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

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| 13. SUPPLEMENTARY NOTES                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                  |                          |                                         |                                               |                           |
| 14. ABSTRACT<br>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 young adults. We identified major themes including: caregiver stress, relationships, health challenges, financial, resources, safety, work/school, health success, appointments, medication management, transition to adult doctor, and self-care. Within Aim 2a of the study we utilized the themes from Aim 1, findings from previous literature, and experts in the field to develop an ASD-specific HRI outcome measure. The HRI measure covers 8 domains. The individual items and response options were evaluated and revised by experts in the field, caregivers and youth with ASD. Cognitive interviewing and full-scale pretesting were then conducted to examine the validity, appropriateness, and user-friendliness of the measure. |                  |                          |                                         |                                               |                           |
| 15. SUBJECT TERMS<br>youth with ASD, health-related independence, health care transition, qualitative methods, measure development                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                  |                          |                                         |                                               |                           |
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| a. REPORT<br>U                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | b. ABSTRACT<br>U | c. THIS PAGE<br>U        | 19a. NAME OF RESPONSIBLE PERSON USAMRMC |                                               |                           |
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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 (Aim 2b) through an iterative process, using expert, caregiver, and youth with ASD feedback, pilot testing, and pretesting of the measure. We hypothesized that key themes associated with HRI can be organized in order to develop an instrument that measures these factors in a broader population.

## 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 2 Completion Updates**

| <b>Specific Aim 2a:</b><br>Develop and test an ASD-specific HRI outcome measure through an iterative process using qualitative findings from Aim 1 and experts in the field. |                          |                            |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|----------------------------|
| <b>Aim and Task</b>                                                                                                                                                          | <b>Targeted timeline</b> | <b>Completed date or %</b> |
| <b>Major Task 1:</b> Develop initial set of items that reflect the key concepts identified in Aim 1                                                                          | Oct 2015-March 2016      | Completed April 2016       |
| <b>Major Task 2:</b> Pilot test HRI measure and revise if necessary                                                                                                          | April 2016-Oct 2016      | Completed October 2016     |

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

(1) Major Activities and (2) Objectives from Approved Statement of Work

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

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p style="text-align: center;"><b>Specific Aim 2a:</b></p> <p>Develop and test an ASD-specific HRI outcome measure through an iterative process using qualitative findings from Aim 1 and experts in the field.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <p><b>Major Task 1:</b> Develop initial set of items that reflect the key concepts identified in Aim 1</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <p>Objective 1: Team examines key concepts identified in qualitative data and matches them with previously developed measures when possible</p> <ul style="list-style-type: none"> <li>• Meeting with experts and research group to determine initial constructs from themes generated from qualitative data that should be used in the outcome measure</li> <li>• Examined and drew from constructs from HCT scales that could be relevant</li> <li>• Health-related independence was defined</li> <li>• Team of experts voted on each construct regarding importance and ranking each for how each construct fits within the context of our definition of HRI</li> <li>• List of 12 constructs for HRI measure was developed</li> </ul> |
| <p>Objective 2: Study team will develop items for all other concepts and match with response options/scores</p> <ul style="list-style-type: none"> <li>• One question development session with research team</li> <li>• Two brainstorming sessions with clinical experts and caregiver advocates to generate questions for each construct and put in question pool</li> <li>• Clinical experts grouped into paired teams to iteratively create questions. Pairs created an average of 10 questions per construct.</li> </ul>                                                                                                                                                                                                              |
| <p>Objective 3: Add scales developed in previous literature to examine HCT, caregiver wellbeing and possible predictors of HRI and HCT</p> <ul style="list-style-type: none"> <li>• Conducted literature review for validated measures</li> <li>• Relevant scales and HCT scales were included in the question pool for teams to evaluate</li> <li>• Permission was obtained from all scale developers for scales and survey questions used within the larger survey.</li> </ul>                                                                                                                                                                                                                                                          |
| <p>Objective 4: Combine previously developed items with new items and evaluate measurement tool for clarity, readability, ease of use, and content validity; Revise if necessary</p> <ul style="list-style-type: none"> <li>• One construct eliminated because of repetitiveness. 8 constructs remain.</li> <li>• A team meeting (PI, Co-I's, other experts in field) was held to rank-order questions for each facet according to the HRI survey, focus groups and individual interviews, previously validated measures, and expert caregiver opinion</li> <li>• HRI tool evaluated for clarity, readability, ease of use, and content validity</li> </ul>                                                                               |
| <p>Milestone Achieved:</p> <ul style="list-style-type: none"> <li>• Preliminary version of a HRI outcome measure</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <p><b>Major Task 2:</b> Pilot test HRI measure and revise if necessary</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <p>Objective 1: Administer measure to a small sample of caregivers of youth with ASD in cognitive interviews (10-20 caregivers identified by the TCRC) and pilot testing (20-25 caregivers) formats.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |

**Cognitive Interviews**

- Contacted 85 potential participants via email and/or mail
- Screened and scheduled 17 potential participants
- 15 caregivers completed cognitive interviews at the Thompson Center

**Pretesting**

- Contacted 134 potential participants via email and/or mail
- 21 participants completed the pretest survey
- 12 participants completed the pretest survey and follow-up phone call

Objective 2: Revise text of items and/or scoring options based on caregiver feedback, reiterate process if necessary.

- Cognitive interview feedback was transcribed and analyzed.
- Changes were made to survey questions and response option based on feedback.
- Pretest feedback was compiled and analyzed.
- Changes were made to questions, survey format and response options based on feedback.

Milestone(s) Achieved:

- Complete and test HRI outcome measure

### (3) Significant Results or Key Outcomes

Major Task 1: Develop initial set of items that reflect the key concepts identified in Aim 1

#### HRI Measure Development

- Measurement development process:
  - List of 12 constructs for HRI measure was developed from qualitative data and expert panel discussion. *10/30/2015*
  - Research team conducted a literature review for surveys measuring aspects of each of the 12 constructs. *11/12/2015*
  - A list of all potentially relevant activities related to each construct was developed based on qualitative findings in Aim 1 and other HCT scales that used similar constructs. *11/18/2015*
  - Two question development meetings held with clinicians from the Thompson Center to create question pool for each construct. *01/8/2016 and 01/12/2016*
  - Questions from relevant health care transition (HCT) and other scales were added to the question pool to consider in developing constructs. *01/20/2016*
  - Semantically similar questions were reduced. *01/22/2016*
  - Protocol established for teams of two clinicians and caregivers to examine questions in each construct and determine the extent to which they meet the criteria for HRI. *01/24/2016*
  - An average of 10 questions were created in an iterative process (from protocol above) in groups of 2 by the team for each of the nine constructs. *02/1/2016- 03/18/2016*
  - A team meeting (PI, Co-I's, other experts in field) was held to rank-order questions for each facet according to the HRI survey, focus groups and individual interviews, previously validated measures, and expert caregiver opinion. *03/24/2016*
  - One construct eliminated because of overlap in other constructs and repetitiveness. *03/24/2016*
  - Initial draft of HRI measure completed and prepared for distribution for Cognitive interviews and Pretesting *04/01/2016*
  - Cognitive interview guide was created. *04/14/2016*
  - Cognitive interview training session was held at the Thompson Center. *04/19/2016*
  - Recruited caregivers for cognitive interviews at the Thompson Center (sent letters or emails to 85 potential participants; screened 92 participants; 17 caregivers scheduled). 15 caregivers completed cognitive interviews. *April-June 2016*
  - Cognitive interviews transcribed to ensure detailed analysis. *05/29/2016*
  - Cognitive interview data was compiled and analyzed. *05/26/2016*
  - Changes were made to HRI survey questions based on feedback. *05/26/2016*
  - Created electronic version of HRI measure on REDCap for pretesting *06/10/2016*

- Recruited caregivers for pretesting the HRI measure either electronically or at the Thompson Center *June 2016*
- Completed 5 follow-up calls after caregivers completed electronic HRI measure *June 2016*

Major Task 2: Pilot test HRI measure and revise if necessary

### **Cognitive Interviews**

- The caregiver demographic table for those involved in the Cognitive Interviews (Appendix 1) was developed to show the demographic characteristics for our study population (n=15 of caregivers of young adults with ASD). The average age for caregivers was 50 years, with a range of 36 to 62 years. All of caregivers participating in the study were the young adult's biological mother or father. Caregiver education was relatively high, with 70% of caregivers with a Bachelor's degree or higher. The average age of young adults in which the caregivers were answering questions about was 17.9 years, with a range of 16 to 21 years.
- Topics covered within the Cognitive Interviews included youth's knowledge and ability related to: 1) medical and mental health conditions (3 questions), 2) Youth's Self-Care (2 questions), 3) Medication Management (1 questions), 4) Health care visits (5 questions), 5) Safety (4 questions), 6) Sexual Health (4 questions), 6) Health Care Financial Management (4 questions), 7) Developing goals for future / goal planning (2 questions). Feedback from caregivers on each of these issues improved our understanding of these often rarely discussed topics and assisted in the revision of survey questions, word definitions provided within the survey, and response options. Data from this portion of the study will be presented within a podium presentation at the American Public Health Association Conference (Nov. 2) and a poster presentation at the Health Care Transition Research Conference (Oct. 26<sup>th</sup>).

### **Pretesting**

- The caregiver demographic table for those involved in the Pretest Survey (Appendix 2) was developed to show the demographic characteristics for our study population (n=21 of caregivers of young adults with ASD). The average age for caregivers was 50.3 years, with a range of 37 to 62 years. A majority of caregivers participating in the study were the young adult's biological mother or father (90.5%). Caregiver education was relatively high, with 57.1% of caregivers with a Bachelor's degree or higher. The average age of young adults in which the caregivers were answering questions about was 19.9 years, with a range of 16 to 25 years.

- Final Health-related Independence measure is presented in appendix 3.

**Table 3: Health-related Independence measure topics:**

|                                                                                                                                                                                                                                                               |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Knowledge about medical and mental health conditions <ul style="list-style-type: none"> <li>• Knowledge of physician and mental health conditions and symptoms</li> <li>• Information seeking</li> <li>• Youth knowing how to take care of illness</li> </ul> |
| Self-Care <ul style="list-style-type: none"> <li>• Personal care</li> <li>• Activities of daily living</li> </ul>                                                                                                                                             |
| Medication Management <ul style="list-style-type: none"> <li>• Knowledge of medications</li> <li>• Understanding how/when to take medications</li> </ul>                                                                                                      |
| Health care visits <ul style="list-style-type: none"> <li>• Having a family/primary care doctor and seeing them regularly</li> <li>• Youth answering questions on own asked by doctor/nurse</li> <li>• Youth making appointments on own</li> </ul>            |
| Safety <ul style="list-style-type: none"> <li>• Household safety</li> <li>• Community safety</li> <li>• Internet safety</li> </ul>                                                                                                                            |
| Sexual Health <ul style="list-style-type: none"> <li>• Youth knowledge of becoming pregnant and consequences/risks</li> <li>• Youth knowledge and safety about STDs</li> <li>• Youth knowledge of condoms and birth control</li> </ul>                        |
| HC Financial Management <ul style="list-style-type: none"> <li>• Financial transactions</li> <li>• Managing money/budget</li> <li>• Health Insurance</li> </ul>                                                                                               |
| Developing goals for future / goal planning <ul style="list-style-type: none"> <li>• Having conversation about what YA want for own future</li> <li>• Creating and executing a plan</li> </ul>                                                                |

- Follow-up Phone call (N= 12)

**Table 4** Pretesting Phone Call Discussion Results\* (n = 12)

| Variable                                  | Frequency | Percent |
|-------------------------------------------|-----------|---------|
| <i>Survey Satisfaction</i>                |           |         |
| Describe overall experience taking survey |           |         |
| Excellent to Very Good                    | 8         | 66.6    |
| Response option difficulty                | 4         | 33.3    |
| Not good, many difficulties               | 0         | 0       |
| Was survey easy to take                   |           |         |
| Yes                                       | 12        | 100     |
| No                                        | 0         | 0       |
| <i>Any Difficulties</i>                   |           |         |
| Any question difficult to understand      |           |         |
| Yes                                       | 2         | 16.6    |
| No                                        | 10        | 83.3    |
| Any question difficult to answer          |           |         |
| Yes                                       | 5         | 41.6    |

|                                           |    |      |
|-------------------------------------------|----|------|
| No                                        | 7  | 58.3 |
| Did the response options make sense       |    |      |
| Yes                                       | 9  | 75   |
| No                                        | 3  | 25   |
| <i>Interest in questions</i>              |    |      |
| First time thought about questions/topics |    |      |
| Yes                                       | 9  | 75   |
| No                                        | 3  | 25   |
| Did the questions surprise you            |    |      |
| Yes                                       | 2  | 16.6 |
| No                                        | 10 | 83.3 |
| <i>Appropriateness of Length</i>          |    |      |
| Time to complete survey                   |    |      |
| 5-10 minutes                              | 7  | 58.3 |
| 11-16 minutes                             | 4  | 33.3 |
| 23-30 minutes                             | 1  | 8.3  |
| Number of questions appropriate           |    |      |
| Yes                                       | 12 | 100  |
| No                                        | 0  | 0    |
| Any time your become fatigued             |    |      |
| Yes                                       | 0  | 0    |
| No                                        | 12 | 100  |

#### (4) Other Achievements

- Additional surveys we have culminated and obtained permission to use in the national data collection portion of the project (year 3)

Table 5: Surveys to be used in national survey

| Topics:                                | Measures:                                                                                                                                                                                                                       |
|----------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Demographics                           | • Demographic Survey (Young adult and caregiver demographic information)                                                                                                                                                        |
| Health-Related Independence            | • Health-Related Independence Scale                                                                                                                                                                                             |
| Service Utilization/Unmet Need         | • Nicolaidis' Pre-survey for Autistic Participants                                                                                                                                                                              |
| Health Care Transition Readiness       | • STARx Questionnaire - Parents<br>• 2005/06 National Survey of Children With Special Health Care Needs (NS-CSHCN)<br>• 2016 National Survey of Children's Health (NSCH)                                                        |
| Healthcare Transition Success          | • Got Transition? Sample Health Care Transition Feedback Survey for Parents/Caregivers<br>• 2005/06 National Survey of Children With Special Health Care Needs (NS-CSHCN)<br>• 2016 National Survey of Children's Health (NSCH) |
| Quality of Care                        | • Nicolaidis' Pre-survey for Autistic Participants<br>• 2005/06 National Survey of Children With Special Health Care Needs (NS-CSHCN)<br>• 2016 National Survey of Children's Health (NSCH)                                     |
| Self-Determination / Caregiver Support | • AIR Self-Determination Scale                                                                                                                                                                                                  |
| Caregiver Quality of Life              | • Care-related Quality of Life instrument – 7D (CarerQoL-7D)                                                                                                                                                                    |

(5) Stated goals not met:

The grant proposal anticipated conducting pretesting of the HRI measure with 20 to 25 caregivers. We have met this goal based on the number of surveys completed (n = 21); however, connects with participants via follow-up phone calls has been more challenging. Thus far we have completed 12 pretests and follow-up calls with caregivers. We plan to increase recruitment with recruitment phone calls. With that being said, although the goal of pretesting with 20 to 25 caregivers has not been met, data saturation and appropriate sample size for this study has been achieved.

(6). Methodology:

*Cognitive interviewing to test newly developed measure:* We conducted a thorough examination of the measure to determine functionality, appropriateness, and feasibility of the scale, domains, and individual items. We utilized previously developed cognitive interview procedure to administer the scale to caregivers of youth with ASD (depending on saturation of information) and young adults with ASD 18-26 years old. In addition to simply marking their responses, respondents were encouraged to share their understanding of and reaction to the items and to the instrument as a whole. These interviews lasted approximately 1 to 1.5 hours and caregivers and young adults received \$25 cash incentive for their participation. The text of the survey and scoring was revised based on these cognitive interviews.

*Pretest of newly developed measure:* Once the measures were refined, we developed an electronic and written version of the instrument to be administered to caregivers of youth with ASD and young adults with ASD 18-26 years old. This involved a full-scale pretest of the survey. Participants were able to choose which version (electronic or written) of the instrument to complete and test the instrument in person or online. Once they completed the survey, participants were asked to record problems with any items, such as ambiguous wording and appropriateness of length.

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

- 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.
- **How were the results disseminated to communities of interest?**
  - In terms of our results, the community of interest includes families and health care providers

- 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
- **What do you plan to do during the next reporting period to accomplish the goals?**
  - In the next year, the team plans to:
    - 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.
      - 1) Recruit subjects and distribute survey for completion.
        - Develop list of eligible caregivers for survey distribution
        - Distribute survey with preliminary phone call and reminders
        - Distribute additional survey and/or follow-up with previous participants as needed
        - Distribute incentives to participants returning completed surveys and send completed surveys to project PI.
      - 2) Data inputting, analysis and publication development
        - Enter survey responses into database, clean data, and develop data dictionary
        - Conduct preliminary analysis on HRI scale (factor analysis, construct validity, etc.)
        - Conduct logistic regression to determine predictors of HRI, HTC, and caregiver wellbeing
        - Prepare results for publication

#### 4. IMPACT:

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

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

## 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**
  - Developing items for the HRI measure required more iterations than we expected. This has extended our timeline for this phase of our project. However, the cognitive interviews have been completed and pretesting of the measure is near completion.
  - We expanded the study to include young adults in cognitive interviews (MU IRB approval 8/15/2016; Submitted to DOD 8/16/2016). This may increase the time it will take to recruit participants and conduct interviews.
    - We will continue this activity as a separate aim, thus not interrupting collection of caregiver data.
    - We will continually review progress toward our recruitment and participation goals and revise our strategy as needed.
- **Changes that had a significant impact on expenditures**
  - Greg Petroski's salary increased from 2% to 10% in December due to work so actuals are less than what was proposed. However, this change may not be considered significant.
- **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.**
  - N/A
- **Significant changes in use of biohazards and/or select agents**
  - N/A

## 6. PRODUCTS:

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

- **Journal publications.**

- One manuscript was accepted with revisions
      - Cheak-Zamora, NC, and Teti, M. "Sexual and Relationship Interest, Knowledge and Experiences among Adolescents with Autism Spectrum Disorder" In revision; Journal of Autism and Developmental Disability. 5/29/2016
    - Two manuscript currently under-review
      - Cheak-Zamora, NC, and Teti, M. "Financial situation, money management skills and desires for financial independence of youth with ASD" Submitted to Journal of Consumer Affairs. 6/30/2016
      - Cheak-Zamora, NC, Michelle Teti, Maurer-Batjer, A, and Koegler, E. "Exploration and comparison of adolescents with Autism Spectrum Disorder and their caregivers' perspectives on transitioning to adult health care and adulthood". Submitted to Journal of Pediatric Psychology. 9/1/2016
    - One manuscripts currently being prepared for submission
      - Cheak-Zamora, NC, Regan, K, and Teti, M. "Transition readiness and independence assessment for young adults with Autism Spectrum Disorder: Development and testing of the Health Related Independence (HRI) Questionnaire" In preparation to Journal of Pediatric Nursing. 6/30/2016

- **Books or other non-periodical, one-time publications.**

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

- Two podium presentations accepted to American Public Health Association conferences
      - 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.

- 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
- One podium presentations accepted to Health Care Transition Research Consortium conferences
  - 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.
- Two poster presented at Pediatric Academic Societies and International Meeting for Autism Research (IMFAR) conferences
  - 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. May11-14.
  - 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.
- **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 2 of this study, we developed an electronic survey (i.e., demographic survey and Health-related Independence measure) on REDCap (Research Electronic Data Capture). REDCap is a secure web application for building and managing online surveys and databases. We used REDCap to disseminate our survey to participants via email who then completed the survey by selecting the provided link and filling in the electronic survey. For year 3 of this study, the national survey will be created on REDCap and shared with the 5 participating clinics for their use. 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?**

**Table 6: Project personal information**

|                                   |                                                                                                                                                                                                                                                                                                                           |
|-----------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Name:                             | Nancy Cheak-Zamora                                                                                                                                                                                                                                                                                                        |
| Project Role:                     | Principal Investigator                                                                                                                                                                                                                                                                                                    |
| Researcher Identifier (ORCID ID): | 0000-0003-3645-3469                                                                                                                                                                                                                                                                                                       |
| Nearest person month worked:      | 3                                                                                                                                                                                                                                                                                                                         |
| Contribution to Project:          | 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. |
| Funding Support:                  | N/A                                                                                                                                                                                                                                                                                                                       |

|                                   |                                                                                                                                                                                                                                                                            |
|-----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Name:                             | Michelle Teti                                                                                                                                                                                                                                                              |
| Project Role:                     | Co-Investigator                                                                                                                                                                                                                                                            |
| Researcher Identifier (ORCID ID): | 0000-0002-3943-3810                                                                                                                                                                                                                                                        |
| Nearest person month worked:      | 1                                                                                                                                                                                                                                                                          |
| Contribution to Project:          | 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:      | 10                          |

|                          |                                                                                                                                   |
|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------|
| Contribution to Project: | 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, conducting follow-up phone calls, and creating reports and presentations. |
| Funding Support:                  | N/A                                                                                                                                        |

- **Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**
  - 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: Cognitive Interview Demographics
- Appendix 2: Pretesting Demographics
- Appendix 3: Health-related Independence measure
- Appendix 4: Complete Survey to be used on National Survey (this includes HRI measure)

## Appendix 1: Cognitive Interview Demographics

**Table 6** Caregiver Demographic Characteristics (*n* = 15)

| Variable                                        | Percent |
|-------------------------------------------------|---------|
| <i>Demographic variables</i>                    |         |
| Relation to Young Adult with ASD                |         |
| Biological Mother                               | 90      |
| Biological Father                               | 10      |
| Young Adult's Ethnicity                         |         |
| Not Hispanic or Latino                          | 80      |
| Young Adult's Race                              |         |
| White                                           | 60      |
| Young Adult's Gender                            |         |
| Male                                            | 70      |
| Young Adult's Highest level of education        |         |
| Some high school                                | 40      |
| High school                                     | 60      |
| Young adult's chronic condition(s)              |         |
| Sleep disorders                                 | 30      |
| Allergies                                       | 60      |
| Anxiety and mood disorders                      | 40      |
| Depression                                      | 40      |
| Caregiver's education level                     |         |
| High school graduate                            | 10      |
| Some college, no degree                         | 20      |
| Bachelor's degree                               | 50      |
| Master's degree                                 | 20      |
| <i>Condition specific variables</i>             |         |
| Current diagnosis                               |         |
| Autism or Autistic disorder                     | 40      |
| Asperger Syndrome                               | 30      |
| Autism Spectrum Disorder                        | 30      |
| Severity of ASD                                 |         |
| Mild                                            | 20      |
| Moderate                                        | 70      |
| Severe                                          | 10      |
| Young adult's level of independence             |         |
| Some self-care skills but needs a lot of help   | 30      |
| Good self-care skills but still needs some help | 50      |
| Mostly or completely independent                | 20      |
| Young adult's level of communication            |         |
| Few or no verbal skills                         | 10      |
| Some verbal skills                              | 30      |
| Good verbal skills                              | 20      |
| Excellent verbal skills                         | 40      |

## Appendix 2: Pretesting Demographics

**Table 7** Caregiver Demographic Characteristics ( $n = 21$ )

| Variable                                        | Percent |
|-------------------------------------------------|---------|
| <i>Demographic variables</i>                    |         |
| Relation to Young Adult with ASD                |         |
| Biological Mother                               | 80.9    |
| Biological Father                               | 9.5     |
| Adopted Mother                                  | 4.8     |
| Other                                           | 4.8     |
| Young Adult's Ethnicity                         |         |
| Not Hispanic or Latino                          | 95.2    |
| Young Adult's Race                              |         |
| White                                           | 85.7    |
| Asian, American Indian, or Alaskan Native       | 9.5     |
| Young Adult's Gender                            |         |
| Male                                            | 90.5    |
| Young Adult's Highest level of education        |         |
| Some high school                                | 19      |
| High school                                     | 57.1    |
| Some or vocational program                      | 14.3    |
| Bachelor's Degree                               | 9.5     |
| Young adult's chronic condition(s)              |         |
| Asthma                                          | 14.3    |
| Behavior or conduct disorder                    | 14.3    |
| Attention-deficit hyperactivity disorder (ADHD) | 19      |
| Skin conditions                                 | 19      |
| Gastrointestinal issues                         | 23.8    |
| Sleep disorders                                 | 28.6    |
| Allergies                                       | 28.6    |
| Anxiety and mood disorders                      | 47.6    |
| Depression                                      | 33.3    |
| Caregiver's education level                     |         |
| Some college, no degree                         | 42.9    |
| Bachelor's degree                               | 33.3    |
| Master's degree                                 | 19      |
| Professional school degree                      | 4.8     |
| <i>Condition specific variables</i>             |         |
| Current diagnosis                               |         |
| Autism or Autistic disorder                     | 28.6    |
| Asperger Syndrome                               | 33.3    |
| PDD NOS                                         | 4.8     |
| Autism Spectrum Disorder                        | 33.3    |

|                                                 |      |
|-------------------------------------------------|------|
| Severity of ASD                                 |      |
| Mild                                            | 42.9 |
| Moderate                                        | 38.1 |
| Severe                                          | 9.5  |
| Young adult's level of independence             |      |
| Few self-care skills, dependent on others       | 4.7  |
| Some self-care skills but needs a lot of help   | 14.3 |
| Good self-care skills but still needs some help | 42.9 |
| Mostly or completely independent                | 38.1 |
| Young adult's level of communication            |      |
| Few or no verbal skills                         | 4.8  |
| Some verbal skills                              | 14.3 |
| Good verbal skills                              | 33.3 |
| Excellent verbal skills                         | 47.6 |

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### **Appendix 3: Health-related Independence measure**

#### **Health-Related Independence**

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 person may not need guidance, while for other tasks or situations 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
- ☐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
- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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

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). (\*Hover over text for examples)

- ☐ 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. (\*Hover over text for examples)

- ☐ 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

- 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.\* (\*Hover over question for examples)
- ☐Strongly agree
  - ☐Agree
  - ☐Disagree
  - ☐Strongly disagree
- 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.\* (\*Hover over question for examples)

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ My young adult does not get online I do not know what my young adult knows on this subject

38 My young adult understands the restrictions on pornography\* based on legal and family rules. (\*Hover over text for examples)

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

39 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
- ☐ My young adult does not get online
- ☐ 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

42 My young adult can explain how sexually active people protect themselves from sexually transmitted infections\*. (\*Hover over text for examples)

- ☐ 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\*. (\*Hover over text for examples)

- ☐ 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. (\*Hover over text for examples)

- ☐ 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. (\*Hover over text for examples)

- ☐ 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

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. (\*Hover over text for examples)

- ☐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. (\*Hover over text for examples)

- ☐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. (\*Hover over text for examples)

- ☐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

56 My young adult can develop goals\* that satisfy [his\_her] own needs and wants. (\*Hover over text for examples)

- ☐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. (\*Hover over text for examples)

- ☐ 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 to reach [his\_her] goals\*. (\*Hover over text for examples)

- ☐ 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\*. (\*Hover over text for examples)

- ☐ 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

## Appendix 4: Complete Survey to be used on National Survey (this includes HRI measure)

### 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 instructions specify otherwise, please select the answer choice (only one) which 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
- ☐ Biological Father
- ☐ Stepmother
- ☐ Stepfather
- ☐ Adoptive Mother
- ☐ Adoptive Father
- ☐ Other (please specify): \_\_\_\_\_

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

3) What is your young adult's gender?

- |                                                |                                            |
|------------------------------------------------|--------------------------------------------|
| <input type="checkbox"/> Female                | <input type="checkbox"/> Male              |
| <input type="checkbox"/> Transgender Female*   | <input type="checkbox"/> Transgender Male* |
| <input type="checkbox"/> Gender non-conforming |                                            |

(\*Hover over text for examples)

4) What is your young adult's ethnicity?

- ☐ Not Hispanic or Latino
- ☐ Hispanic or Latino

5) What is your young adult's race?

- |                                                    |                                                                    |
|----------------------------------------------------|--------------------------------------------------------------------|
| <input type="checkbox"/> White                     | <input type="checkbox"/> Native Hawaiian or Other Pacific Islander |
| <input type="checkbox"/> Black or African-American | <input type="checkbox"/> American Indian or Alaska Native          |

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

- |                                                                                      |                                                                         |
|--------------------------------------------------------------------------------------|-------------------------------------------------------------------------|
| <input type="checkbox"/> Less than 8th grade                                         | <input type="checkbox"/> Associate degree                               |
| <input type="checkbox"/> 1 <sup>st</sup> through 12 <sup>th</sup> grade (no diploma) | <input type="checkbox"/> Bachelor's degree (e.g., BA, AB, BS, BBA)      |
| <input type="checkbox"/> High School graduate                                        | <input type="checkbox"/> Master's degree (e.g., MA, MS, MEng, MEd, MBA) |
| <input type="checkbox"/> GED or equivalent                                           | <input type="checkbox"/> Professional school degree (MD, DDS, DVM, JD)  |

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

- ☐ Yes
  - ☐ High school
  - ☐ Vocational or trade school
  - ☐ College

- ☐ No  
☐ Other (please specify): \_\_\_\_\_

**8) Does your young adult currently have paid employment?**

- ☐ Yes, full time paid employment  
☐ Yes, part time paid employment  
☐ No

**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 (in years) at time of CURRENT diagnosis? \_\_\_\_\_**

**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) 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): \_\_\_\_\_

**18) 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)                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Anoxia                                                                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Anxiety disorders (such as social phobia, panic disorder, etc.)                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Asthma or other lung problems                                                                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Attention-deficit hyperactivity disorder (ADHD)                                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bipolar disorder                                                                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Dental problems                                                                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Depression (such as major depressive disorder, seasonal affective disorder, etc.)                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Diabetes                                                                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Disruptive behavior disorders (such as Conduct disorder or Oppositional Defiant disorder)             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Ear, nose, and throat problems                                                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Epilepsy or Seizure disorder                                                                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Gastrointestinal issues (such as constipation, chronic diarrhea, nausea, vomiting, acid reflux, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Genetic disorder                                                                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Headaches                                                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hearing problems                                                                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Heart conditions                                                                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Intellectual disability/disorder (previously called Mental Retardation)                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Learning disorder                                                                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Loss of skills/regression                                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Obsessive Compulsive Disorder (OCD)                                                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

|                                                                       |                          |                          |                          |
|-----------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|
| Schizophrenia                                                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Skin conditions (such as psoriasis or eczema)                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sleep disorders (such as problems getting to sleep or staying asleep) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Tics                                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Tourette Syndrome                                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vision problems                                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If other health condition, specify: _____                             |                          |                          |                          |

19) Does your young adult take any prescription medications?

☐ Yes

If yes, number of prescription medications: \_\_\_\_\_

☐ No

☐ Unsure

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

☐ Yes

If yes, number of over the counter medications: \_\_\_\_\_

☐ No

☐ Unsure

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

☐ Biological Mother

☐ Biological Father

☐ Stepmother

☐ Stepfather

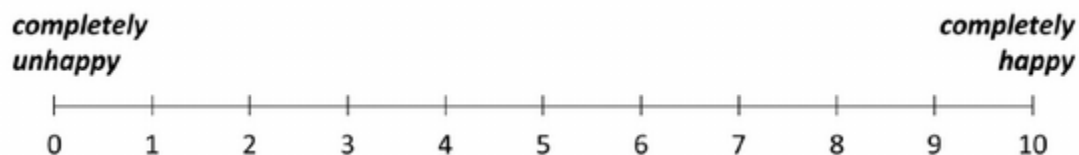
☐ Adoptive Mother

☐ Adoptive Father

☐ Siblings

☐ Other (please specify): \_\_\_\_\_

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



23) 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)?

☐ Very motivated

☐ Somewhat motivated

☐ Somewhat unmotivated

☐ Very unmotivated

**These are questions about YOU:**

**24) What is your age? (in years) \_\_\_\_\_**

**25) What is your marital/partner status?**

- |                                               |                                    |
|-----------------------------------------------|------------------------------------|
| <input type="checkbox"/> Never Married        | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Married              | <input type="checkbox"/> Divorced  |
| <input type="checkbox"/> Domestic Partnership | <input type="checkbox"/> Widowed   |

**26) What is your gender? (\*Hover over text for examples)**

- |                                                |                                            |
|------------------------------------------------|--------------------------------------------|
| <input type="checkbox"/> Female                | <input type="checkbox"/> Male              |
| <input type="checkbox"/> Transgender Female*   | <input type="checkbox"/> Transgender Male* |
| <input type="checkbox"/> Gender non-conforming |                                            |

**27) What is your ethnicity?**

- ☐ Not Hispanic or Latino  
☐ Hispanic or Latino

**28) What is your race?**

- |                                                    |                                                                    |
|----------------------------------------------------|--------------------------------------------------------------------|
| <input type="checkbox"/> White                     | <input type="checkbox"/> Native Hawaiian or Other Pacific Islander |
| <input type="checkbox"/> Black or African-American | <input type="checkbox"/> American Indian or Alaska Native          |
| <input type="checkbox"/> Asian                     | <input type="checkbox"/> Unknown                                   |

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

- |                                                                                      |                                                                         |
|--------------------------------------------------------------------------------------|-------------------------------------------------------------------------|
| <input type="checkbox"/> Less than 8th grade                                         | <input type="checkbox"/> Associate degree                               |
| <input type="checkbox"/> 1 <sup>st</sup> through 12 <sup>th</sup> grade (no diploma) | <input type="checkbox"/> Bachelor's degree (e.g., BA, AB, BS, BBA)      |
| <input type="checkbox"/> High School graduate                                        | <input type="checkbox"/> Master's degree (e.g., MA, MS, MEng, MEd, MBA) |
| <input type="checkbox"/> GED or equivalent                                           | <input type="checkbox"/> Professional school degree (MD, DDS, DVM, JD)  |
| <input type="checkbox"/> Some college, no degree                                     | <input type="checkbox"/> Doctoral degree (e.g., PhD, EdD)               |

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

- |                                                                                      |                                                                         |
|--------------------------------------------------------------------------------------|-------------------------------------------------------------------------|
| <input type="checkbox"/> No second caregiver                                         | <input type="checkbox"/> Some college, no degree                        |
| <input type="checkbox"/> Less than 8th grade                                         | <input type="checkbox"/> Associate degree                               |
| <input type="checkbox"/> 1 <sup>st</sup> through 12 <sup>th</sup> grade (no diploma) | <input type="checkbox"/> Master's degree (e.g., MA, MS, MEng, MEd, MBA) |
| <input type="checkbox"/> High School graduate                                        | <input type="checkbox"/> Professional school degree (MD, DDS, DVM, JD)  |
| <input type="checkbox"/> GED or equivalent                                           | <input type="checkbox"/> Doctoral degree (e.g., PhD, EdD)               |

**31) What is your family's household income?**

- |                                               |                                               |
|-----------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Under \$15,000       | <input type="checkbox"/> \$50,000 to \$74,999 |
| <input type="checkbox"/> \$15,000 to \$24,999 | <input type="checkbox"/> \$75,000 to \$99,999 |
| <input type="checkbox"/> \$25,000 to \$34,999 | <input type="checkbox"/> \$100,000 and over   |
| <input type="checkbox"/> \$35,000 to \$49,999 |                                               |

**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): \_\_\_\_\_

### **Health-Related Independence**

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 person may not need guidance, while for other tasks or situations 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
- ☐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
- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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\*. (\*Hover over text for examples)

- ☐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

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). (\*Hover over text for examples)

- ☐ 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. (\*Hover over text for examples)

- ☐ 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

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.\* (\*Hover over question for examples)

- ☐Strongly agree
- ☐Agree
- ☐Disagree
- ☐Strongly disagree

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.\* (\*Hover over question for examples)

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ My young adult does not get online I do not know what my young adult knows on this subject

38 My young adult understands the restrictions on pornography\* based on legal and family rules. (\*Hover over text for examples)

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

39 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
- ☐ My young adult does not get online
- ☐ 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

42 My young adult can explain how sexually active people protect themselves from sexually transmitted infections\*. (\*Hover over text for examples)

- ☐ 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\*. (\*Hover over text for examples)

- ☐ 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. (\*Hover over text for examples)

- ☐ 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. (\*Hover over text for examples)

- ☐ 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

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. (\*Hover over text for examples)

- ☐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. (\*Hover over text for examples)

- ☐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. (\*Hover over text for examples)

- ☐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

56 My young adult can develop goals\* that satisfy [his\_her] own needs and wants. (\*Hover over text for examples)

- ☐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. (\*Hover over text for examples)

- ☐ 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 to reach [his\_her] goals\*. (\*Hover over text for examples)

- ☐ 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\***. (\*Hover over text for examples)

- ☐ 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              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Preventative health care                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Mental health or counseling                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Dental care                                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Prescription services                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Physical, occupational, or speech service              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Life skills therapy/ Independence training             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vocational services/ Supported employment              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Case management/ Service coordinator/ Care coordinator | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Access/ Mobility services                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Socialization training                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Personal assistance                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Residential care planning                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Socialization training                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2. Did your young adult receive *all* the services that [he\_she] needed?

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

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

4. During the past 12 months, how many times did your young adult go to the hospital emergency room for [his\_her] own health?\* (\*Hover over text for examples)

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

### Health Care Transition Readiness

Please check the answer that describes your young adult most.

Please check the one 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

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 check 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

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 check 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

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

### Healthcare Transition Success

These questions are about both your 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?\* (\*Hover over question for examples)

- ☐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?\* (\*Hover over question for examples)

- ☐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

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\*? (\*Hover over text for examples)

☐ 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?

☐ Age \_\_\_\_\_

☐ 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 care

### Quality of Care

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\*? (\*Hover over text for examples)
  - ☐ Yes
  - ☐ No
7. During the past 12 months, did anyone help your family arrange or coordinate your young adult's care?
  - ☐ Yes
  - ☐ No

8. During the past 12 months, did your family need extra help arranging or coordinating your young adult's health care?
- ☐ Yes
- 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
- ☐ No
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. [He\_She] 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. [He\_She] 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\*

1. At home, people listen when my young adult describes what [he\_she] wants and is good at.
  - ☐ Always
  - ☐ Almost always
  - ☐ Sometimes
  - ☐ Almost never
  - ☐ Never

2. 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
3. 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
4. At home, my young adult is allowed to act on [his\_her] plans right away.
- ☐ Always
  - ☐ Almost always
  - ☐ Sometimes
  - ☐ Almost never
  - ☐ Never
5. 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
6. 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

#### WHAT HAPPENS AT SCHOOL

1. At school, people listen when my young adult talks/describes about what [he\_she] wants and is good at.
- ☐ Always
  - ☐ Almost always
  - ☐ Sometimes
  - ☐ Almost never

☐Never

2. At school, 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

3. At school, 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

4. At school, my young adult is allowed to act on [his\_her] plans right away.

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

5. At school, 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

6. At school, people understand my young adult when [he\_her] has to change plans to meet [his\_her] own goals. They offer advice and encouragement.

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

### **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.\* (\*Hover over question for examples)

- ☐None
- ☐Some
- ☐A lot

3. I have problems with my own mental health.\* (\*Hover over question for examples)

- ☐None
- ☐Some
- ☐A lot

4. I have problems combining my care tasks with my daily activities.\* (\*Hover over question for examples)

- ☐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.\* (\*Hover over question for examples)

- ☐None
- ☐Some
- ☐A lot

7. I have problems with my own physical health.\* (\*Hover over question for examples)

- ☐None
- ☐Some
- ☐A lot

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

