that best fits your young adult's ability to complete the tasks today.

1. My young adult can describe his/her physical health conditions to someone else.
☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

2. My young adult can describe his/her mental health conditions to someone else.
☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

3. My young adult can fill out a medical history form.
☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

4. My young adult can name his/her primary and specialty doctors.
☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete

5. My young adult can explain how his/her ASD affects his/her everyday life.
☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

6. My young adult can seek out information about ASD and his/her other health conditions to learn more about them.
☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

7. My young adult can accurately report area of pain or discomfort.
☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task

Health-Related Independence

☐Totally dependent on the parent or caregiver to complete task

8. My young adult can identify when he/she needs to seek care because he/she is experiencing physical health issues.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

9. My young adult can identify when he/she needs to seek care because he/she is experiencing mental health issues.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

10. My young adult can consent to tests/treatment.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

11. If my young adult does not agree with or understand a treatment plan given by a doctor, he/she can ask questions about it.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

12. My young adult can complete personal grooming tasks such as dressing, brushing teeth, or combing or brushing hair.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

13. My young adult can choose clothes appropriately for weather or occasion.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

14. My young adult can mix and cook simple foods, including frying eggs, making pancakes, or heating food in microwave.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task

Health-Related Independence

☐Totally dependent on the parent or caregiver to complete task

15. My young adult can do household tasks, including picking up around the house, putting things away, or light housecleaning.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

16. My young adult can get themselves around using transportation.*

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

17. My young adult can make a simple schedule.*

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

18. My young adult can adhere to a simple schedule.*

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

19. My young adult can handle routine financial transactions.*

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

20. My young adult can manage a personal bank account.*

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

21. My young adult can maintain a personal budget.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

Health-Related Independence

22. My young adult can name the medication(s) he/she currently takes if someone asks him/her.

☐ Independent. Can complete task without adult guidance or support
☐ Needs some assistance or prompting to complete task
☐ Requires substantial help to complete task
☐ Totally dependent on the parent or caregiver to complete task

23. My young adult can explain* what will happen if he/she does not take his/her medication(s).

☐ Independent. Can complete task without adult guidance or support
☐ Needs some assistance or prompting to complete task
☐ Requires substantial help to complete task
☐ Totally dependent on the parent or caregiver to complete task

24. My young adult can take his/her medication(s) as prescribed.

☐ Independent. Can complete task without adult guidance or support
☐ Needs some assistance or prompting to complete task
☐ Requires substantial help to complete task
☐ Totally dependent on the parent or caregiver to complete task

25. My young adult can refill a prescription when he/she needs to.

☐ Independent. Can complete task without adult guidance or support
☐ Needs some assistance or prompting to complete task
☐ Requires substantial help to complete task
☐ Totally dependent on the parent or caregiver to complete task

26. My young adult can explain which provider* to seek based on his/her health concerns.

☐ Independent. Can complete task without adult guidance or support
☐ Needs some assistance or prompting to complete task
☐ Requires substantial help to complete task
☐ Totally dependent on the parent or caregiver to complete task

27. My young adult can participate in routine health care visits.

☐ Independent. Can complete task without adult guidance or support
☐ Needs some assistance or prompting to complete task
☐ Requires substantial help to complete task
☐ Totally dependent on the parent or caregiver to complete task

28. My young adult can ask and answer questions of his/her doctor/nurse.

☐ Independent. Can complete task without adult guidance or support
☐ Needs some assistance or prompting to complete task
☐ Requires substantial help to complete task
☐ Totally dependent on the parent or caregiver to complete task

Health-Related Independence

29. My young adult can make an appointment with his/her doctor.
- ☐Independent. Can complete task without adult guidance or support
- ☐Needs some assistance or prompting to complete task
- ☐Requires substantial help to complete task
- ☐Totally dependent on the parent or caregiver to complete task

30. My young adult knows or could find out where to go for his/her doctor appointments.
- ☐Independent. Can complete task without adult guidance or support
- ☐Needs some assistance or prompting to complete task
- ☐Requires substantial help to complete task
- ☐Totally dependent on the parent or caregiver to complete task

31. My young adult can remember to go to his/her health care appointments.
- ☐Independent. Can complete task without adult guidance or support
- ☐Needs some assistance or prompting to complete task
- ☐Requires substantial help to complete task
- ☐Totally dependent on the parent or caregiver to complete task

32. My young adult knows how to call 911 in an emergency such as a fire.
- ☐Strongly agree
- ☐Agree
- ☐Disagree
- ☐Strongly disagree

33. My young adult knows who to answer and not answer the door to if he/she is home alone.
- ☐Strongly agree
- ☐Agree
- ☐Disagree
- ☐Strongly disagree

34. My young adult can safely stay home alone for any length of time.
- ☐Strongly agree
- ☐Agree
- ☐Disagree
- ☐Strongly disagree

35. My young adult can cooperate with law enforcement if needed.*
- ☐Strongly agree
- ☐Agree
- ☐Disagree
- ☐Strongly disagree

Health-Related Independence

36. My young adult knows what to do if he/she gets lost.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

37. My young adult knows what is appropriate to disclose on the Internet.*

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

38. My young adult knows when he/she is being bullied, especially online, and to go to someone about it.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree
☐I do not know what my young adult knows on this subject

39. My young adult understands the restrictions on pornography* based on legal and family rules.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree
☐I do not know what my young adult knows on this subject

40. My young adult can explain that pregnancy results from intercourse or vaginal sex between a woman and a man.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

41. My young adult can explain how sexually active people protect themselves from unwanted pregnancy.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

Health-Related Independence

42. My young adult can explain how sexually active people protect themselves from sexually transmitted infections.*

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

43. My young adult can name a person to talk/communicate with if he/she has questions about sex.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

44. My young adult can recognize if he/she was the recipient of inappropriate sexual contact.*

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

45. My young adult understands it is wrong to engage in sexual contact* with a person who says they do not want it.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

46. My young adult can distinguish between a romantic relationship and a friendship.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

47. My young adult can recognize when he/she is in an abusive* relationship.

☐Strongly agree
☐Agree
☐Disagree
☐Strongly disagree

48. My young adult can explain why health insurance is important.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

Health-Related Independence

49. My young adult can provide health insurance information when asked.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

50. My young adult can explain what the monthly cost is for his/her health insurance.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

51. My young adult can explain what additional costs* he/she may have for health care.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

52. My young adult can describe the main benefits* provided by a health insurance plan.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

53. My young adult can contact a customer service representative with questions* about their health insurance.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

54. My young adult can compare health plans with respect to premiums, covered services, deductibles, and copayments.

☐Independent. Can complete task without adult guidance or support
☐Needs some assistance or prompting to complete task
☐Requires substantial help to complete task
☐Totally dependent on the parent or caregiver to complete task

55. My young adult knows what he/she needs, likes, and is good at.

☐Strongly agree
☐Agree
☐Neither agree nor disagree
☐Disagree
☐Strongly disagree

Health-Related Independence

56. My young adult can develop goals* that satisfy his/her own needs and wants.

❑Independent. Can complete task without adult guidance or support
❑Needs some assistance or prompting to complete task
❑Requires substantial help to complete task
❑Totally dependent on the parent or caregiver to complete task

57. My young adult's goals are realistic.

❑Strongly agree
❑Agree
❑Disagree
❑Strongly disagree

58. My young adult can identify at least two steps* to reach his/her goals.

❑Independent. Can complete task without adult guidance or support
❑Needs some assistance or prompting to complete task
❑Requires substantial help to complete task
❑Totally dependent on the parent or caregiver to complete task

59. My young adult can initiate action on his/her goals.*

❑Independent. Can complete task without adult guidance or support
❑Needs some assistance or prompting to complete task
❑Requires substantial help to complete task
❑Totally dependent on the parent or caregiver to complete task

60. My young adult can self-evaluate progress when completing his/her goals.*

❑Independent. Can complete task without adult guidance or support
❑Needs some assistance or prompting to complete task
❑Requires substantial help to complete task
❑Totally dependent on the parent or caregiver to complete task

Service Utilization/Unmet Need

1. During the past 12 months, was there any time when your young adult needed any of the following services?

	No	**Yes**	**Unsure**
Medical care for physical health problems	☐	☐	☐
Preventative health care	☐	☐	☐
Mental health or counseling	☐	☐	☐
Dental care	☐	☐	☐
Prescription services	☐	☐	☐
Physical, occupational, or speech service	☐	☐	☐
Life skills therapy/ Independence training	☐	☐	☐
Vocational services/ Supported employment	☐	☐	☐
Case management/ Service coordinator/ Care coordinator	☐	☐	☐
Access/ Mobility services	☐	☐	☐
Socialization training	☐	☐	☐
Personal assistance	☐	☐	☐
Residential care planning	☐	☐	☐

2. Did your young adult receive ALL the services that he/she needed?

	No	**Yes**	**Unsure**
Medical care for physical health problems	☐	☐	☐
Preventative Health Care	☐	☐	☐
Mental health or counseling	☐	☐	☐
Dental Care	☐	☐	☐
Prescription services	☐	☐	☐
Physical, occupational, or speech service	☐	☐	☐
Life skills therapy/ Independence training	☐	☐	☐
Vocational Services/ Supported employment	☐	☐	☐
Case management/ Service coordinator/ Care coordinator	☐	☐	☐
Access/ Mobility services	☐	☐	☐
Socialization training	☐	☐	☐
Personal assistance	☐	☐	☐
Residential care planning	☐	☐	☐

3. During the past 12 months, how many times did your young adult see a doctor or other healthcare professional about his/her own health at a doctor's office, a clinic, or some other place?

❑0 times
❑1 times
❑2-3 times
❑4 or more times

Service Utilization/Unmet Need

4. During the past 12 months, how many times did your young adult go to the hospital emergency room for his/her own health?

☐0 times
☐1 times
☐2-3 times
☐4 or more times

Health Care Transition Readiness

Please select the answer that shows how often your young adult has done each thing in the past 3 months.

1. How often did your young adult make an effort to understand what his/her doctor told him/her?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

2. How often did your young adult take his/her medicines on his/her own?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

3. How often did your young adult ask his/her doctor or nurse questions about his/her illness, medicines, or medical care?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

4. How often did your young adult make his/her own appointments?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

5. How often did your young adult need someone to remind him/her to take his/her medicines?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

Health Care Transition Readiness

6. How often did your young adult use things like pillboxes, schedules, or alarm clocks to help him/her take his/her medicines when he/she was supposed to?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

7. How often did your young adult use the internet, books, or other guides to find out more about his/her illness?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

8. How often did your young adult forget to take his/her medicines?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

9. How often did your young adult work with his/her doctor to take care of new health problems that came up?

☐Never
☐Almost Never
☐Sometimes
☐Almost Always
☐Always
☐Not needed for my young adult's care

Some patients know a lot about their health and some patients don't. Please select the answer that best describes how much your young adult knows about his/her health.

10. How much does your young adult know about his/her illness?

☐Nothing
☐Not Much
☐A Little
☐Some
☐A Lot
☐Not needed for my young adult's care

Health Care Transition Readiness

11. How much does your young adult know about taking care of his/her illness?

- ☐Nothing
- ☐Not Much
- ☐A Little
- ☐Some
- ☐A Lot
- ☐Not needed for my young adult’s care

12. How much does your young adult know about what will happen if he/she doesn't take his/her medicines?

- ☐Nothing
- ☐Not Much
- ☐A Little
- ☐Some
- ☐A Lot
- ☐Not needed for my young adult’s care

Some patients may find it hard to do certain things. How easy or hard is it for your young adult to do the following things? Please select the answer that best describes how easy or hard you feel this is/will be for your young adult.

13. How easy or hard is it for your young adult to talk/communicate with his/her doctor?

- ☐Very hard
- ☐Somewhat hard
- ☐Neither hard nor easy
- ☐Somewhat easy
- ☐Very easy
- ☐ Not needed for my young adult’s care

14. How easy or hard is it for your young adult to make a plan with his/her doctor to care for his/her health?

- ☐Very hard
- ☐Somewhat hard
- ☐Neither hard nor easy
- ☐Somewhat easy
- ☐Very easy
- ☐Not needed for my young adult’s care

15. How easy or hard is it for your young adult to see his/her doctor by himself/herself?

- ☐Very hard
- ☐Somewhat hard
- ☐Neither hard nor easy
- ☐Somewhat easy
- ☐Very easy
- ☐Not needed for my young adult’s care

Health Care Transition Readiness

16. How easy or hard is it for your young adult to take his/her medicines like he/she are supposed to?

☐ Very hard
☐ Somewhat hard
☐ Neither hard nor easy
☐ Somewhat easy
☐ Very easy
☐ Not needed for my young adult’s care

17. How easy or hard is it for your young adult to take care of himself/herself?

☐ Very hard
☐ Somewhat hard
☐ Neither hard nor easy
☐ Somewhat easy
☐ Very easy
☐ Not needed for my young adult’s care

Health Care Transition Success

These questions are about both you and your young adult's experience changing from pediatric to adult health care.

1. Did your young adult's health care provider discuss with you or have an office policy that informed you at what age your young adult may need to change to a new provider who treats mostly adults?

- ☐Yes
- ☐No
- ☐Seeing a provider that treats children and adults

2. Did your young adult talk/communicate with his/her health care provider alone while you waited in the waiting room?

- ☐Yes
- ☐No

3. Did your young adult's health care provider actively work with him/her to gain skills to manage his/her own health and health care?

- ☐A lot
- ☐Some
- ☐A little
- ☐Not at all

4. Did your young adult's health care provider actively work with him/her to think about and plan for the future?

- ☐A lot
- ☐Some
- ☐A little
- ☐Not at all

5. Did your young adult's health care provider explain legal changes in privacy, decision-making, and consent that take place at 18 years of age?

- ☐Yes
- ☐No

6. Did your young adult's health care provider actively work with him/her and you to create a written plan to meet his/her health goals and needs?

- ☐Yes
- ☐No

7. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your young adult ages?

- ☐Yes
- ☐No

Health Care Transition Success

8. Did/does your young adult's health care provider assist in identifying a new adult provider to transfer to?

☐Yes
☐No
☐Seeing a provider that treats children and adults

9. Did/does your young adult feel prepared to change to an adult health care provider or an adult model of care?

☐Very prepared
☐Somewhat prepared
☐Not prepared
☐Not applicable

10. At what age did your young adult change to an adult health care provider or an adult model of care?

☐Has transitioned
Age when transitioned: _______
☐Has not yet transitioned (skip to number 12b)

11b. Did your young adult's adult health care provider have his/her medical records before the first visit?

☐Yes
☐No
☐Don't Know
☐Have not had first visit yet

12a. How easy or hard was it for your young adult to move from pediatric to adult care?

☐Very hard
☐Somewhat hard
☐Neither hard nor easy
☐Somewhat easy
☐Very easy
☐Not needed for my young adult's care

12b. How easy or hard do you think it will be for your young adult to move from pediatric to adult care?

☐Very hard
☐Somewhat hard
☐Neither hard nor easy
☐Somewhat easy
☐Very easy
☐Not needed for my young adult's ca

Quality of Care

These questions are about the quality of care your young adult receives from health care providers.

1. During the past 12 months, how often did all the young adult's doctors and other health providers spend enough time with him/her?

☐Always
☐Usually
☐Sometimes
☐Never

2. During the past 12 months, how often did all young adult's doctors and other health providers help you feel like partner in young adult's care?

☐Always
☐Usually
☐Sometimes
☐Never

3. How often did your young adult's health care provider explain things in a way that was easy to understand?

☐Always
☐Usually
☐Sometimes
☐Never

4. How often did your young adult's health care provider listen carefully to you?

☐Always
☐Usually
☐Sometimes
☐Never

5. Did your young adult's health care provider show sensitivity to your family's values and customs?

☐A lot
☐Some
☐A little
☐Not at all

6. Did your young adult's health care provider share information with you about community resources?

☐Yes
☐ No

7. During the past 12 months, did anyone help your family arrange or coordinate your young adult's care?

☐Yes
☐No

Quality of Care

8. If yes, how often do you get as much help as you need arranging or coordinating your young adult's health care?

☐Always
☐Usually
☐Sometimes
☐Never

9. Overall, how satisfied are you with the communication among this young adult's doctors and other health care providers?

☐Very satisfied
☐Somewhat satisfied
☐Somewhat unsatisfied
☐Very unsatisfied
☐Young adult only has one health care provider

10. During the past 12 months, did you need your young adult's providers to communicate with young adult's school or other programs?

☐Yes
If yes, how satisfied with that communication?
    ☐Very satisfied
    ☐Somewhat satisfied
    ☐Somewhat dissatisfied
    ☐Very dissatisfied
☐No

11. I feel I can trust my young adult's primary care provider to take care of his/her needs.

☐Strongly agree
☐Agree
☐Neither agree or disagree
☐Disagree
☐Strong disagree

12. Overall, how would you rate the quality of health care your young adult receives from his/her primary care provider?

☐Excellent
☐Good
☐Fair
☐Poor

Self-Determination / Caregiver Support

Please answer these questions about how your young adult goes about getting what he/she wants or needs. This may occur at school, or after school, or it could be related to your young adult’s friends, other family members, a job or hobby.

THINGS MY YOUNG ADULT DOES

1. My young adult sets his/her own goals to satisfy wants or needs. My young adult thinks about his/her own abilities when setting goals.

☐Always
☐Almost always
☐Sometimes
☐Almost never
☐Never

2. My young adult figures out how to meet goals alone; he/she makes plans and decides what to do independently.

☐Always
☐Almost always
☐Sometimes
☐Almost never
☐Never

3. My young adult begins work on plans to meet his/her goals as soon as possible.

☐Always
☐Almost always
☐Sometimes
☐Almost never
☐Never

4. My young adult checks his/her own progress when completing his/her plan. My young adult asks others what they think of his/her progress.

☐Always
☐Almost always
☐Sometimes
☐Almost never
☐Never

5. If my young adult’s plan doesn’t work, he/she tries another one to meet his/her goals.

☐Always
☐Almost always
☐Sometimes
☐Almost never
☐Never

WHAT HAPPENS AT HOME

6. At home, people listen when my young adult describes what he/she wants and is good at.

☐ Always
☐ Almost always
☐ Sometimes
☐ Almost never
☐ Never

7. At home, people let my young adult know that he/she can set his/her own goals to get what he/she wants or needs.

☐ Always
☐ Almost always
☐ Sometimes
☐ Almost never
☐ Never

8. At home, my young adult has learned how to make plans to meet his/her own goals and to feel good about them.

☐ Always
☐ Almost always
☐ Sometimes
☐ Almost never
☐ Never

9. At home, my young adult is allowed to act on his/her plans right away.

☐ Always
☐ Almost always
☐ Sometimes
☐ Almost never
☐ Never

10. At home, my young adult has someone to tell him/her when he/she is meeting his/her own goals.

☐ Always
☐ Almost always
☐ Sometimes
☐ Almost never
☐ Never

11. At home, people understand my young adult when he/she has to change plans to meet his/her own goals. They offer advice and encouragement.

☐ Always
☐ Almost always
☐ Sometimes
☐ Almost never
☐ Never

Page 2, #3. What is your young adult's gender?
Transgender Female* biologically male, identifies and presents as female
Transgender Male* biologically female, identifies and presents as male
Gender non-conforming* does not follow gender stereotypes

Page 2, #6. What is your young adult's highest level of education?
Post-baccalaureate* Master's Degree (e.g., MA, MS, MEng, MEd, MBA), Professional school degree (MD, DDS, DVM, JD), or Doctoral degree (e.g., PhD, EdD)

Page 4, #18. How motivated is your young adult to learn skills* that will enhance their ability to live independently or more independently?
* such as learning money management skills, grocery shopping, home maintenance

Page 6, #26. What is your gender?
Transgender Female* biologically male, identifies and presents as female
Transgender Male* biologically female, identifies and presents as male
Gender non-conforming* does not follow gender stereotypes

Page 7, #29. What is the highest level of education you have completed?
Post-baccalaureate* Master's Degree (e.g., MA, MS, MEng, MEd, MBA), Professional school degree (MD, DDS, DVM, JD), or Doctoral degree (e.g., PhD, EdD)

Page 7, #30. What is the highest level of education completed by the second caregiver?
Post-baccalaureate* Master's Degree (e.g., MA, MS, MEng, MEd, MBA), Professional school degree (MD, DDS, DVM, JD), or Doctoral degree (e.g., PhD, EdD)

Page 11, #16. My young adult can get themselves around using transportation*.

* by driving, taxi, bus, walking, biking, etc

Page 11, #17. My young adult can make a simple schedule*.

*develop a to-do list, list of what to do after school, and/or a routine for bathing, grooming, and dressing

Page 11, #18. My young adult can adhere to a simple schedule*.

*follow a to-do list or routine for bathing, grooming, and dressing

Page 11, #19. My young adult can handle routine financial transactions*.

*make retail purchases, know the change that should be returned, use a credit card

Page11, #20. My young adult can manage a personal bank account*.
*write checks, pay bills, make online payments, and determine balances

Page 12, #23. My young adult can explain* what will happen if he/she does not take his/her medication(s).
* if they do not take their seizure medication, they are likely to have a seizure

Page 12, #26. My young adult can explain which provider* to seek based on his/her health concerns.
* general doctor, specialist, counselor

Page 13, #35. My young adult can cooperate with law enforcement if needed.*
* showing ID or giving the name and number of a parent

Page 14, #37. My young adult knows what is appropriate to disclose on the Internet.*
*knowing not to give out phone number, address, medical information

Page 14, # 39. My young adult understands the restrictions on pornography* based on legal and family rules.
* looking at nude magazines or websites, sending or receiving nude photos

Page 15, #42. My young adult can explain how sexually active people protect themselves from sexually transmitted infections*.
* Chlamydia, HIV, or Herpes

Page 15, #44. My young adult can recognize if he/she was the recipient of inappropriate sexual contact*.
*unwanted touching or other unwanted sexual advances

Page 15, #45. My young adult understands it is wrong to engage in sexual contact* with a person who says they do not want it.
* kissing, touching, excessive hugging, etc.

Page 16, #47. My young adult can recognize when he/she is in an abusive* relationship.
* emotionally, such as yelling or name-calling; physically, such as hitting; or sexually, such as unwanted touch

Page 16, #51. My young adult can explain what additional costs* he/she may have for health care.
* co-payments, deductible costs

Page 16, #52. My young adult can describe the main benefits* provided by a health insurance plan.
* emergency care, physician services, vision care, prescription drugs, etc.

Page16, #53. My young adult can contact a customer service representative with questions* about their health insurance.
* regarding benefits or billing

Page 17, #56. My young adult can develop goals* that satisfy his/her own needs and wants.
* getting a job, going to college, or living independently

Page 17, #58. My young adult can identify at least two steps* to reach his/her goals.
* for getting a job, 1) checking job postings, 2) practicing filling out applications

Page 17, #59. My young adult can initiate action on his/her goals*.
* getting a job, going to college, or living independently

Page 17, #60. My young adult can self-evaluate progress when completing his/her goals*.
*getting a job, going to college, or living independently

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Original Research Article

Exploration and Comparison of Adolescents With Autism Spectrum Disorder and Their Caregiver's Perspectives on Transitioning to Adult Health Care and Adulthood

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Abstract

Background Adolescents with autism spectrum disorder (ASD) experience challenges achieving independence. Few studies assess both adolescents and caregivers' needs as adolescents transition to adult health care. **Objective/Methods** This study explored and compared the health-related independence experiences of 27 adolescents with ASD and their caregivers. Caregivers participated in focus groups and adolescents participated in semi-structured interviews. **Results** Thematic analysis of dyads' responses highlighted three common themes: (a) efforts toward independence, (b) low self-efficacy for adolescents' independence, and (c) desire for independence. Nuances in responses indicated that although members of dyads shared many experiences, they were not communicating these experiences with each other. **Conclusion** Results suggest both groups understand the importance of health-related independence and are motivated to achieve independence but lack skills and supports. Improved communication about experiences and goals between caregivers, adolescents, and the care team are needed. These findings can inform future interventions to better support adolescents' transition to adult health care.

Key words: adolescents; autism spectrum; health care services; parents; parent–adolescent communication; qualitative methods.

Adolescence is a time of intense physical, psychological, and environmental growth and change. Adolescents with autism spectrum disorder (ASD) experience similar challenges to teenagers without ASD but often to a greater degree owing to their diagnosis. ASD is a complex neurodevelopmental disorder characterized by impairments in verbal and nonverbal communication and social interactions, as well as restrictive or repetitive behaviors (American Psychiatric Association, 2013). In adolescence, symptoms can manifest in limited or inadequate social networks, restricted decision-making ability, and difficulties learning new skills and adapting to new environments (Mazurek, 2014; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). While increased anxiety is typical for all adolescents during this transition period, the prevalence of comorbid psychiatric conditions is higher for adolescents with ASD (Coury, Jones, Klatka, Winklosky, & Perrin, 2009; Mazurek & Kanne, 2010; Myers & Johnson, 2007).

As adolescents with ASD transition out of the school system, additional strains may make them feel more vulnerable, such as changes in environment and schedule, increased complexity of social relationships, and decreased structured social engagement (Barnhill, 2001; van Steensel, Bögels, & Perrin, 2011; White, Oswald, Ollendick, & Scahill, 2009). Many adolescents with ASD exit high school without a job or higher education placement, resulting in long hours at home with little to do (Cheak-Zamora, Teti, & Maurer-Batjer, 2016; Shattuck et al., 2012; Taylor & Seltzer, 2010). This lack of stimulation and interaction may exacerbate the adolescent's difficulties with self-esteem, motivation, or current comorbid psychiatric condition (Cheak-Zamora, Teti, & First, 2015; Gillott & Standen, 2007; Taylor & Seltzer, 2011b).

In addition to losing one's connection with the education system, increased age is associated with a decline in medical, mental health, speech therapy, and case management services for adolescents with ASD (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). Shattack and colleagues' (2011) study showed that 2 years after high school nearly 40% of adolescents with ASD received no health care services. The complexity of this transition period and lack of services not only negatively impacts the adolescents, but their caregivers as well. As adolescents transition into adulthood, caregivers report additional psychological stress including increased uncertainty, anxiety, and depression (Cheak-Zamora et al., 2015; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004; Taylor & Seltzer, 2011b).

Adolescent and caregiver outcomes have been shown to improve when adolescents and their caregivers receive timely transition services that marry the exiting of child-based services to the entrance into adult-based care (McDonagh, Southwood, & Shaw, 2006). Health care transition (HCT) services provide structured transition services that help adolescents prepare for an adult-model of care, ensure health insurance retention and a smooth transition to adult care, and promote adolescents' independent management of health care and life needs (U.S. Department of Health and Human Services, 2008). HCT planning supports have been shown to improve the individual's health care knowledge, decision-making skills, vocational success, and quality of life in other adolescents with special health care needs (Lotstein, Inkelas, Hays, Halfon, & Brook, 2008; McDonagh et al., 2006). Unfortunately, only 40% of adolescents with special health care needs receive even basic HCT services and 21% of adolescents with ASD receive such services (Cheak-Zamora, Yang, Farmer, & Clark, 2013).

Although we know adolescents with ASD have many complex health care needs, no study has examined how independent adolescents with ASD are at managing the broader range of health care needs (referred to as health-related independence) like talking to the doctor, arranging visits, or managing one's medications (Cheak-Zamora et al., 2015; DePape & Lindsay, 2015; Levy & Perry, 2011). Caregivers' perspectives on the service needs of their adolescents have been well documented, but qualitative studies examining and comparing caregivers and adolescents' perspectives on the transition into adulthood are lacking (Hendricks & Wehman, 2009; Murphy, Clegg, & Almack, 2011). Even with frequent calls for the perspectives of persons with ASD within research, few studies have documented adolescents' perspectives on what transition supports they need or desire for their future (Blum et al., 1993; DePape & Lindsay, 2015; Grant & Pan, 2011; McDonagh et al., 2006). As a result, researchers and practitioners lack insight into what adolescents with ASD and their caregivers perceive to be their greatest needs during the transition to adulthood and adult care. This lack of understanding significantly affects adolescents' access to care, safety, quality of life, and ability to live independently, as well as the effectiveness of future HCT interventions (Binks, Barden, Burke, & Young, 2007; Golnik, Ireland, & Borowsky, 2009; Stewart, 2009). The goal of this study was to explore and compare the perspectives of adolescents with ASD and their caregivers by examining their HCT and health-related independence experiences and needs through interviews and focus groups.

Method

Recruitment and Eligibility

Caregivers and adolescents with ASD were recruited from three different ASD treatment and support agencies in three cities in the Midwest United States. Study fliers were provided to agency staff for distribution to clients and patients by mail and displayed in local clinic settings. Interested participants contacted the research team to complete a screening questionnaire. Eligibility criteria for adolescents included being between the ages of 16 and 25 years, having an ASD diagnosis, able to read and speak English, and capable of engaging in required study activities, as measured by adolescent- and caregiver-reported verbal ability. Diagnosis of ASD and age were verified through clinical record review. Caregivers had to be a primary caregiver of an adolescent, age 16–25 years, with an ASD diagnosis to be eligible. For this analysis, we included caregivers and adolescents only if both parties in the dyad completed the research study. Ten caregivers were excluded from this analysis because their adolescents were not able to and/or did not want to participate in the study; no additional adolescents were excluded.

The final sample included 27 caregiver and adolescent dyads. The sample size was determined to be sufficient for data saturation based on findings from previous studies with adolescents with ASD. These studies indicated that a sample of ≥ 15 participants resulted in repeating patterns and sufficient data to answer research questions about health independence (Cheak-Zamora et al., 2015).

Project Procedures

Caregivers took part in 90-min focus groups, while adolescents participated in 30- to 60-min semi-structured individual interviews. Our previous research provided evidence regarding the best method to use with each group (Cheak-Zamora & Teti, 2015; Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Caregivers offer rich dialog in groups and add questions to the discussion as they interact with each other (Cheak-Zamora & Teti, 2015; Teti et al., 2016). Adolescents, on the other hand, prefer one-on-one conversations where they experience less anxiety and overstimulation (Cheak-Zamora & Teti, 2015; Teti et al., 2016).

Group facilitators and interviewers had experience working with adolescents with ASD and were trained on how to use the group and interview guides. The social-ecological model of readiness for transition to adult care (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011) informed the development of the interview guide and overall research questions. Both guides were also developed based on the authors' previous experience conducting qualitative research with adolescents with ASD (Cheak-Zamora et al., 2015), the health-related independence literature (Cheak-Zamora et al., 2014), and feedback from ASD practitioners, researchers, and caregivers of adolescents with ASD. Group and interview guide questions were pilot tested by clinicians ($n = 6$), caregivers ($n = 4$), and adolescents with ASD ($n = 2$). Pilot testing resulted in wording changes to improve the understandability of questions, and additional specific probes to encourage participant engagement.

Both the focus group and the interview guide included 12 questions and addressed the same content—the question wording was adapted slightly in some cases for group or individual use accordingly (see interview guide in Appendix). The questions covered various areas, including health care needs and experiences, health and self-care skills, safety, challenges, and resources. Adolescent interviews also included prompts, preparatory multiple choice reflection questions, and the use of a white board, to support adolescents' communication as needed. For example, adolescents answered a multiple-choice question about activities they do to stay healthy to spur their thinking before answering. Interviewers wrote examples the adolescent came up with (e.g., exercise) on a white board to help them think in concrete terms about the question (e.g., What do you need to be able to exercise on your own?). Additional supports for adolescents included: (a) written outlines of the interview process and sample questions before the interview session, (b) the opportunity to bring an advocate (i.e., support person) if needed (none did), (c) an introductory "ice-breaker" period with refreshments and unstructured conversations, and (d) opportunities for breaks if participants needed time to think about a question or appeared nervous or frustrated.

Caregivers and adolescents also completed a demographic survey (Table I). Caregivers and/or study staff assisted adolescents in completing this survey if needed. Caregivers were also present while adolescents (<18 years old) reviewed and signed the assent form or if needed for those reviewing the consent forms (≥18 years old).

Data Analysis

Data were analyzed using methods of thematic analysis to capture and compare experiences and attitudes of health independence between both groups (Guest, MacQueen, & Namey, 2012). Analysis steps included initial and more specific coding, analytical memos, and organizational matrices and reports. After the groups and interviews were conducted, transcribed, and entered into Atlas ti (Scientific Software Development, 2011), the second and third author (i.e., the coders) reviewed all of the transcripts to conduct initial coding of the data. The goal of the first round of coding was to identify all quotes and sections of text that addressed caregiver and adolescent perspectives about independence. Coders analyzed the data sets separately. The coders met regularly to share their initial coding and eliminated major discrepancies so that the first round of coding represented consensus from both coders. Initial coding resulted in an independence data report for each group—100 pages for caregivers and 200 pages for adolescents.

The coders reviewed the independence data reports in more detail to conduct more specific coding. They created a codebook that identified and defined six major independence themes in both data sets (e.g., independence challenges, independence successes, independence desires, making appointments, attending appointments, follow-up care, and health management). Both coders started the analysis (e.g., matching text to codes) 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 next round of coding, coder agreement was 90%, so the coders completed the analysis on all transcripts—meeting weekly to discuss coding, preliminary findings, and analyses memos.

The coders created a matrix that outlined and defined each of the six themes and a report that listed example quotes under each theme. They reviewed this report, agreed on, collated, and revised the six themes

Table I. *Demographic Characteristics for Adolescents and Caregivers (n = 27 Dyads)*

Variable	Percent
Adolescent demographic variables	
Gender	
Male	74.1
Race/ethnicity	
Non-Hispanic White	96.3
Highest level of education	
Some high school	15.4
High school	61.6
Some college 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 hr	30.8
≥20 hr	26.9
Youth's health insurance status	
Private	60.0
Public	16.0
Both private and public	16.0
Other	8.0
Condition-specific variables	
Current diagnosis	
Autism/autistic disorder	33.3
Asperger syndrome	40.8
PDDNOS	7.4
Autism spectrum disorder	7.4
>1 of these	11.1
Severity of autism spectrum disorder	
Mild	77.8
Moderate	22.2
Severe	0
Limited abilities compared with peers	
Yes	51.9
No	29.6
Do not know	18.5
Caregiver demographic variables	
Relation to adolescent	
Mother	77.8
Father	11.1
Other	11.1
Race/ethnicity	
Non-Hispanic White	96.3
Marital status	
Married	69.2
Never married	7.7
Separated, divorced, or widowed	23.1
Mother's highest level of education	
High school	15.3
Some college or associates degree	50.2
Bachelor's degree	19.2
Graduate degree	15.3
Father's highest level of education	
High school	32.0
Some college or associates degree	28.0
Bachelor's degree	20.0
Graduate degree	20.0
Household income	
<$15,000	8.0
$25,000–$49,999	32.0
$50,000–$99,999	44.0
≥$100,000	16.0

to capture the three most salient themes in the data. The coders then conducted a second round of specific coding using the procedures outlined above for the three specific themes detailed in the results section. Then the coders again created a matrix that outlined and defined each of the three final themes and a report that listed example quotes under each theme by adolescent and caregiver dyad, to organize the data for the results section. The coders compared caregiver and adolescent data to decide how to present and organize the findings. 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.

Results

Participants

Demographic and condition-specific characteristics for caregivers and adolescents ($n = 27$) were presented in Table I. Adolescent participants ranged in age from 16 to 25 years old ($\bar{x} = 19.19$; $SD = 2.83$). The majority of the adolescent sample was non-Hispanic White and male, while the majority of caregivers were non-Hispanic White and female (mothers of adolescents). Most adolescents within our study had a diagnosis of Asperger's Syndrome (40.7%) or Autism/Autistic Disorder (33.3%). The majority of adolescents rated their ASD symptoms as mild (75%), but half said their ASD limited their activity compared with their peers. While no adolescent reported having an intellectual disability, 27% of their caregivers reported their adolescent had an intellectual disability. Regarding health care needs, 67% of the adolescents reported having one or more co-morbid conditions with 60% reporting a physical condition and 64% reporting a mental health condition. Within the 27 adolescent and caregiver dyads, we included one set of siblings and 3 mother–father pairs from the same family.

Summary of Results

Three themes arose from both caregivers' and adolescents' accounts: (a) efforts toward independence, (b) low self-efficacy for adolescents' independence, and (c) desire for independence (Table II). Although there were slightly different perspectives presented in caregiver and adolescent narratives for each theme, overall the two groups agreed more than they differed. Each theme and sub-theme were described in further detail below via quotes and text describing overall patterns in caregiver and adolescent discussions and matched quote sets from caregivers and their children. Random initials are used to protect participants' identity.

Table II. *Thematic Analysis Summary*

Theme	Subtheme	Exemplar quote
Efforts toward independence	Caregivers: Small victories of independence	"We started using the medicine dividers. You just have to remind him in the mornings." "She was actually seeing a counselor on her own for a while and going on her own in college."
	Adolescents: Small steps toward independence	"I *do* [manage my medications], well, I don't put them in the container for which day I take them. My Mom does that part. But *I know when to take them*" "Mom stays in the room [during medical appointment]. . .but [my mom] doesn't answer the questions."
Low self-efficacy for adolescents' independence	Caregivers: Uncertainty	"You don't really know what [adolescents with autism] are capable of. So, [although you support their independence] at the same time you don't want to push so hard that it's uncomfortable for them." "I felt like it [guardianship] was going to limit him—because what am I saying? I'm saying, 'Well, you can't handle this, so I'm going to handle it for you.' And my goal is for him to be independent?"
	Adolescents: Discomfort; inexperience	"[Going to the doctor alone would be] pretty scary because I don't know if I'm going to mess up." "[I] goes with everything [parents] do. [Mom even tracks symptoms] I usually pace around, but then my mom notices, and she gets me the medicine."
Desire for independence	Caregivers: Want independence for child; admit they can do more to support adolescents	"I feel like I'm Edith Enabler. And he would do better if I wasn't." "[Independence was] what we've been working at all along." "Sometimes I step back and think, 'Are you doing way too much? Should you let him make some of these choices and these decisions? Would it make him better able to get out in the world?'"
	Adolescents: Independence key to higher quality of care	"[It would] make me feel more like an adult if they would talk to me more. If they [parents] weren't there, you know, if I could just do it myself." "[Feel] angry, discouraged, and mad" when ignored by doctors. "They probably think, oh, he's just autistic. He can't answer these questions because he'll get confused. Like, yeah, kind of, if you ask the wrong question. If you don't ask it in [a simple way]. . .I put my headphones in"

Efforts Toward Independence

In group and interview discussions, both caregivers and adolescents identified similar core components to medical care: (a) identifying a medical need, (b) making an appointment, (c) accessing (i.e., getting to) the appointment, (d) attending the appointment, and (e) following up on medical instructions. Both caregivers and adolescents were reluctant to describe adolescents' independent engagement with any of these steps as completely successful or doable. Similarly, both groups agreed that health-related independence is challenging. For example, E.I. described achieving medical independence as "trying to fit into a round hole when [the child's] got an [edge]." Her son similarly added that independence was a daunting responsibility. Several other adolescents described health care independence as "uncomfortable," which also corresponded with E.I.'s analogy.

Caregivers and Adolescents Describe Small Steps Toward Progress

Despite discomfort and apprehension, caregivers and adolescents described *small* steps they were taking to work toward or even achieve independence. Minor but important discrepancies in caregiver and adolescent accounts did exist, yet both groups commented on efforts toward independence in the areas of provider communication, medication, and appointment management.

For instance, N.T. explained how she wrote a script to help her daughter communicate with a provider independently:

> I write down a [script]. . ."Here's your name. Here's your birthdate. Here's your telephone number." Because when she gets like nervous, she can't remember those things, even though she knows all of them. I make her write it all down, I say, "Because they're going to ask your name, they're going to ask your birthdate, and they're going to ask your phone number, and about your medicine."

B.T. also explained that she is able to talk with a doctor independently. She said that her mom stays in the room, but remarked that "[my mom] doesn't answer the questions." B.T. did not reference the role of her mother's script in her ability to respond to the doctor. E.L. said that they were improving her son's independence skills via "special classes" but that he still "was not capable of making medical appointments" and "needs help with medication." When asked to describe his role in managing his medical care independently, U.L. also said that he "hadn't reached the point yet" to make his own appointments but described his medications in a slightly more positive way than his caregiver:

> I *do* [manage my medications], well, I don't put them in the container for which day I take them. My Mom does that part. But *I know when to take them*… I take them in the morning, and then again at night, and I only take one pill at school.

In a similar fashion, K.K. explained how she worked with her son to help him manage his medications more independently with a reminder tool, "We started using the medicine dividers. You just have to remind him in the mornings, go take your pills. And you have to tell him what day. And [then] he can take them by himself." E.E. agreed that he took his medicine, but said he did so without a parental reminder, all but "one of 31 days in the month." K.C. described her daughter's independence by explaining, "She was actually seeing a counselor on her own for a while and going on her own in college." Her daughter, F.C., also described going to medical appointments without her mother as an example of her autonomy, but in her account, she did not go on her own, but did independently solicit help: "People offered to go with me, [and] I would actually take them up on this." Although the two groups presented slight differences in the examples that they gave of health independence actions, small steps toward independence were apparent in both groups' accounts.

Low Self-Efficacy for Adolescents' Independence

Both caregivers and adolescents expressed low-self efficacy for health care independence. Caregivers' lack of confidence stemmed from uncertainty about their child's capacity as well as what role they should assume to best support their child's autonomy. Adolescents also expressed uncertainty, but their lack of confidence came largely from a lack of experience taking independent health care steps.

Caregiver Uncertainty

T.D. summarized many caregivers' sentiments when she described her child's health care independence, "You don't really know what [adolescents with autism] are capable of. So, [although you support their independence] at the same time you don't want to push so hard that it's uncomfortable for them." Her son admitted he did not make his appointments or take his medicines by himself, but then noted, "The only [thing] I truly need right now [to be independent] is to learn how to operate my washing machine/drying machine." His statement suggested that although he had a bit more confidence about independence than his mother, her assessment of his abilities was likely correct, as he was not fully considering his health care needs in the definition of his autonomy. Caregivers overwhelmingly said that they did not know how to gauge their child's potential.

A common thread in discussions was the challenge of identifying a child's "real" age. When asked if his child could handle more of his medical care independently, K.L. said, "I'm not sure. That's the biggest part with kids on the spectrum. They're usually three years behind everybody else, if not more. Honestly, I don't know if my son will be able to [manage his health care]." His son admitted that his father did encourage him to do more for himself but that he still did not take his medicines by himself or take the lead in conversations with providers because his parents "knew more." Q.H. similarly explained that her daughter does not go through the aging process like others who "wake up [everyday] an older person…She's almost 20 now, she still sees herself as 15, she still looks and acts like 15…It will take her longer to get to a neurological age that other people get to quicker."

Caregivers were also confused about their role in their child's path toward independence. Decisions about guardianship—the legal appointment of someone to make decisions for another person who is unable to make those decisions on their own—were particularly problematic. Many caregivers said that they felt forced to remain involved in their child's care even if they described guardianship as against their ultimate goal. For example, T.W. explained:

> I guess I felt like it [guardianship] was going to limit him—because what am I saying? I'm saying, "Well, you can't handle this, so I'm going to handle it for you." And my goal is for him to be independent?

Many others agreed but were uncertain about what would happen if they were not in the doctor's office with their child or there to check in regarding problems. B.L. for example said it was just too hard for her to take the risks—"We are afraid to leave him by himself for too long—90% chance he would be fine but 10% chance it would be disastrous." Her son, M.L., said that "I'd like to live alone someday" but agreed that "I'm worried about being alone. I'm afraid I can't take care of myself."

Adolescents Lack Experience

Adolescents were also uncertain about acting independently—mostly because they lacked experience. Most of their examples revolved around the potential discomfort of acting in a new way. For example, M.L. said he would be "nervous" if the doctor wanted to talk to him alone and that it might "go particularly poorly if he was in a 'bad mood'." He said his fears stemmed from "not really knowing what would happen." His caregiver confirmed that he preferred that she take the lead in bringing up issues with providers and that he "did not like to talk about it himself." Similarly, U.L. also said that going to the doctor alone would be "pretty scary because I don't know if I'm going to mess up."

S.U. said going to the doctor without his parents would be challenging because "I'm not used to it… go there on my own, having to know all this information and stuff like that." His caregiver confirmed that "A lot of times his answers are 'out there'…And as a parent we know how to interpret [the information he is trying to convey]." T.L. described how he just usually "goes with everything [his parents] do" regarding his health and said his mom even keeps track of his symptoms: "[My mom handles my medicine for anxiety]. I usually pace around, but then my mom notices, and she gets me the medicine." And then of course there was the issue of talking with the doctor during the appointment. Several adolescents were unsure about what it would be like to talk with a physician because as A.I. explained, "Sometimes [my doctor] will talk to me for like a minute and then she'll go back and talk to my mom," which did not establish a routine or familiar rapport. Her mom agreed she felt like she needed to be involved because "she still plays with toys…" and "is not in the mind frame to make decisions on her own."

Desire for Independence

Nearly all of the caregivers said that independence for their child was a desired goal and most adolescents agreed. What that independence should look like and how it could be achieved were more challenging questions, but both groups' desire for autonomy for children with ASD prevailed in participant discussions.

Caregivers Want to Promote Child Independence

E.M. said, for example, "That's what life is supposed to be. They're supposed to get older. They're supposed to do their own thing, and they're supposed to leave you. That's how it's supposed to be." E.I. also noted that independence was "what we've [her and her son] been working at all along." Her son confirmed that "I want to get through life. I mean, I don't want to end up a person who is still living with their parents… [They] can't hold my hand forever."

Several caregivers' motivation was driven strongly by their recognition and concern that they would not always be there to guide their child. K.N. explained, "I'm always afraid that we're going to pass away and she's going to be left here [so] I want her to be totally independent." B.L. agreed, "You want them to be able to survive after you're gone…You want them to be able to take care of themselves without you."

At the same time, caregivers also admitted that they could be part of the problem and that they were willing to make changes. E.I. said, "I feel like I'm Edith Enabler. And her son would do better if I wasn't." N.C. explained, "Probably a good portion of [my son's] problem is cutting the apron strings—me cutting the apron strings. Because I've always just been so protective." B.L. agreed that she could "encourage more input [from her son]" regarding his role in health care independence. During the focus groups, a few caregivers, like E.I., T.W., and E.M., also realized that their children probably could handle more tasks on their own, like going into their appointment independently. E.I.'s son supported their statements by indicating it would be a "boost" to be more involved in his own medical appointments.

For Adolescents, Independence is Key to Higher Quality Care

Many adolescents wanted to overcome their fears for the benefit of independence. F.C. said it was "really important" to have alone time with her doctor and O.X. said that was especially true for "private stuff." Several adolescents, like E.E., were upset when their doctors did not talk directly to them: "I've had doctors that have ignored me. That have experimented on me…I sat there and was like in my head, Okay, f*** you, too." His caregiver while not aware of (or did not discuss) his anger, admitted that:

> I definitely do too much for him…And sometimes I step back and think, "Are you doing way too much? Should you let him make some of these choices and these decisions? Would it make him better able to get out in the world?"

Similarly, E.S. was "Angry, discouraged, and mad" when ignored by doctors. He said:

> They probably think, oh, he's just autistic. He can't answer these questions because he'll get confused. Like, yeah, kind of, if you ask the wrong question. If you don't ask it in [a simple way]…I put my headphones in, like, you know, I'm done with this cr*p.

His mom for her part admitted she encouraged independence but was not sure if he could achieve it and thus, lacked confidence in giving him more autonomy.

S.U. said it did not offend him when his doctor talked to his parents but it would "make me feel more like an adult if they would talk to me more. If they [parents] weren't there, you know, if I could just do it myself." T.L. also said it would be "really nice" to be in the room without his parents ("if they would allow it") to make his own appointment. He explained, that his parents needed to "let me grow up at some point…my mom babies me…It's embarrassing." When the interviewer asked if he talked about this with his mom he said, "No, I don't want to hurt her feelings." His parents, in their responses, did not indicate that they knew he wanted more freedom and did focus mostly on their concerns about "the skills that he would require to be able to do these things to manage his own health care and his own self care."

Over and over again, adolescents responded like S.U. when he was asked if he could make his own appointment, "I could probably do it, but I haven't done it." U.L. had a specific plan to start acting independently, "By the number of medicines I have to take a day, like, learning how much medicine goes in each slot for the weekend pill box." He now takes the pills and his parents set up the pillbox but he thought he could do this. S.T. said he explained his pain to his doctor without his mom in the room and it "felt really good." He said he wanted to try more of these conversations in the future.

Discussion

Much work has been done to improve the lives and functioning levels of children with ASD; however, comparatively little attention has been paid to adolescents as they age into adulthood (Howlin & Moss, 2012; Levy & Perry, 2011). This study aimed to understand and compare the HCT experiences of adolescents with ASD and their caregivers. This ability to examine the caregivers' and adolescents' experiences separately as well as analyze their responses together provided a unique opportunity to see how needs and values around health-related independence coincided and deviated. We discovered that (1) adolescents and caregivers are making efforts to improve adolescents' independence; (2) adolescents and caregivers have low self-efficacy for adolescents' independence; and (3) both groups desired to improve adolescents' independence and described ways in which they could achieve independence.

Given the importance of independence to adolescents with ASD's overall well-being, it was encouraging to see that both adolescents and caregivers prioritized the adolescents' independence and health-related independence (i.e., ability to independently manage one's own health care needs). Unfortunately, caregivers described feeling uncomfortable and apprehensive about letting their adolescents become more responsible for their health care needs. Similar to caregivers of adolescents with other special health care needs, caregivers within this study described fears that centered on the adolescents' safety and protection, which increased as both groups aged. Many caregivers specifically discussed who would take care of their son/daughter/adult-child after they were no longer able to (Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Phelps, McCammon, Wuensch, & Golden, 2009; Taylor & Seltzer, 2011b).

Caregivers wanted to change their role as the "responsible one" but did not know how to do this while ensuring their own adolescent's safety. Regardless of disability or condition type, caregivers have been shown to lack preparation and understanding of the transition to adult health care for their adolescent (Reiss, Gibson, & Walker, 2005). Caregivers within this study also had difficulty knowing what responsibilities their adolescent could handle. Caregivers described, at length, how their adolescents with ASD develop differently and often slower than typically developing peers. This made it difficult for them to determine appropriate expectations. Although previous work has acknowledged the difference between chronological age and psychological age of people with ASD, there are few recommendations regarding how to incorporate this into expectations for the transition process for these adolescents (Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012).

For adolescents in this and other studies, independence and/or some level of autonomy were the goals (Cheak-Zamora, Teti, Maurer-Batjer, & Halloran, 2016; Humphrey & Lewis, 2008; Rossetti, Ashby, Arndt, Chadwick, & Kasahara, 2008). Adolescents in this study described their lack of experience as a key component of the fear and anxiety they described. Specifically, they had little to no experience talking to the doctor, arranging visits, and managing medications. Previous studies show that increased anxiety among adolescents with ASD may affect motivation and inhibit the adolescent from taking a more active role in managing their care (Cheak-Zamora & Teti, 2015; Hillier, Fish, Siegel, & Beversdorf, 2011). Young adults with severe disabilities also report little real-world experience and few opportunities to gain experience but fear and anxiety around these issues seem less prevalent among this group than among youth with ASD (Cooney, 2002; Rehm et al., 2012). A better understanding of adolescents' anxiety issues around new experiences and independence, and how it effects their transition to adulthood among adolescents with ASD, specifically, is imperative.

Caregivers in this study came to a consensus that adolescents with ASD deserve to be treated as adults and to experience an adult-model of care whenever possible. Previous studies indicate that this concept is often hard for caregivers of adolescents with ASD and health care providers to subscribe to, as they have spent years making decisions for these adolescents (Cheak-Zamora & Teti, 2015; Rehm et al., 2012; Taylor & Seltzer, 2011a). Caregivers specifically discussed the need to relinquish control and create opportunities for adolescents to exert independence. Similarly, adolescents stated that they needed their caregivers to "let go" a little so they could gain more experiences and autonomy. Adolescents described knowing that they could do more and wanting to make an effort to take on more responsibility. These are among the first findings to point clearly to adolescents' willingness to take on more adult responsibilities, particularly related to managing their health care needs. Previous research has shown that even small activities (e.g., doctors asking youth questions, getting youth opinions about treatment choices) promote adolescents' independence and improve the likelihood of successful transition to adult health care (Bryant &

Walsh, 2009; Carter, Austin, & Trainor, 2011; Cheak-Zamora, Teti, Maurer-Batjer, et al., 2016; Kirby, 2016; Rossetti et al., 2008).

Adolescents' resilience to adversity within this and other studies was also encouraging and indicated that early well-supported opportunities for independence may alleviate much of the adolescents' anxiety and increase the adolescents' confidence (Cheak-Zamora, Teti, Maurer-Batjer, et al., 2016; Schwean & Saklofske, 2008). Adolescents showed resilience in that even when describing emotionally charged topics, such as feeling ignored, disrespected in the doctor's office, and misunderstood, they continued to strategize ways to improve their lives.

To our knowledge, this was the first study that compared adolescents with ASD and their matched caregivers' experiences during the transition to adulthood. Overall caregivers and adolescents agreed on most issues and shared many of the same concerns. Caregivers and adolescents had similar perspectives on the need for health-related independence but slightly different perspectives regarding the adolescent's level of independence. Previous research on families with adolescents with various health care needs indicated that caregivers and adolescents report similar barriers and needs but report slightly different priorities and expectations (Bryant & Walsh, 2009; Cheak-Zamora et al., 2015; Hauser & Dorn, 1999). Within this and previous studies on adolescents with ASD, it was not clear the extent to which caregivers and adolescents talk to one another about these issues. Adolescents with ASD may have difficulty communicating these desires to their parents owing to lack of communication skills, lack of clear and concrete goals, and fear (Cheak-Zamora et al., 2015). Participants within this study described many of these concepts including: not wanting to disappoint their parents, not knowing how to explain their desires, and fear of failing if they tried to be more independent. Future research is needed to specifically examine the communication patterns between caregivers and adolescents with ASD to determine whether differences in views and limited communication patterns truly exist.

Study Limitations

This was a qualitative study; as such, we did not aim to collect generalizable data but to explore the experiences of specific caregiver and adolescent dyads in detail. This study may not have captured the experiences of caregivers and adolescents who differ from the study population (e.g., adolescents with some verbal ability, participants from urban areas, racial/ethnic minorities). For adolescents, individual interviews were an effective data collection method, but combining multiple forms of input over a longer time period (e.g., focus groups and individual interviews or multiple interview sessions) would have provided more opportunities for dialog with adolescents with communication challenges and helped them feel more comfortable with the research setting. Using interviews for adolescents and focus groups for parents, although ideal for data collection purposes, may have limited our ability to explore data at the dyad level. Asking additional questions about health-related independence and independence in general may have resulted in more information about specific transition issues and needs. Future research may want to specifically explore HCT and health-related independence topics such as changing physicians and specialists, medication management, sexual and relationship knowledge, and physical and mental health needs. Additionally, we did not conduct subgroup analyses by age, gender, or employment status, as it was not in line with the initial exploratory aims of our analysis. Further examining these factors is extremely important in understanding the population and developing tailored intervention.

Clinical Implications

Although numerous HCT interventions have been conducted on adolescents with special health care needs, such as cerebral palsy and juvenile diabetes, no HCT intervention has been developed for adolescents with ASD (Schwartz et al., 2011; Watson, 2012). This study helped to identify several specific service needs for caregivers and adolescents with ASD. An intervention that included communication skill building for the adolescent and caregivers was an identified need for both groups.

For adolescents with ASD, it is important to remember that independence does not necessarily mean complete autonomy. An intervention that balances adolescent, parent, and provider communication, skills, and support may be more appropriate than one that pushes adolescents to be autonomous (Rehm et al., 2012; Rossetti et al., 2008). Interventions for adolescents with ASD should be tailored to their specific goals and needs, and include education and role-playing activities to enhance communication (Hume, Loftin, & Lantz, 2009). Caregivers will need guidance on how to facilitate and support their adolescents' independence, as well as individual support as they move from an authoritative to facilitative role within their adolescents' life (Kuhlthau et al., 2016; Watson, Parr, Joyce, May, & Le Couteur, 2011).

Notably absent in both caregiver and adolescent narratives were accounts of interactions with providers. A HCT intervention for adolescents with ASD should include provider and health system participation. Health care providers are essential in promoting autonomy by asking adolescents health care questions directly, meeting with adolescents individually for at least part of the health care visit, and asking and promoting the adolescents' self-identified goals. Other adjustments to the health care visit may include alterations to the clinic environment (e.g., providing adolescent with clinic room on arrival), allowing alternative communication methods, and using specific and precise language and instructions (Hall, Kriz, Duvall, Nguyen-Driver, & Duffield, 2015).

Conclusion

Our study used qualitative methods best suited for adolescents with ASD and their caregivers to understand and compare each person's experiences and perspectives as the adolescent transitions to adulthood. The comparison is important to advance knowledge of both groups' needs, as their accounts are not always congruent. Although the caregivers and adolescents expressed anxiety and uncertainty about the adolescents' future, each group described being encouraged and willing to try to promote independence and become independent, respectively. These findings further supported the need for well-established HCT services that are initiated early and involve adolescents and caregivers in the process—as well as providers. Further, our findings reiterate the importance of understanding the perspectives of both caregivers and adolescents and of helping improve communication between caregivers, adolescents, and providers to achieve shared independence goals. Although they often described similar experiences, each group provided distinct views and needs that will assist in building tailored interventions and improving our understanding of this underserved population.

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References

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5®)*. American Psychiatric Pub.

Barnhill, G. P. (2001). Social attributions and depression in adolescents with Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities*, *16*, 46–53. doi:10.1177/108835760101600112

Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation*, *88*, 1064–1073. doi:10.1016/j.apmr.2007.04.018

Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the society for adolescent medicine. *Journal of Adolescent Health*, *14*, 570–576.

Bryant, R., & Walsh, T. (2009). Transition of the chronically ill youth with hemoglobinopathy to adult health care: An integrative review of the literature. *Journal of Pediatric Health Care*, *23*, 37–48. doi:10.1016/j.pedhc.2008.04.009

Carter, E. W., Austin, D., & Trainor, A. A. (2011). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies*, *23*, 50–63. doi:10.1177/1044207311414680

Cheak-Zamora, N. C., Farmer, J. E., Mayfield, W. A., Clark, M. J., Marvin, A. R., Law, J. K., & Law, P. A. (2014). Health care transition services for youth with Autism Spectrum Disorders. *Rehabilitation Psychology*, *59*, 340–348. doi:10.1037/a0036725

Cheak-Zamora, N. C., Teti, M. (2015). "You think it's hard now . . . It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services. *Autism*, *19*, 992–1001. doi:10.1177/1362361314558279

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). "Transitions are scary for our kids, and they're scary for us": Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, *28*, 548–60.

Cheak-Zamora, N. C., Teti, M., & Maurer-Batjer, A. (2016). Capturing experiences of youth with ASD via photo exploration: Challenges and resources becoming an adult. *Journal of Adolescent Research*, 1–29. doi:10.1177/0743558416653218

Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., & Halloran, D. (2016). Snapshots of growing up: Youth with autism explore adulthood through photovoice. *Journal of Developmental and Behavioral Pediatrics*, *37*, 433–441. doi:10.1097/dbp.0000000000000313

Cheak-Zamora, N. C., Yang, X., Farmer, J. E., & Clark, M. (2013). Disparities in transition planning for youth with Autism Spectrum Disorder. *Pediatrics*, *131*, 447–454. doi:10.1542/peds.2012-1572

Cooney, B. F. (2002). Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation*, *40*, 425–435. doi:10.1352/0047-6765(2002)040<0425:epotoy>2.0.co;2

Coury, D., Jones, N. E., Klatka, K., Winklosky, B., & Perrin, J. M. (2009). Healthcare for children with autism: The autism treatment network. *Current Opinion in Pediatrics*, *21*, 828–832. doi:10.1097/MOP.0b013e328331eaaa

DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with Autism Spectrum Disorder. *Qualitative Health Research*, *25*, 569–583. doi:10.1177/1049732314552455

Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities*, *11*, 359–370. doi:10.1177/1744629507083585

Golnik, A., Ireland, M., & Borowsky, I. W. (2009). Medical homes for children with autism: A physician survey. *Pediatrics*, *123*, 966–971. doi:10.1542/peds.2008-1321

Grant, C., & Pan, J. (2011). A comparison of five transition programmes for youth with chronic illness in Canada. *Child: Care, Health and Development*, *37*, 815–820. doi:10.1111/j.1365-2214.2011.01322.x

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied Thematic Analysis*. Thousand Oaks: Sage Publications.

Hall, T., Kriz, D., Duvall, S., Nguyen-Driver, M., & Duffield, T. (2015). Healthcare transition challenges faced by young adults with Autism Spectrum Disorder. *Clinical Pharmacology and Therapeutics*, *98*, 573–575. doi:10.1002/cpt.254

Hauser, E. S., & Dorn, L. (1999). Transitioning adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing*, *25*, 479–489. Retrieved from http://weblinks3.epnet.com

Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with Autism Spectrum Disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, *24*, 77–88. doi:10.1177/1088357608329827

Hillier, A. J., Fish, T., Siegel, J. H., & Beversdorf, D. Q. (2011). Social and vocational skills training reduces self-reported anxiety and depression among young adults on the autism spectrum. *Journal of Developmental and Physical Disabilities*, *23*, 267–276. doi:10.1007/s10882-011-9226-4

Howlin, P., & Moss, P. (2012). Adults with Autism Spectrum Disorders. *Canadian Journal of Psychiatry*, *57*, 275–283.

Hume, K., Loftin, R., & Lantz, J. (2009). Increasing independence in Autism Spectrum Disorders: A review of three focused interventions. *J Autism Dev Disord*, *39*, 1329–1338. doi:10.1007/s10803-009-0751-2

Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, *12*, 23–46. doi:10.1177/1362361307085267

Kirby, A. V. (2016). Parent expectations mediate outcomes for young adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*, 1643–1655. doi:10.1007/s10803-015-2691-3

Kuhaneck, H. M., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. R. (2010). A qualitative study of coping in mothers of children with an Autism Spectrum Disorder. *Physical and Occupational Therapy in Pediatrics*, *30*, 340–350. doi:10.3109/01942638.2010.481662

Kuhlthau, K. A., Delahaye, J., Erickson-Warfield, M., Shui, A., Crossman, M., & van der Weerd, E. (2016). Health care transition services for youth with Autism Spectrum Disorders: Perspectives of caregivers. *Pediatrics*, *137(Suppl 2)*, S158–S166.

Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorder*, *5*, 1271–1282.

Lotstein, D. S., Inkelas, M., Hays, R. D., Halfon, N., & Brook, R. (2008). Access to care for youth with special health care needs in the transition to adulthood. *Journal of Adolescent Health*, *43*, 23–29. doi:10.1016/j.jadohealth.2007.12.013

Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with Autism Spectrum Disorders. *Autism*, *18*, 223–232. doi:10.1177/1362361312474121

Mazurek, M. O., & Kanne, S. M. (2010). Friendship and internalizing symptoms among children and adolescents with ASD. *Journal of Autism and Developmental Disorders*, *40*, 1512–1520. doi:10.1007/s10803-010-1014-y

McDonagh, J. E., Southwood, T. R., & Shaw, K. L. (2006). The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Paediatric and Adolescent Rheumatology*, *46*, 161–168.

Murphy, E., Clegg, J., & Almack, K. (2011). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*, 63–73. doi:10.1111/j.1468-3148.2010.00565.x

Myers, S. M., & Johnson, C. P. (2007). Management of children with Autism Spectrum Disorders. *Pediatrics*, *120*, 1162–1182. doi:peds.2007-2362 [pii] 10.1542/peds.2007-2362

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *43*, 2710–2719. doi:10.1007/s10803-013-1833-8

Phelps, K. W., McCammon, S. L., Wuensch, K. L., & Golden, J. A. (2009). Enrichment, stress, and growth from parenting an individual with an Autism Spectrum Disorder. *Journal of Intellectual and Developmental Disability*, *34*, 133–141. doi:10.1080/13668250902845236

Rehm, R. S., Fuentes-Afflick, E., Fisher, L. T., & Chesla, C. A. (2012). Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. *ANS. Advances in Nursing Science*, *35*, E57–E72. doi:10.1097/ANS.0b013e3182626180

Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics*, *115*, 112–120. doi:10.1542/peds.2004-1321

Rossetti, Z., Ashby, C., Arndt, K., Chadwick, M., & Kasahara, M. (2008). "I like others to not try to fix me": Agency, independence, and autism. *Journal of Intellectual and Developmental Disability*, *46*, 364–375. doi:10.1352/2008.46:364-375

Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child:*

Care, Health and Development, *37*, 883–895. doi:10.1111/j.1365-2214.2011.01282.x

Schwean, V., & Saklofske, D. (2008). Resiliency *factors in youth with* Asperger's Disorder. Retrieved from https://policywise.com/wp-content/uploads/resources/2016/07/Resiliency_in_Youth_with_Aspergers_Disorder_Final_Report.pdf

Scientific Software Development. (2011). Atlas.ti (Version 6.2). Berlin.

Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, *10*, 234–247. doi:10.1002/mrdd.20038

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an Autism Spectrum Disorder. *Pediatrics*, *129*, 1042–1049. doi:10.1542/peds.2011-2864

Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an Autism Spectrum Disorder. *Archives of Pediatrics and Adolescent Medicine*, *165*, 141–146. doi:10.1001/archpediatrics.2010.279

Stewart, D. (2009). Transition to adult services for young people with disabilities: Current evidence to guide future research. *Developmental Medicine and Child Neurology*, *51(Suppl 4)*, 169–173. doi:10.1111/j.1469-8749.2009.03419.x

Taylor, J. L., & Seltzer, M. M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, *40*, 1431–1446. doi:10.1007/s10803-010-1005-z

Taylor, J. L., & Seltzer, M. M. (2011a). Changes in the mother-child relationship during the transition to adulthood for youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *41*, 1397–1410. doi:10.1007/s10803-010-1166-9

Taylor, J. L., & Seltzer, M. M. (2011b). Employment and post-secondary educational activities for young adults with Autism Spectrum Disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, *41*, 566–574. doi:10.1007/s10803-010-1070-3

Teti, M., Cheak-Zamora, N., Lolli, B., & Maurer-Batjer, A. (2016). Reframing autism: Young adults with autism share their strengths through photo-stories. *Journal of Pediatric Nursing*, *31*, 619–629. doi:10.1016/j.pedn.2016.07.002

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2008). The National Survey of *children with special health care needs chartbook* 2005–2006. Rockville, MD.

van Steensel, F. J., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with Autistic Spectrum Disorders: A meta-analysis. *Clinical Child and Family Psychology Review*, *14*, 302–317. doi:10.1007/s10567-011-0097-0

Watson, A. R. (2012). Continuity in transition from paediatric to adult healthcare. *The journal of the Royal College of Physicians of Edinburgh*, *42*, 3–4. doi:10.4997/JRCPE.2012.101

Watson, R., Parr, J. R., Joyce, C., May, C., & Le Couteur, A. S. (2011). Models of transitional care for young people with complex health needs: A scoping review. *Child: Care, Health and Development*, *37*, 780–791. doi:10.1111/j.1365-2214.2011.01293.x

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with Autism Spectrum Disorders. *Clinical Psychology Review*, *29*, 216–229. doi:10.1016/j.cpr.2009.01.003

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ORIGINAL PAPER

Financial Capabilities Among Youth with Autism Spectrum Disorder

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Abstract Youth with Autism Spectrum Disorder (ASD) experience significant difficulties assuming adult responsibilities and achieving independence. Little is known about their desire or ability to manage their own finances. This study explored the financial circumstances, money management skills, and desires for financial independence among 27 youth with ASD. Youth took part in 30–60 min semi-structured interviews about independence. Strategies of theme analysis identified three critical themes about finances and emerging adulthood for youth with ASD. Youth (1) defined independence by being able to manage their finances, (2) worried about their lack of money management skills, and (3) cited poor financial skills as barrier to independence. Results suggest youth with ASD understand the importance of financial capability and strive for financial independence, but lack the skills and support needed to achieve their financial goals. This study provides preliminary information for clinicians, educators, and researchers to develop financial capability modules for youth with ASD.

Keywords Autism spectrum disorder · Youth/young adults · Independence · Financial capabilities · Money management · Qualitative methods

Introduction

Over three million people in the U.S. are estimated to have an Autism Spectrum Disorder (ASD) diagnosis (Autism Speaks 2012). With annual diagnosis rates surpassing juvenile diabetes, cancer, and HIV/AIDS combined, ASD is frequently described as an emerging epidemic. ASD is a complex disorder characterized by impairments in verbal and nonverbal communication and social interactions, as well as restrictive or repetitive behaviors. These impairments, plus high rates of comorbidities, result in this population having multifaceted needs, such as health care, education, and support services (Shogren and Plotner 2012).

The increased rates of diagnoses and complex needs of youth with ASD contribute to the necessity for transition services and life skills training. Although early intervention therapies have been shown to improve functioning and communication for children with ASD, more services are needed for youth, particular as they transition into adulthood and beyond. Unfortunately, services become more scarce and fragmented as children end their high school careers (Friedman et al. 2013). As high as two-thirds of youth with ASD had little or no participation in transition planning services (Cameto et al. 2004). The lack of services may help explain why youth with ASD experience low rates of education, employment, and community participation, and demonstrate poor social outcomes (Friedman et al. 2013; Shattuck et al. 2012; Shogren and Plotner 2012;

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Wagner et al. 2005). These findings suggest that current transition models are insufficient for meeting the needs of youth with ASD (Shattuck et al. 2012).

Transition services currently provided to youth with special health care needs (YSHCN) are inadequate partly due to the lack of curriculum on financial management and decision-making skills, even though these are integral components of a holistic transition plan for vulnerable young people. Personal finance has been identified as one of the six priority areas for people with learning disabilities in the UK (Williams et al. 2008). Research within the U.S. indicates that connecting to financial institutions as a young person aids long-term financial well-being (Friedline 2015; Friedline et al. 2016; Peters et al. 2016a). For people with disabilities, being able to manage ones' own finances increases overall independence and improves psychological well-being and income attainment (Abbott and Marriott 2013; Hendricks and Wehman 2009; Taylor et al. 2011). Research also suggests that many individuals with mild intellectual disabilities are able to make at least some of their personal finance decisions (Suto et al. 2005a). Although little is known about the financial skills of individuals with ASD, it is likely that many, depending on cognitive functions, can make financial discussions with assistance or training.

Few studies provide information about the current practices of money management among YSHCN, particularly youth with ASD. We do know that only half of individuals with learning disabilities have control over their own money and youth with ASD are less financially independent than other YSHCN, often relying on their parents well into adulthood (Friedman et al. 2013; Hume et al. 2014). One study examined the use of specific financial tools among YSHCN and found that only one-third of these individuals have personal checking accounts and 20% have a credit card 2 years after high school (Wagner et al. 2005). For financial health of youth with ASD specifically, few youth in high school had checking accounts (10%) or credit cards (.5%), and although access to checking accounts had increased to 33%, credit card ownership was still low (2.5%) 2 years later (Wagner et al. 2005). These low rates of banking service utilization indicate a lack of financial autonomy among YSHCN.

Despite the importance of financial autonomy and increased independence it provided for YSHCN, financial management, and decision-making skills are often seen as outside the purview of human service professionals working with young people and the topic is a rarely discussed component of transition planning for all people with disability (Peters et al. 2016b). According to the (Council for Economic Education 2016), only 17 states require students to complete a personal finance class in high school. Educational supports, such as a financial literacy curriculum in both schools and independent living programs, and the inclusion of financial management goals in one's Individual Education Plan (IEP) could increase autonomy and ultimately the quality of life of individuals with disabilities (Mittapalli et al. 2009; Suto et al. 2005b).

Unfortunately, there is a lack of consensus on what a successful financial education program and goals look like. Colleges have successfully developed a seminar-based curriculum that has been shown to increase students' financial knowledge and financial responsibility but these homogenous programs will likely not meet the need of younger students and/or students with disabilities (Borden et al. 2008). It is likely that for youth and people with disabilities the most effective financial education program aims its curriculum at a unique population or individual with a focus on a specific financial concern, such as building credit (McCormick 2009).

More research is needed to ascertain current financial practices, preferences for learning how to manage finances, and perceived barriers among youth with autism specifically (Batavia and Beaulaurier 2001; Williams et al. 2008). Future studies examining the financial health and knowledge of people with ASD will help identify factors associated with financial vulnerability (Batavia and Beaulaurier 2001; Suto et al. 2005a). The goal of this study was to explore the experiences of youth with ASD as they transition to adulthood.

Method

Participants

Youth with ASD were recruited from three ASD treatment and support agencies in cities in the U.S. Midwest. Agency staff distributed study fliers to clients by mail and in local clinic settings. Interested participants contacted the research team to complete screening questionnaires. Eligibility criteria included youth between 16 and 25 years of age who have an ASD diagnosis (clinical record review), can read and speak English, and are able to engage in required study activities, as measured by adolescent- and caregiver-reported functional ability. The final sample included 27 youth. Based on preliminary data analyses and findings from previous studies, the sample is of sufficient size to ensure data saturation (Cheak-Zamora and Teti 2014; Cheak-Zamora et al. 2015).

Procedure

Participants took part in 30–60 min semi-structured interviews. Interviewers ($n = 3$) had experience working with adolescents with ASD and were trained on how to utilize the interview guide. Adolescents and their caregivers were sent written outlines of the interview process and the interview questions a week before the individual interviews. Participants were encouraged to contact the project staff if they had any questions and were permitted to bring an advocate (support person) with them to the interview if needed (none did). Upon arrival, adolescents and their caregivers participated in introductory “ice-breakers” with refreshments and unstructured conversations with interviewers. Interviewers then reviewed the consent form and interview process with the adolescents and caregivers (depending on youth’s age and desire for caregiver inclusion).

Interviews consisted of adolescents generally talking about themselves and their health care needs while completing the demographic survey, followed by a description of the interview topics, and a series of open-ended questions related to each topic. Interviewers also developed multiple choice reflection questions to make concepts more concrete and help adolescents switch to new topics (Kvale and Brinkmann 2009). Additionally, opportunities for breaks were provided if participants needed time to think about a question or appeared nervous or frustrated. As a result of these strategies, all youth, even those with limited communication skills, contributed within the interview session on discussion on every topic.

Measures

The measurement tool presented here is part of a larger study on health-related independence among youth with ASD. We developed the interview guide based on the authors’ experiences conducting qualitative research on youth with ASD (Cheak-Zamora et al. 2015), the health independence literature (Cheak-Zamora et al. 2014), and feedback from ASD practitioners, researchers, and caregivers. The research team piloted interview questions with clinicians, caregivers, and youth with ASD. The final guide included 12 questions with open and closed prompts. The research team developed preparatory multiple choice reflection questions related to the core questions to provide youth with visual reference point. Additional supports for youth included: (1) use of a white board to enhance their communication; (2) written outlines of the interview process and sample questions sent to participants prior to the interview session; (3) an introductory “ice-breaker” period with refreshments and unstructured conversations; (4) opportunities for breaks if participants needed time to think about a question or appeared nervous or frustrated. The majority of data for this analysis comes from the following three questions: “What does it mean to be an adult?”; “What are you looking forward to about becoming an adult?” and “What worries you about becoming an adult?” All participants also completed a demographic and health status survey.

Data Analyses

We analyzed interview data using theme analysis, including initial and axial coding, analytical memos, and organizational matrices and reports (Guest et al. 2012). All of the authors generated codes for analysis by consulting the existing literature on issues of independence in youth with ASD, and inductively, from data provided by the youth themselves (Guest et al. 2012). The final codebook included ten items, including codes to capture “finance,” the focus of this analysis. The second author and a Research Assistant conducted the analysis. Initial coding involved reviewing the transcripts line by line to identify how participants’ experiences 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 60%. The coders clarified the code definitions, and coded another 25% of data. After the second round of coding, coder agreement was 90%, so the coders completed the analysis on all of the transcripts—meeting weekly to discuss coding, preliminary findings, and analysis memos. The coders then reviewed the initial coding analysis and conducted axial coding to consolidate, clarify, and expand the codes and identify final themes. Finally, a matrix that outlined and defined each of the final themes and a report that listed example quotes under each theme was created in order to organize the data for the results section.

Results

The majority of youth ($n = 20$) were male with a mean age of 19 years (range 16 to 25 years; Table 1). Most youth within our study described themselves as having Asperger’s Syndrome (41%) or Autism/Autistic Disorder (33%). The majority of youth rated their ASD symptoms as mild (75%), with half saying their ASD limited their activity compared to peers. While most participants (92%) reported having excellent or good verbal skills, many also said they had difficulty expressing needs using spoken language (23%) and difficulty with pragmatic or social language (15%). Although no youth reported having an intellectual disability 27% of their caregivers (as part of the large study) reported their child had an intellectual disability.

Three important sub-themes about finances arose in the data: (1) many youth defined being an adult and on their own by being able to manage their finances; (2) youth worried about their lack of skills managing their finances and expressed the need for further education; and (3) youth

Table 1 Demographic characteristics and condition specific variables ($n = 27$)

Variable	Frequency	Percent
Demographic variables		
Gender (male)	20	74.1
Age		
16–18	15	55.6
19–25	12	44.4
Race (white)	26	96.3
Highest level of education		
Some high school	4	15.4
High school	16	61.5
Some college or vocational program	6	23.0
Current Employment (yes)	12	46.2
Hours worked or volunteered weekly		
Not working	11	42.3
1–19 h	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
Condition specific variables		
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

felt that the potential lack of income was a barrier to independence and exposed them to additional risks.

Managing Finances Defines Adulthood

When asked what it meant to be an adult or to achieve independence, many participants described financial concerns ($n = 15$). For instance, Trevor, an 18-year-old, said responsibility meant "paying the bills," a task with which he needed help. Amber, a 24-year-old, said being independent meant "learning to count money," and that to be an adult, she would need to "start paying for my own bills and, like, pay for my cell phone, pay for my food, pay for rent." Zarah, a 17-year-old, also equated independence with "counting money" and said she was "working on that." Jacob, a 17-year-old, was one of six youth who said that being independent meant "filing taxes…writing checks, make a bank statement, [and learning to] buy a house." He said that he still needed to "figure all of that out." He was not particularly confident, though, and reported that, "[I] would never own a credit card in my life." For other youth, money was what worried them about adulthood. Rick admitted:

> Well, I *don't want* to pay taxes. And the driving thing, having a job…all of the responsibilities that come with [adulthood], sometimes I just want to stay a kid. I just don't want to have a bunch of responsibility all the time.

Youth Worry about Lack of Financial Skills

Like several other participants, Liam, an 18-year-old, said he was excited about growing up for the chance to "earn money" but the majority of youth lacked confidence when it came to knowing how to manage their finances. Derek, a 17-year-old, had a savings fund, but said he also "liked to blow money." He expressed great frustration that his employer paid him every 2 weeks because he needed money "now." Many youth ($n = 18$) cited financial help as a skill necessary for transitioning to adulthood. A few participants, like Amber, expressed frustration that she did not learn about finances in school—and said she needed a finance class:

> So many people don't know how to do check books. I'm like, "Why don't they teach this at school?" Instead of teaching [kids] something that very few of them will actually use ever again, or the only time they'll use it is if they're going to be a scientist or something.

Similarly, Emily, a 25-year-old, said that classes were needed to teach kids "how to work with money, both on the basic level of transactions, and then budgeting; and then understanding taxes and how that works… I mean, that's just never covered in school." Zarah, a 17-year-old, described needing basic financial skills saying, "Like learn how to count money. I really don't know how to count money, but I'm working on it, though." Alex said he learned math but was rusty and needed to learn how to pay his bills so he could "have electricity in his house," if he rented or owned a home. David, a 17-year-old, agreed that the math he learned in school was not sufficient and said he needed basic living skills and "at least a calculator" to be independent:

> I mean, they're giving you calculus, all this cr*p. I mean, for me, yeah, I might need that being in nuclear physics. But you know, everybody else, unless they're going to be like the same exact thing or a carpenter, they're not going to really need that.

Poor Financial Management Compromises Youth's Independence

The lack of financial management skills, according to youth, had serious consequences for their ability to grow and develop into adulthood. Without an income or saved money, they could not drive, live on their own, or take care of a family. For example, Amy said she was 20, and was ready for her own place, but it was hard for her to save money and her parents did not always help her because they did not agree with her goal, saying, "You don't need your own place right now." David worried about being taken advantage of, especially in relationships—"I don't want another girl that is just here for my money and stuff. I'm like, I work hard for this money. And then like I deserve this money for me and my benefits." But he did worry about "taking care of my children and wife and making sure I have enough food on the table for them." Steven, a 17-year-old, also said he needed money if he wanted to get married. Trevor said he would have to go to his mom for help with "buying and selling a house." Derek expressed a real concern about what would happen to him financially "just in case my parents die."

Discussion

Although financial management is one of many skills youth with ASD need to become independent, this study shows the importance of these skills and how they can contribute to increased independent and quality of life for youth within our study. Our research illuminates how youth with ASD perceive financial well-being, their experiences, and aspirations for the future. Three specific themes emerged from the youth's dialogue: (1) Many youth defined being on their own by being able to manage their finances; (2) Youth worried about their lack of skills managing their finances and expressed the need for further education; and (3) The potential lack of financial management skills was viewed as a barrier to independence and exposed them to additional risks. Overall, youth were concerned about their financial wellbeing and wanted more education and resources on managing their finances.

Youth within this study desire more independence, even discussing wanting to live independently someday. Being responsible with money was central to youth with ASD's desired to become independent, but few had the skills to do it. These findings align with other studies showing that youth with ASD and other disabilities report low levels of experience with money management and a lack of financial supports (Livingstone 2007; Wagner et al. 2005). Youth with ASD achieve independence at lower rates than other YSHCN, signifying a need for more focused independent skill building for this group (Hume et al. 2014). Although most youth would benefit from financial management education (Borden et al. 2008), the youth in this study seem to lack even basic skills, such as counting money, making a transaction, or paying a bill. Youth's lack of financial management skills and stated desire for these skills should sound a call to policy makers and disability specialists to enhance funding and training in this area.

Youth within this study expressed a great deal of worry, anxiety, and frustration regarding their lack of financial skills. Youth reported lacking confidence and having negative experiences with managing their money. They were disappointed that these skills were not taught in high school. The literature suggests adults with ASD "have a fear of failure" and are more likely to avoid making decisions than their typically developing peers, especially when coupled with anxiety and depression (Luke et al. 2012; South et al. 2011). Taken together, it appears that youth's fears, lack of knowledge, and perceived need for skills make financial decision-making challenging, if not impossible for youth with ASD. Research in other fields suggest that empowering children to take responsibility and make decisions early in life, while providing them opportunities to exert their independence, leads to improved decision making and independence in young adults and adults (Peters et al. 2016a). More research is needed regarding how these training practices can be applied to financial skill-building and decision-making for youth with ASD.

Research shows that young adults with ASD are vulnerable to predatory behavior, such as "payday" lending and having money stolen by personal assistants (Abbott and Marriott 2013; Mittapalli et al. 2009). Similarly, youth within this study recognized that their lack of experience and knowledge about financial management likely put them at increased risk. Our findings highlight the importance of implementing financial management programs early and tailoring them to the specific needs of youth with ASD in order to diminish these risks. Based on programs for people with other disabilities, we have also learned the importance of tailoring the material to the individual's age and developmental needs. Further, key features of many successful programs are the identification of discrete objectives for each session and pairing financial literacy training with experiential opportunities (Huang et al. 2015; Mandell and Klein 2009; Mittapalli et al. 2009). Additional strategies are starting educational programs early, providing children and youth opportunities to use money with supervision, and addressing the youth's general stress about financial situations. Other examples include minimizing stimuli, providing additional time, and offering encouragement (Luke et al. 2012).

Current educational programs and research on financial capability of people with ASD are scarce and neither are tailored to the individual needs of this population (Mittapalli et al. 2009). To our knowledge, no research to date has included youth with ASD in the development of these programs, resulting in a lack of input in selecting curricular topics and the method for providing information. Youth in this study asked for assistance and training on routine activities like counting money, paying bills, and writing checks, as well as complex activities such as paying taxes and buying a house. Participation in life skills courses and job training has been shown to increase independent living skills and empowerment in youth with ASD (Bonete et al. 2015; Neary et al. 2015; Taylor and Seltzer 2011). Studies are needed that develop, implement, and evaluate financial education interventions. Empirically validated financial training could be incorporated into existing school and job programs, and encouraged at clinical and therapeutic visits as part of the transition to adulthood and adult care.

Lastly, youth within this study participated in various academic and vocational services while in school. However, evidence is mixed as to the effectiveness of financial management programs in secondary education alone (Collins and Odders-White 2015; Mittapalli et al. 2009). Unfortunately, our participants had limited access to these services after exiting the secondary education system. Although many caregivers may understand the importance of developing these skills, they themselves often lack comfort and expertise in the area, and in any case are already overburdened (Cheak-Zamora et al. 2015). Taken together this indicates that the responsibility for building financial capability for these youth cannot be relegated to front line staff and caregivers alone and that there is a great need for these additional collaborations. Financial institutions can play an important role in providing additional support and expertise. These institutions should recognize their responsibility to partner with and advocate for individuals with disabilities and to provide sensible financial products for people with disabilities (Abbott and Marriott 2013).

Some institutions have taken initiative in providing more services for those with disabilities, but still more can be done for this population. For example, some finical institutions have dedicated phone lines to assist consumers, staff, and family members. Other institutions have developed models in which "companion" within the financial system service assist consumers in working through financial decisions (Williams and Porter 2011). The latter practice is akin to another emerging innovation, which involves "financial coaches" assigned to individuals to help guide decision making and develop financial capability (Center for Financial Security 2015). Human service agencies and financial institutions should invest time and money to develop resources and services for this population.

Limitations

Our study was a qualitative study; as such, we did not aim to collect generalizable data but to explore the experiences of specific youth in detail. Consequently, it does not reflect the experiences of youth who differ from our study population, such as participants from urban areas or racial and ethnic minorities. The use of individual interviews served the goals of data collection for most but not all participants. In future research, combining focus groups with individual interviews would provide more opportunities for individual reflection. Focus groups may also provide enhanced comfort and thereby improve participation among youth with communication challenges. In addition, the interview protocol at times relied on open-ended questions germane to exploratory research; asking detailed and direct questions about money management may result in more information about specific money problems, experiences, or needs.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interest.

Informed Consent Informed consent was obtained from all individual participant included in the study.

References

Abbott, D., & Marriott, A. (2013). Money, finance and the personalisation agenda for people with learning disabilities in the UK: Some emerging issues. *British Journal of Learning Disabilities*, *41*(2), 106–113. doi:10.1111/j.1468-3156.2012.00728.x.

Autism Speaks (2012). What is autism? What is autism spectrum disorder? http://www.autismspeaks.org/what-autism.

Batavia, A. I., & Beaulaurier, R. L. (2001). The financial vulnerability of people with disabilities: Assessing poverty risks. *Journal of Sociology & Social Welfare*, *28*(1), 139–162.

Bonete, S., Calero, M. D., & Fernandez-Parra, A. (2015). Group training in interpersonal problem-solving skills for workplace adaptation of adolescents and adults with Asperger syndrome: A preliminary study. *Autism*, *19*(4), 409–420. doi:10.1177/1362361314522354.

Borden, L., Lee, S., Serido, J., & Collins, D. (2008). Changing college students' financial knowledge, attitudes and behavior through seminar participation. *Journal of Family and Economic Issues*, *29*(1), 23–40. doi:10.1007/s10834-007-9087-2.

Cameto, R., Levine, P., & Wagner, M. (2004). *Transition Planning for Students with Disabilities. A Special Topic Report from the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International.

Center for Financial Security (2015). Financial coaching: Review of existing research. (Issue Brief No. 10.1). http://fyi.uwex.edu/financialcoaching/files/2015/10/FinancialCoaching_10.1.pdf.

Cheak-Zamora, N. C., Farmer, J. E., Mayfield, W. A., Clark, M. J., Marvin, A. R., Law, J. K., & Law, P. A. (2014). Health care transition services for youth with autism spectrum disorders. *Rehabilitation Psychology*, *59*(3), 340–348. doi:10.1037/a0036725.

Cheak-Zamora, N. C., & Teti, M. (2014). "You think it's hard now … It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services. *Autism*, *19*(8), 992–1001. doi:10.1177/1362361314558279.

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). 'Transitions are scary for our kids, and they're scary for us': Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, *28*(6), 548–560. doi:10.1111/jar.12150.

Collins, J. M., & Odders-White, E. (2015). A framework for developing and testing financial capability education programs targeted to elementary schools. *The Journal of Economic Education*, *46*(1), 105–120. doi:10.1080/00220485.2014.976325.

Council for Economic Education (2016). Survey of the states: Economic and personal finance education in our nation's schools 2016. Council for Economic Education. http://councilforeconed.org/wp/wp-content/uploads/2016/02/sos-16-final.pdf.

Friedline, T. (2015). A developmental perspective on children's economic agency. *Journal of Consumer Affairs*, *49*(1), 39–68. doi:10.1111/joca.12062.

Friedline, T., Despard, M., & Chowa, G. (2016). Preventive policy strategy for banking the unbanked: Savings accounts for teenagers? *Journal of Poverty*, *20*(1), 2–33. doi:10.1080/10875549.2015.1015068.

Friedman, N., Warfield, M. E., & Parish, S. L. (2013). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry*, *3*(2), 181–192. doi:10.2217/NPY.13.13.

Guest, G. S., MacQueen, K. M., & Namey, E. E. (2012). *Applied Thematic Analysis*. Thousand Oaks, CA: SAGE.

Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, *24*(2), 77–88. doi:10.1177/1088357608329827.

Huang, J. I. N., Nam, Y., Sherraden, M., & Clancy, M. (2015). Financial capability and asset accumulation for children's education: Evidence from an experiment of child development accounts. *Journal of Consumer Affairs*, *49*(1), 127–155. doi:10.1111/joca.12054.

Hume, K., Boyd, B. A., Hamm, J. V., & Kucharczyk, S. (2014). Supporting independence in adolescents on the autism spectrum. *Remedial and Special Education*, *35*(2), 102–113. doi:10.1177/0741932513514617.

Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing*. Thousand Oaks, CA: SAGE.

Livingstone, J. (2007). Banking matters to me: The experiences of people with a learning disability seeking to use banking products and services (978-1-906249-00-7). http://www.friendsprovidentfoundation.org/wp-content/uploads/2013/03/ARC_Banking_Matters_to_Me__-_Summary.pdf.

Luke, L., Clare, I., Ring, H., Redley, M., & Watson, P. (2012). Decision-making difficulties experienced by adults with autism spectrum conditions. *Autism*, *16*(6), 612–621. doi:10.1177/1362361311415876.

Mandell, L., & Klein, L. S. (2009). The impact of financial literacy education on subsequent financial behavior. *Journal of Financial Counseling and Planning*, *20*(1), 15–24.

McCormick, M. H. (2009). The effectiveness of youth financial education: A review of the literature. *Journal of Financial Counseling and Planning*, *20*(1), 70–83.

Mittapalli, K., Belson, S.I., Ahmadi, H., Itani, Z., Wilsey, M., Swamy, N., & Taylor, H. (2009). Financial literacy for youth with disabilities. (DOLU089428189FL). Gaithersburg, MD Social Dynamics, LLC. http://www.dol.gov/odep/research/FinancialEducationYouthDisabilitiesLiteratureReview.pdf.

Neary, P., Gilmore, L., & Ashburner, J. (2015). Post-school needs of young people with high-functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, *18*, 1–11. doi:10.1016/j.rasd.2015.06.010.

Peters, C. M., Sherraden, M., & Kuchinski, A. M. (2016a). From foster care to adulthood: The role of income. *Journal of Public Child Welfare*, *10*(1), 39–58. doi:10.1080/15548732.2015.1090940.

Peters, C. M., Sherraden, M., & Kuchinski, A. M. (2016b). Growing financial assets for foster youths: Expanded child welfare responsibilities and caseworker role tension. *Journal of Social Work*, *61*(4), 340. doi:10.1093/sw/sww042.

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, *129*(6), 2011–2864. doi:10.1542/peds.2011-2864.

Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and developmental disabilities*, *50*(1), 16–30. doi:10.1352/1934-9556-50.1.16.

South, M., Dana, J., White, S. E., & Crowley, M. J. (2011). Failure is not an option: Risk-taking is moderated by anxiety and also by cognitive ability in children and adolescents diagnosed with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *41*(1), 55–65. doi:10.1007/s10803-010-1021-z.

Suto, W. M., Clare, I. C., Holland, A. J., & Watson, P. C. (2005a). Capacity to make financial decisions among people with mild intellectual disabilities. *Journal of Intellectual Disability Research*, *49*(3), 199–209. doi:10.1111/j.1365-2788.2005.00635.x.

Suto, W. M., Clare, I. C., Holland, A. J., & Watson, P. C. (2005b). The relationships among three factors affecting the financial decision making abilities of adults with mild intellectual disabilities. *Journal of Intellectual Disability Research*, *49*(3), 210–217. doi:10.1111/j.1365-2788.2005.00647.x.

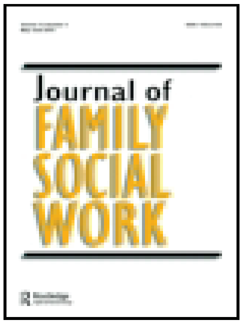
Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *The Journal of Autism and Developmental Disorders*, *41*(5), 566–574. doi:10.1007/s10803-010-1070-3.

Taylor, M., Jenkins, S., & Sacker, A. (2011). Financial capability, income and psychological well-being. ISER Working Paper 2011-18, Colchester: University of Essex. https://www.iser.essex.ac.uk/research/publications/working-papers/iser/2011-18.pdf.

Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). *After high school: a first look at the postschool experiences of youth with disabilities. A Report from the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International. http://www.nlts2.org/reports/2005_04/nlts2_report_2005_04_complete.pdf.

Williams, V., Marriott, A., & Townsley, R. (2008). *Shaping our future: A Scoping and consultation exercise to establish research priorities in learning disabilities for the next ten years*. London: HMSO, National Co-ordinatingCentre for NHS Service Delivery and Organisation R&D (NCCSDO). http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1610-152_V01.pdf.

Williams, V., & Porter, S. (2011). *Your life, your choice: qualitative research carried out as part of the 'support planning and brokerage' initiative*. London: Office for Disability Issue. http://www.ndti.org.uk/uploads/files/support-planning-and-brokerage-research-findings.pdf.



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A qualitative study of stress and coping with transitioning to adulthood with autism spectrum disorder

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A qualitative study of stress and coping with transitioning to adulthood with autism spectrum disorder

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ABSTRACT

The transition into adulthood can be stressful and challenging for adolescents with autism spectrum disorder (ASD) and their caregivers. Few studies have examined the perspectives of adolescents with ASD and their caregivers during the transition to adulthood. This qualitative study utilized the method of four focus groups with 19 caregivers and 13 adolescents with ASD. Main themes of stress reported by participants included encountering challenges in accessing services, difficulties with adapting to transition changes and managing multiple responsibilities, and vocation and higher education challenges. Main themes of coping reported by participants included accessing support from community services, receiving support from family, friends, and teachers, and seeking opportunities for self-determination. These findings provide insight into adolescent and caregiver perceptions of the challenges they face when youth transition to adulthood with ASD, along with resources and coping strategies they have found helpful. Implications are provided to assist social workers and practitioners in supporting adolescents with ASD and their caregivers during the transition to adulthood.

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Adolescence; adulthood; autism; caregiving; coping; stress; transition

The transition from adolescence to adulthood often includes a series of new challenges such as living independently, gaining employment, attaining postsecondary education, building social relationships, and forming new roles and identities (Scheer, Unger, & Brown, 1996). For adolescents living with autism spectrum disorder (ASD), the typical difficulties of transitioning to adulthood are further compounded by ASD-related challenges with social interactions, communication skills, repetitive behaviors, and comorbid conditions (Cheak-Zamora, Teti, & First, 2015; Frith, 2004; Smith & Anderson, 2014). ASD is defined as a lifelong developmental disability consisting of a continuum of impairments in social interactions and communications skills, and the existence of restricted or repetitive behaviors or movements (American Psychiatric Association, 2013). The number of individuals in the United States diagnosed with ASD has

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significantly increased at a rate of 10% to 17% annually (Hendricks, 2010), and it is estimated that 50,000 American adolescents with ASD will turn age 18 each year (Roux, Shattuck, Cooper, & Anderson, 2013).

The literature on transitioning to adulthood with ASD has reported significant challenges for youth with ASD as they transition into adulthood, including living independently, gaining employment, and achieving a postsecondary education. In a review of the literature on transitioning with ASD, Hendricks and Wehman (2009) found the majority of adolescents with ASD often reside with their parents or are dependent on parental support well into adulthood. Additional studies reveal that fewer than 25% of young adults with ASD live independently and work in competitive jobs (Levy & Perry, 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Eaves and Ho (2008) report that young adults with ASD average only 5 hours of part-time work per week. Likewise, studies reveal that adolescents with ASD do not fare as well in postsecondary education and academic achievement as their typically developing peers (Hendricks & Wehman, 2009). The National Council on Disability (2003) reports that students with disabilities experience significant barriers to access and retention in postsecondary institutions.

In addition to the challenges of navigating multiple transitions, studies indicate that the transition phase is associated with an increased risk of mood disorders in individuals with ASD (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). Bellini (2006) found that adolescents with ASD were more likely to become depressed or to suffer from increased anxiety during the transition years. Further compounding these challenges and stressors of transitioning, many young adults with ASD often lose entitlement to services and formal supports after they exit high school and may find greater challenges retaining such services when compared to adolescents with other disabilities (Shattuck et al., 2012). The lack of service provision often compels caregivers to fill in the gaps in care. Caregiver stress is a common theme in studies conducted with families of children with intellectual disability, and particularly ASD (Abbeduto et al., 2004; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Phelps, McCammon, Wuensch, & Golden, 2009). When youth with ASD transition to adulthood, caregivers have reported moderate to high levels of stress and anxiety when attempting to secure support systems for their adolescent with ASD (Taylor, Seltzer, Greenberg, & Shattuck, 2012; Newsome, 2008). Previous research has also demonstrated a link between parental stress, anxiety, and depression (Abbeduto et al., 2004). In short, adolescents with ASD and their caregivers face numerous challenges and stressors during the transition to adulthood (Smith & Anderson, 2014).

Qualitative research is a helpful tool for exploring the lived experiences of caregivers and adolescents with ASD (Humphrey & Lewis, 2008). However, the majority of ASD-related qualitative studies tend to focus on caregivers' experiences with meeting the needs of younger children with ASD. Studies examining adolescent and caregiver experiences and perceptions when transitioning to adulthood with ASD are lacking (Depape & Lindsay, 2015). As a result, researchers and practitioners lack insight into adolescent and caregiver experiences. For these reasons, this qualitative study focused on understanding the multiple stressors affecting adolescents with ASD and their caregivers during the transition into adulthood, coping strategies used by such adolescents and caregivers, and strategies and resources that social workers and practitioners can employ to support families during the transition process. Social work professionals (e.g., medical social workers, school social workers, community support workers, and case managers) often work collaboratively with youth with ASD and their families by organizing resources and support services (Newsome, 2008). Therefore, it is important for social work professionals to have insight into adolescent and caregiver experiences during the difficult time of transitioning to adulthood with autism.

Theoretical framework

The family stress theory is a helpful framework for understanding the impact of the stressors faced by families when adolescents with ASD transition into adulthood (McCubbin et al., 1980; Patterson, 2002). Family stress theory portrays the family as a "system," where experiences of one family member affect the experiences of other family members. Each family member's perception of and reaction to family stressors affects the entire family's ability to adapt during transitions or crisis (McCubbin et al., 1980; Patterson, 2002). Of particular concern in this study are caregiver and adolescent perspectives on coping with the challenges of transitioning to adulthood (e.g., living independently, vocational challenges, managing health care needs). *Stress* and *coping* are defined as the cognitive and behavioral efforts made to meet the demands that tax or overwhelm a person or family's resources (Lazarus & Folkman, 1984). Coping is viewed as a transitional process, whereby coping methods vary across time and contexts to balance the changing demands of stressful events (Lazarus & Folkman, 1984; McCubbin et al., 1980).

The family stress theory (McCubbin, Needle, & Wilson, 1985; Rutter, 1993) together with the ecological systems theory (Bronfenbrenner, 1979) suggest that families are nested within larger environmental systems such as schools, medical/professional systems, and federal policies. The famiy's ability to cope may depend on various factors such as individual coping strategies, family and social support, educational support, and access to community resources. To further research in transitioning to adulthood with autism, we specifically explored adolescent and caregiver experiences with transition stressors and examined their strategies for coping with these stressors.

Method

Research questions and design

This qualitative study used a phenomenological approach to describe the meaning of the lived experiences for adolescents with ASD and their caregivers when transitioning into adulthood (Creswell, 1998). The study's research questions included (1) What are the key challenges and stressors within the transition phase for adolescents with ASD and their caregivers? and (2) What key strategies and resources have been used to cope with stressors and challenges? To answer these questions, the phenomenological approach was chosen because the study seeks to understand the essence of youth and caregiver personal experiences when youth transition and to arrive at common themes across all participants' experiences.

Eligibility and recruitment

After receiving approval for the study from the Institutional Review Board (IRB) at the authors' institution, convenience sampling methods were used to recruit participants. Study flyers were posted at several clinics that serve adolescents with ASD, located in urban and rural areas in a state in the Midwest. Study flyers were also e-mailed to addresses from the clinics' mailing lists. Caregivers were eligible to participate if the adolescent had an ASD diagnosis, were between age 15 and 25 years, and had at least minimal verbal ability. Nineteen caregivers (n = 19) and 13 youth (n = 13) attended the focus groups. Six of the caregiver participants did not have a youth participant in the youth focus groups. A total of four focus groups were conducted. At the first site location we conducted a focus group with nine caregiver participants and a focus group with four youth participants. At the second site location we conducted a focus group with 10 caregiver participants and a focus group with nine youth participants. All participants were provided with an outline of the research study and focus group questions. Prior to obtaining consent to participate in the study, we provided all participants with a statement that explained their right to withdraw from the study at any time. We also allowed time for each participant to ask questions about the study and what their participation would entail.

Participants

Adolescent participants (n = 13) ranged from age 15 to 22 years and were primarily male (n = 11). Caregiver participants (n = 19) were primarily female (n = 17) and the majority (n = 18) were parents of an adolescent, where only one caregiver was an aunt of an adolescent with ASD. All caregivers reported providing daily care for their adolescent and the majority (*n* = 18) of caregivers reported residing in the same home.

As shown in Table 1, the majority of caregivers (*n* = 16) reported their youth as having good verbal and self-care skills whereas the remainder (*n* = 3) indicated their youth had only some verbal and self-care skills and needed help. One youth did not report on current education level, and two did not report on daily activities. For those that did, five reported currently attending high school, and the remaining seven had graduated from high school. For those who exited high school (*n* = 7), two had part-time employment or volunteered, one attended an adult day care, and three reported staying at home most days. Although some of the adolescent participants reported attending postsecondary education, none of the participants were currently enrolled at the time of the study.

Procedure and data collection

We utilized four focus groups (two for adolescents, two for caregivers) to explore norms and commonly shared experiences among the respective groups (Krueger, 1994). Focus groups for adolescents and caregivers were conducted separately to provide space for both groups to reflect on their individual viewpoints exclusively among their peers. We used semistructured focus group questions to explore adolescent and caregiver perspectives on the transition from adolescence to adulthood. The focus group questions for youth and caregivers were developed from research findings conducted by the authors and discussions among the research team, which included caregivers and clinicians. We used semistructured focus group guides that centered on exploring caregiver and youth perceptions on the transition from

Table 1. Youth functional ability, daily activity, and current educational level.

	Number of adolescent participants
Caregiver reported youth's functional ability	
Few or no verbal and self-care skills; dependent on others	0
Some verbal and self-care skills, but still needs a lot of help	3
Good verbal and self-care skills, but still needs some help	14
Mostly or completely independent	2
Youth reported daily activity	
Adult day care	1
Part-time work or volunteer	2
Looking for employment	1
Read, sleep, play video games, other	2
High school	5
Youth reported current educational program	
High school	5
Graduated/exited high school	7
College	0

Note. Two youths did not respond to daily activity and one youth did not respond to education question.

adolescence to adulthood. Example questions for adolescents included “What aspect(s) of becoming an adult do you feel most confident about?” and “What help do you need the most as you become an adult?” Example questions for caregivers included What kind of help does your child need to become an adult?” and “What aspect(s) of your child’s transition to adulthood do you feel most confident about?”

All focus groups had one facilitator and one assistant who compiled notes to record important observations about the group process and participants’ responses to the questions. All focus group sessions were recorded on a digital recorder and were transcribed verbatim. At the end of each session, study participants received a US$50 gift card and a handout on local support services.

Facilitating support for adolescent participants

Adolescents with ASD who participated in the study were provided with additional accommodations and support to help facilitate discussion and assist participants in feeling comfortable with the focus group environment. Prior to participating in the sessions, all participants received outlines of the focus group process and examples of the questions that would be asked. All participants were encouraged to contact the research staff if they had any questions. The first 30 minutes of the group session was used as an introductory period, where adolescents were able to have unstructured conversations with fellow participants and facilitators. The introductory session was followed by a 60- to 90-minute discussion on transitioning to adulthood. Facilitators provided discussion prompts and additional encouragement when needed (Kaehne & O’Connell, 2010). For example, in addition to the focus group guides provided, facilitators also used images and photographs to further orient adolescent participants to each question related to transitioning to adulthood (e.g., learning to drive, applying for a job).

To promote participation from all of the group members, the facilitators began by directing questions to the entire group and allowing adolescent participants to respond. To encourage participation from youths who did not respond, the facilitators asked if they had any additional comments to add to the discussion. All of the adolescent participants, even those with limited communication skills, contributed verbal responses to the focus group discussions. Adolescent participants were also given the opportunity to bring an advocate (support person) with them to the focus group, and one adolescent participant brought a sibling to serve as her advocate during the group session.

Analysis

After removing participant identifiers and replacing names with pseudonyms, we had the data professionally transcribed verbatim. We used a phenomenological approach (Creswell, 1998) to analyze data to discover overarching theoretical categories with the aid of NVivo 10, a computer software package. We analyzed adolescent and caregiver transcripts separately to identify themes for each group. Authors reviewed the transcripts multiple times to become familiar with the content. We read the transcripts line by line and conducted an open coding process to develop initial codes. During this initial stage of coding, we utilized the words and phrases of the participants to better understand their experiences and to designate data into early categories of "conveyed meanings" (Creswell, 1998; Strauss & Corbin, 1990). As our coding stages progressed, we refined our codes into broader categories to understand how the conveyed meanings related to one another and to identify central themes (Creswell, 1998). We also used the constant comparative method to draw out substantial units of data and consistently compared new data with previous data until reaching saturation. The emerging main themes were then analyzed and compared with one another to address each research question (Creswell, 1998; Lazarus & Folkman, 1984).

We employed a number of techniques to ensure the trustworthiness and credibility of our findings (Lincoln & Guba, 1985). Through the analytic process, we wrote notes throughout all phases of coding to refine and develop themes that emerged. After coding the data, we generated reports that supported the evidence for the main themes that emerged and then reviewed and discussed the findings. ITo increase credibility of our analysis, we conducted 3 months of intensive coding and refining and then discussed our findings until we reached consensus (Lincoln & Guba, 1985).

Results

Perceived stressors and challenges

Our findings indicated a variety of stressors and challenges reported by caregivers and adolescents with ASD when transitioning to adulthood. These main themes included encountering challenges in receiving services, difficulties with adapting to transition changes and managing multiple responsibilities, and higher education and vocation challenges.

Challenges in receiving services

Caregivers and youth discussed concerns about the lack of services and supports for adolescents with ASD as they aged into adulthood. One caregiver described how services and supports ended when her child entered adolescence.

> I think everything has been focused on the young and there's nothing that has caught up with the amount of need required for the older kids. And, I think that's going to be the issue coming down the road because you're going to have a larger number of kids with this diagnosis, and then there's nothing that is helpful after a certain amount [of time] … the focus is more on the younger kids up to 10 years old … the teens are left out in the cold. (Shannon, caregiver)

When discussing the challenge of receiving services, another caregiver participant explained that she felt her son had been "abandoned" by many service providers once he graduated high school.

> We have an autism center; they don't even want to try to help us. All we get is a newsletter…. I wish that services would increase because I feel that they get to a certain age and everything's abandoned for them and where do you then point them to? (Mary, caregiver).

Some of the youth participants supported their caregivers' beliefs by expressing a lack of confidence about the services they were receiving. One youth participant, Dillon (age 20) stated, "The few organizations set up to 'help' me—they push me in directions that I don't want to go."

Difficulties adapting to change and managing multiple responsibilities

The unpredictability of transitioning into new environments was particularly stressful for many of the adolescent participants. Caregivers and adolescents reported difficulties with youth adapting to the changes of entering adulthood and managing multiple responsibilities. One adolescent described the difficulties he experienced with change and how he preferred to focus on the present and avoid discussing the future:

> I only like thinking about what's I can only see in front of me, not the entire thing. I don't want to find out what my colleges are, my opportunities are yet. I want to focus on the now. I don't want to think about the then … it stresses me out. (Matt, youth, age 17)

Caregiver participants reported similar perspectives about their adolescent experiencing difficulties with change and thinking about the future. One caregiver described her son as being "afraid" about the future:

> He's afraid. He told me he didn't want to think about the future…. He tells me he doesn't want to see more than five steps in front of him because he's worried about what is out there for him and how he's going to succeed and everything. (Karin, caregiver)

Adolescent participants also described how they were already feeling stressed from their current duties and responsibilities. One participant described how she was already stressed and adding in new responsibilities of employment added to her fears of managing multiple responsibilities.

> I do a lot of chores around the house and I don't feel like I'm ready to become an adult yet…. Whenever I get home [from school], I just crash like I'm stressed out all day at school because I'm constantly having homework … and I have exams this week to study for and I'm just a very busy girl. (Haley, youth, age 16)

Caregivers confirmed the challenges of managing multiple responsibilities when their adolescent transitioned to adulthood. For example, one caregiver reported the stress of managing many responsibilities and essentially "keeping two houses":

> We are actually providing the 24-hour supervision for him, my husband and I. So, he's in an apartment. We're paying part of the rent to help, you know, to help with the expenses and everything. So, it's really hard and when I say I'm busy, I'm keeping two houses. (Debbie, caregiver)

Higher education and vocational challenges

Caregiver and adolescent participants also reported various challenges in higher education and vocation settings. Multiple adolescents voiced concerns about entering higher education. For example, one reported, "College is another worry for me." Another explained she couldn't go to college, because she was "not up to college level." Likewise, caregivers reported on the difficulties of youth entering and maintaining higher education. One caregiver described how her son's mental health impacted his ability to sustain college classes:

> When he was diagnosed he said was going to commit suicide … he got on antidepressants and he got better and he tried to take college—he'd taken a lot of college classes in high school and did great…. But, here at [university] we ended up having him drop out the first semester because he ended up back in the [psychiatric] ward when finals were going to be so he would have flunked everything. (Shelly, caregiver)

Another caregiver described the challenges her son experienced with social interactions in college, which ultimately contributed to reduced class attendance and suffering grades.

> We tried getting him through college. Now he is on academic suspension because he failed… He's very smart. His overall IQ is 120 but his social skills are way below that. His Asperger's kicks in every time and all he wants to do is sit at home and play games. (Debbie, caregiver)

Caregivers also reported on a variety of vocational challenges their children had encountered. One described her son's first and only employment experience with an employment agency:

> My son started in a shoe store to do zoning or stocking. He was only there for one hour and the job coach said, "He's not employment material." How, how can you draw a conclusion like that based on only one hour? I was livid. (Erica, caregiver)

Another caregiver reported how her son had been limited to certain jobs such as cleaning or manual labor when seeking employment:

> It's like they pigeonhole him. He's done cleaning jobs since he got out of high school. And, I am thankful that he has a job but I just wish there was some way we could let him be a stocker part of the day because he comes home and he's stressed out and he's mad. (Kim, caregiver)

Adolescent participants also echoed the frustration of being limited to certain jobs. For example, John (age 20) reported, "You know, I want to go to college to get the right job that I want to get and stop cleaning up after other people."

Coping strategies and resources

Caregivers and adolescents reported a variety of strategies to cope with the stressors of transitioning to adulthood with autism. These main themes included: accessing community support; receiving support from friends, family, and teachers; and creating opportunities for self-determination.

Accessing community support

To address the challenges and stress of entering adulthood, many adolescent and caregiver participants discussed the importance of accessing a variety of services from professionals and organizations in the community. One caregiver described how helpful a community agency was in teaching her daughter life skills needed in the transition process.

> We [were] on a waiting list for 6 months but we finally got into [a community agency] and we had [the agency] come out and work with my daughter at home. Worked on her life skills, worked on cooking skills, worked on making a list—seeing if she had the right things for a recipe.… It was wonderful to have [the agency] come into the home and work with her on her life skills. (Sharon, caregiver)

Other caregivers described ways in which their children benefited from outside instruction. One caregiver noted that her son "learns from other people better than he learns from me." Adolescent participants also described benefits of receiving support from community agencies and professionals. One adolescent described how a local agency helped her transition from grade to grade and apply for her first job:

> Someone there [agency] started working with me on schedules and working through from elementary to middle school; from middle school to high school.… My learning strategies is helping with the resume thing and … how to interview for the first time at a job. (Amy, youth, age 18)

Adolescent participants noted the importance of having specific individuals and professionals to help them cope with the stress and anxiety of transitioning to adulthood. One adolescent noted:

> My psychiatrist and my therapist, they've helped me a lot over the years. Well, they helped me go through the things that stress me and that's one of the things that does stress me out, thinking about the future… [They] just talk to me, helps me vent stuff. (Dillon, youth, age 20)

Receiving support from family, friends, and teachers

To address the challenges and stress of entering adulthood, many adolescent and caregiver participants discussed the importance of support from family, friends, and teachers in coping with the challenges of transitioning to adulthood. Caregivers, in particular, were cited as a main support for youth participants. One adolescent participant shared about how her mom provided her with "pointers" on taking her medicine and helping around the house in order to live independently:

> When I was little I always had to get pointers so that I would be forced to take my medicine. And now, I'm learning that I have to take my medicine every day. My mom helps me to be independent, like take my medication and help out around the house. (Haley, youth, age 16)

Family members in general provided additional support for youth becoming independent. One of the youth participants, Tricia, had her sister Malorie (age 15) join her as an advocate at the focus group session. Malorie described how their family was making plans to provide ongoing support to Tricia:

> In five years, my mom moves out of the house, and the house that we're living at now, is hers. So, I mean, it's still going to be under my mom's name but we're going to actually have someone take care of her when she needs it and help her through that. We're trying to get a nurse already to help her.

Participants also reported connecting with teachers and school staff for support in planning their transition to adulthood. One adolescent participant reported, "I usually talk to my counselors in schools privately because I have my own kind of personal [career] goals that I'm trying to strive for." Likewise, caregivers reported school staff as helpful resource for their youth. One caregiver discussed how the school was helping her son prepare for the transition to adulthood by building an area to train students in cooking, housekeeping, and "everyday living."

> They [school] had their Building Trades class build a building that had a living room, a small kitchen and a bed in the building and their Special Needs class will be cooking and housekeeping and doing all of their training there for everyday living. And, the kids even got to help build it. It provided a way to get them to want to learn, you know, because they helped do it and it was for them. (Tish, caregiver)

Creating opportunities for self-determination

Caregivers and adolescents reported on the benefit of providing adolescents with opportunities for self-determination, such as making independent choices and setting goals. One caregiver reported on the effectiveness of creating a folder filled with daily responsibilities such as doing chores, laundry, and employing daily life skills:

> She's got an accordion folder that I made her out of denim and it's her buddy. I mean, everything is in that accordion folder, her entire life is in there.… I have been working since she was little giving her responsibilities around the house: doing her own laundry; doing chores; making her bed … little responsibilities. (Megan, caregiver)

Participants also discussed how volunteering in the community or achieving awards provided a sense of pride and self-esteem. One adolescent stated, "My junior year, my teacher nominated me for an award and I also won an award for horseback riding. It was awesome." Another caregiver reported on the benefits of her son winning a volunteer award:

> My son, back in 2008, he won Volunteer of the Year, Youth Volunteer of the Year … and finding something that gives them an interest, you know, that they're interested in. It gives them a sense of pride and self-esteem. (Mary, caregiver)

Discussion

This study examined stressors and challenges experienced by adolescents with ASD and their caregivers when transitioning to adulthood. The theoretical frameworks of family systems theory, ecological systems theory, and stress and coping were particularly informative in directing our attention to the multiple areas of stress and challenges experienced by adolescents with ASD and caregivers. In this study, the majority of caregivers (but few adolescent participants), were concerned about receiving formal support and services, as many adolescents were no longer entitled to services once they graduated high school. Research has also shown that 25% of the young adults with ASD without intellectual disability (ID) had no daytime activities of any kind (e.g., employment, postsecondary education, or day services) compared to only 8% of young adults with ID (Smith, Greenberg, & Mailick, 2012). Other areas of stress identified in this study included adolescents and caregivers reporting on the difficulties with adapting to changes and the stress of managing multiple responsibilities required for transitioning to adulthood. Some adolescents described feeling stressed out by focusing on the future and "not feeling ready" to take on new responsibilities on top of the multiple roles they were currently managing. Additionally, participants noted obtaining employment and postsecondary education as particularly challenging for individuals with ASD. Vocational and college transition needs have been identified in the literature as fewer than one third have regular employment; most live with caregivers or in supported living and those who are employed are often in jobs that pay below a livable wage (Hendricks & Wehman, 2009; Taylor & Seltzer, 2011).

Our findings report that adolescents and caregivers are utilizing a variety of coping strategies and resources to cope with the stress and challenges of transitioning to adulthood with ASD. Although many caregivers reported the challenges of receiving services for their adolescent, they were quick to point out the resources that have been helpful for coping with the challenges of transitioning to adulthood, such as community agencies to help their adolescent develop independent living skills (e.g. budgeting, shopping, cleaning). Adolescents also noted the importance of accessing support from professionals and caregivers to help them cope with the stress and challenges of preparing for the future. The importance of accessing community services has been noted in multiple studies on caregivers' perspectives on aging into adulthood with ASD (Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014; Newsome, 2008).

Other important coping strategies included support from teachers and school staff and from family and friends. Additionally, caregivers reported on the importance of creating opportunities for self-determination for their adolescent. Previous studies examining the transition from adolescence to adulthood with ASD found that adolescents wanted more independence than they currently had and took pride in assuming responsibility for their own futures (Humphrey & Lewis, 2008; Rossetti, Ashby, Arndt, Chadwick, & Kasahara, 2008). Caregivers in this study noted specific examples of how they have assisted their adolescent in forming more independence and self-determination in a variety of ways (e.g., creating references books for their child; finding volunteer opportunities).

Limitations

There are several limitations related to this study. First, our findings may not capture the experiences of adolescents or caregivers who differ from our sample population, such as those from more urban areas or racial/ethnic minorities. Likewise, our sample of caregivers was primarily female (n = 17) and our sample of adolescents was primarily male (n = 11). Although the focus group discussion worked well for adolescents and caregivers, the group dialogue was sometimes difficult for adolescent participants. For example, though adolescents were generally able to interact well with the facilitator, some had difficulty interacting with each other. It may be helpful to supplement focus groups with individual interviews to increase participation from some adolescents with variant communication levels.

Implications for practice

Our findings have identified several implications for social workers and other practitioners supporting adolescents living with ASD and their caregivers. With regard to challenges in receiving adult services for ASD, social workers and practitioners could work to increase the visibility of transition-related resources and service to help fill gaps in care that families are experiencing when transitioning out-of-school-related services. To increase the visibility of transition-related resources and services, social workers and practitioners need to be knowledgeable about ASD and available community resources. In this study, a few of the caregivers reported a lack of knowledge among social workers about ASD and transition-related services. Prior research has shown that the ways in which social workers understand ASD can affect how they work with these clients (Preece & Jordan, 2007). It may be necessary for practitioners to receive more education and training on supporting individuals with ASD as they transition to adulthood.

Additionally, social workers and practitioners can assist families with the coordination of essential services such as medical treatment, mental health, social skills, independent living, respite care, college support services, and enhanced vocational support. For families who are experiencing a lack of available services for their adolescent, social workers could also collaborate in forming family groups that advocate for more services for individuals living with autism into adulthood.

These findings also suggest that social workers and practitioners should be sensitive to the stressors or challenges faced by adolescents with ASD and their caregivers when transitioning to adulthood. Social workers and practitioners could encourage families in identifying their primary stressors and challenges and collaborate with families in identifying positive coping strategies and resources. The adolescents and caregivers in our study reported a variety of strategies and resources they used to cope with challenges and stressors of transitioning to adulthood. Assisting families in building upon or developing protective factors such as coping strategies and supportive resources has been noted as a promising focus for intervention (Smith & Anderson, 2014).

Conclusion

The transition into adulthood can be stressful for adolescents with ASD and their caregivers. Although findings should not be generalized, they contribute to the knowledge of how adolescents with ASD and caregivers cope with the stressors and challenges of transitioning to adulthood. The perspectives of adolescents with ASD and their caregivers is important in guiding future social work research and practice, as well as the design of future programs, services, and policies supporting transition-aged youth with ASD and their families.

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References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation*, *109*, 237–254. doi:10.1352/0895-8017(2004)109<237:PWACIM>2.0.CO;2

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). Washington, DC: American Psychiatric Publishing.

Bellini, S., (2006). The development of social anxiety in adolescents with autism spectrumdisorders. *Focus on Autism and Other Developmental Disabilities*, *21*, 138–145. doi:10.1177/10883576060210030201

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. London, England: Harvard University Press.

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). "Transitions are scary for our kids and they're scary for us": Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, *28*, 548–560. doi:10.1111/jar.12150

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

Depape, A., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, *25*(4), 569–583. doi:10.1177/1049732314552455

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism Developmental Disorder*, *38*(4), 739–747.

Frith, U. (2004). Emmanuel Miller lecture: Confusions and controversies about Asperger Syndrome. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *45*, 672–686. doi:10.1111/j.1469-7610.2004.00262.x

Gray, D. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, *50*(12), 970–976. doi:10.1111/jir.2006.50.issue-12

Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation*, *32*, 125–134.

Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, *24*, 77–88. doi:10.1177/1088357608329827

Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism: The International Journal of Research and Practice*, *12*, 23–46. doi:10.1177/1362361307085267

Kaehne, A., & O'Connell, C. (2010). Focus groups with people with learning disabilities. *Journal of Intellectual Disabilities*, *14*, 133–145. doi:10.1177/1744629510381939

Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L., & Wilson, F. J. (2000). The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism*, *4*, 117–132. doi:10.1177/1362361300004002002

Krueger, R. (1994). *Focus groups*. Thousand Oaks, CA: Sage.

Kuhaneck, H. M., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. R. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. *Physical & Occupational Therapy in Pediatrics*, *30*(4), 340–350. doi:10.3109/01942638.2010.481662

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.

Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorder*, *5*, 1271–1282. doi:10.1016/j.rasd.2011.01.023

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. London, England: Sage.

McCubbin, H. I., Needle, R. H., & Wilson, M. (1985). Adolescent health risk behaviors: Family stress and adolescent coping as critical factors. *Family Relations*, *34*, 51–62. doi:10.2307/583757

McCubbin, H. L., Joy, C. B., Cauble, A. E., Comeau, J. K., Patterson, J. M., & Needle, R. H. (1980). Family stress and coping: A decade review. *Journal of Marriage & Family*, *42*, 855–871. doi:10.2307/351829

Moodie-Dyer, A., Joyce, H., Anderson-Butcher, D., & Hoffman, J. (2014). Parent–caregiver experiences with the autism spectrum disorder service delivery system. *Journal of Family Social Work*, *17*(4), 344–362. doi:10.1080/10522158.2014.903581

National Council on Disability. (2003). *People with disabilities and postsecondary education*. Retrieved from https://www.ncd.gov/progress_reports/Oct312011

Newsome, W. (2008). Parents perceptions during periods of transition: Implications for social workers serving families coping with autism. *Journal of Family Social Work*, *5*(2), 17–31. doi:10.1300/J039v05n02_03

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family*, *64*, 349–360. doi:10.1111/j.1741-3737.2002.00349.x

Phelps, K. W., McCammon, S. L., Wuensch, K. L., & Golden, J. A. (2009). Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder [Research Support, Non-U.S. Gov't]. *Journal of Intellectual and Developmental Disability*, *34*(2), 133–141. doi:10.1080/13668250902845236

Preece, D., & Jordan, R. (2007). Social worker's understanding of autism spectrum disorders: An exploratory investigation. *British Journal of Social Work*, *37*, 925–936. doi:10.1093/bjsw/bcl089

Rossetti, Z., Ashby, C., Arndt, K., Chadwick, M., & Kasahara, M. (2008). "I like others to not try to fix me": Agency, independence, and autism. *Journal of Intellectual Developmental Disability*, *46*, 364–375. doi:10.1352/2008.46:364-375

Roux, A., Shattuck, P., Cooper, B., & Anderson, K. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the A American Academy of Child and Adolescent Psychiatry*, *52*(9), 931–939. doi:10.1016/j.jaac.2013.05.019

Rutter, M. (1993). Resilience: Some conceptual considerations. *Journal of Adolescent Health*, *14*, 626–631. doi:10.1016/1054-139X(93)90196-V

Scheer, S. D., Unger, D. G., & Brown, M. B. (1996). Adolescents becoming adults: Attributes for adulthood. *Adolescence*, *31*, 127–131.

Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, *10*, 234–247. doi:10.1002/(ISSN)1098-2779

Shattuck, P., Narendorf, S., Cooper, B., Sterzing, P., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, *129*(6), 1042–1049. doi:10.1542/peds.2011-2864

Smith, L., & Anderson, K. (2014). The roles and needs of families of adolescents with ASD. *Remedial and Special Education*, *35*(2), 114–122. doi:10.1177/0741932513514616

Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2012). Adults with autism: Outcomes, family effects, and the multi-family group psychoeducation model. *Current Psychiatry Reports*, *14*(6), 732–738. doi:10.1007/s11920-012-0328-1

Strauss, A., & Corbin, J. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, *13*, 3–21. doi:10.1007/BF00988593

Taylor, J., & Seltzer, M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism Development Disorder*, *41*(5), 566–574. doi:10.1007/s10803-010-1070-3

Taylor, J. L., McPheeters, M. L., Sathe, N. A., & Dove, D. (2012). A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics*, *130*(3), 531–538. doi:10.1542/peds.2012-0682

A Qualitative Comparison of Caregiver and Youth with Autism Perceptions of Sexuality and Relationship Experiences

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Abstract **In Brief** **Author InformationAuthors** **Article MetricsMetrics**

Objectives: Caregivers play a critical role in educating their youth with autism about sex and relationships; yet, we know little about caregivers' ability to deliver this support, youth's perspectives, or the congruence of youth and caregiver experiences. To help fill this gap, we explored and compared the perspectives of caregivers and their youth with autism spectrum disorder about and interactions regarding sex and relationships.

Methods: We conducted qualitative one-on-one interviews with youth (n = 27) and focus groups with their caregivers (n = 29). A semi-structured guide elicited information from both the groups about the youth's physical, emotional, and social transition to adulthood. Thematic analysis, including coding and analytical memos, identified key themes within and across youth and caregiver discussions about sex and relationships.

Results: Thematic analysis of interviews revealed overarching themes about companionship, interest and experience, and access to sexual information across both the groups. Themes included different nuances among caregivers and youth, however. Caregivers expressed more future-oriented concerns than youth and overestimated their knowledge of their youth's interest and experience with sex and comfort confiding in caregivers. Youth described relationships and information sources of which their caregivers were unaware.

Conclusion: Interventions for both caregivers and youth can support healthy and safe intimate relationships among youth with autism spectrum disorder. By comparing youth and caregiver dialogues, this study adds to what we know, and it can be used to develop a blueprint for improving communication patterns that not only include but also extend well beyond sexual health.

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