Study Title: The Autism Resources for Transitional Services (ARTS) Study

Instructions: Thank you for participating in the ARTS Study. The information you provide about yourself, your family, and your child with Autism Spectrum Disorder (ASD) will help researchers better understand how families in Charlottesville, VA and the surrounding counties access and use resources to care for their children with autism as they transition to adulthood. It will take approximately **10-15 minutes** to complete this survey. By participating in the survey, you may enter a **raffle for the chance to win one of three $15 Amazon gift cards** by providing a contact method at the end of this survey. You may skip any questions that make you uncomfortable and you may stop the survey at any time with no consequences.

Section 1: Child with ASD Information. The following questions are about your child.

1. What is your child's age (in years)? _____
2. What is your child's gender? ☐ Female ☐ Male ☐ Prefer not to answer
3. Which of the following describes your child's race? *Please check all that apply.*

   ☐ Black/African/African-American ☐ White/Caucasian ☐ Asian/Pacific Islander

   ☐ Native American ☐ Other ☐ Prefer not to answer
4. Is your child of Hispanic or Latin origin? ☐ Yes ☐ No ☐ Prefer not to answer
5. Was your child professionally diagnosed with a disorder on the spectrum (ASD, Asperger Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, etc.)?

   ☐ Yes ☐ No ☐ Don't know

   If yes, how old was your child when he/she was first diagnosed with ASD? _____
6. Does your child have any medical conditions other than ASD? If yes, what are they?

   ☐ Yes ☐ No **If yes:** _____
7. Does your child have any mental health conditions other than ASD? If yes, what are they?

   ☐ Yes ☐ No **If yes:** _____
8. How would you describe your child's verbal ability?

   ☐ Nonverbal/minimally verbal ☐ Some spoken language ☐ Verbally fluent
9. Was your child's IQ assessed by a health care provider/professional?

   ☐ Yes ☐ No ☐ Don't know

   If yes, what was the result of your child's IQ assessment?

   ☐ High IQ ☐ Average IQ ☐ Low IQ
10. How would you describe your child's overall need for support in day-to-day activities?

    ☐ High need for support ☐ Moderate need for support ☐ Low need for support

11. What type of health care coverage/insurance has your child had in the past 12 months?

    Check all that apply.

    - ☐ Uninsured
    - ☐ Private insurance provided by parent/guardian's employer
    - ☐ Private insurance purchased in the open market
    - ☐ Private insurance purchased from a state-based health exchange (as part of the Affordable Care Act)
    - ☐ Medicaid
    - ☐ Military health care
    - ☐ Other
    - ☐ Don't know

Section 2: Treatments and Therapies for ASD. The following questions are about the treatments and therapies your child with ASD has received **in the past 12 months**. We have included descriptions and examples to help explain each type of treatment and/or therapy.

Behavioral Therapy/Social Skills Training: encourages appropriate behaviors (getting dressed, talking to others) and discourages inappropriate behaviors (self-harm, aggression towards others). Examples include Applied Behavior Analysis (ABA), Discrete Trial Training/Teaching (DTT), Pivotal Response Treatment (PVT), and Verbal Behavior (VB) Therapy/Approach.

Speech and Language Therapy: focuses on improving the understanding and expression of words to support communication.

Occupational Therapy: promotes independent functioning in all aspects of daily life. Therapy focuses on improving motor skills, coordination, and ability to adapt to the surrounding environment to improve daily life skills, such as getting dressed, grooming, writing, and playing.

Physical Therapy: emphasizes physical methods of healing such as massage, heat treatment, and exercise.

Job Coaching: develops skills pertaining to employment including searching for, applying for, and maintaining a job.

Psychological interventions: aims to change an individual's thoughts, behaviors, and actions. Examples include: **Counseling**: Interventions based on talking to a trained professional, **Psychodynamic therapies**: Interventions based on exploring an individual's subconscious thoughts and perceptions. Includes psychoanalysis and hypnotherapy, **Cognitive therapies**: Interventions based on identifying and changing an individual's thought patterns. Includes Cognitive Behavioral Therapy and Mindfulness Training.

Psychiatry: focuses on the diagnosis, treatment, and prevention of mental, emotional, and behavioral disorders with the services of a medical doctor.

Executive Function Training: teaches the cognitive processes that help regulate, control, and manage thoughts and actions (planning, problem solving, attention, reasoning, etc.).

For each question, only include information about treatments and therapies that were **conducted or delivered by a trained therapist or other professional**.

12. In the past 12 months, did your child receive the following treatments? If yes, where did your child receive the following treatments? *Check all that apply.*

	Did child receive treatment?	Home	School	Clinic/ office	Other	Don't know
Behavioral Therapy/Social Skills Training	☐ Yes ☐ No	☐	☐	☐	☐	☐
Speech and Language Therapy	☐ Yes ☐ No	☐	☐	☐	☐	☐
Occupational Therapy	☐ Yes ☐ No	☐	☐	☐	☐	☐
Physical Therapy	☐ Yes ☐ No	☐	☐	☐	☐	☐
Job Coaching	☐ Yes ☐ No	☐	☐	☐	☐	☐
Psychological Interventions	☐ Yes ☐ No	☐	☐	☐	☐	☐
Psychiatry	☐ Yes ☐ No	☐	☐	☐	☐	☐
Executive Function Training	☐ Yes ☐ No	☐	☐	☐	☐	☐
Other Interventions	☐ Yes ☐ No	☐	☐	☐	☐	☐

13. If your child received other interventions, list/describe them here:

_____

14. Were there any barriers to starting and/or continuing the following treatments? If yes, which of the following describes these barriers? *Check all that apply.*

	Behavioral Therapy/ Social Skills Training	Speech and Language Therapy	Occupational Therapy	Physical Therapy	Job Coaching
Any barriers?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Dissatisfied with progress	☐	☐	☐	☐	☐
Dissatisfied with program/provider	☐	☐	☐	☐	☐
Program/provider no longer available	☐	☐	☐	☐	☐
Scheduling difficulties	☐	☐	☐	☐	☐
Cost too much money/insurance didn't cover	☐	☐	☐	☐	☐
Required too much time	☐	☐	☐	☐	☐
Child refused to go or participate	☐	☐	☐	☐	☐
Transportation issues	☐	☐	☐	☐	☐
Didn't know about treatment	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

	Psychological Interventions	Psychiatry	Executive Function Training	Other Interventions
Any barriers?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Dissatisfied with progress	☐	☐	☐	☐
Dissatisfied with program/provider	☐	☐	☐	☐
Program/provider no longer available	☐	☐	☐	☐
Scheduling difficulties	☐	☐	☐	☐
Cost too much money/insurance didn't cover	☐	☐	☐	☐
Required too much time	☐	☐	☐	☐
Child refused to go or participate	☐	☐	☐	☐
Transportation issues	☐	☐	☐	☐
Didn't know about treatment	☐	☐	☐	☐
Other	☐	☐	☐	☐

15. If there were other barriers, list/describe them here:

_____

Section 3: Access and Satisfaction. The following questions are about access to care for your child with ASD and satisfaction with the care received.

16. Does your child have a primary care doctor or provider he/she regularly sees for check-ups or when sick?

    ☐ Yes ☐ No

    If yes, what type of doctor or provider?

    ☐ Pediatric (a provider who sees mostly children)

    ☐ Family medicine (a provider who sees both children and adults)

    ☐ Adult (a provider who sees only adults)

    ☐ Other (please specify): _____

17. Does your child see any specialists?

    ☐ Yes ☐ No

    If yes, what type of specialist? *Check all that apply.*

    ☐ Psychiatrist

    ☐ Neurologist

    ☐ Gastroenterologist (GI doctor)

    ☐ Geneticist

    ☐ Psychologist

    ☐ Other (please specify): _____

18. When was the last time your child had an appointment with a health care provider for medical care related to his/her ASD?

    ☐ Less than 3 months ☐ 3 to 6 months

    ☐ More than 6 months, less than 1 year ☐ More than 1 year

19. In the past 12 months, did your child need a referral to see any doctors or receive any services?

    ☐ Yes ☐ No

    If yes, how was the process of getting referrals?

    ☐ Very easy ☐ Somewhat easy ☐ Neither easy nor hard

    ☐ Somewhat hard ☐ Very hard

20. In the past 12 months, what has been your role in arranging care for your child's ASD? *Check all that apply.*
    - ☐ Scheduled appointments
    - ☐ Attended appointments
    - ☐ Collected referrals
    - ☐ Coordinated care with multiple providers
    - ☐ Reported progress to providers
    - ☐ Discussed future needs/care
    - ☐ Other
21. In the past 12 months, who was the main coordinator of care for your child's ASD?
    - ☐ Primary health care provider
    - ☐ School social worker/psychologist
    - ☐ Case manager/service coordinator
    - ☐ Other professional (such as therapist or counselor)
    - ☐ You (the parent/caregiver)
    - ☐ Other (non-professional)
    - ☐ Don't know
22. How satisfied are you with the **coordination of care** for your child's ASD?

    ☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied
    ☐ Somewhat dissatisfied ☐ Very dissatisfied
23. In the past 12 months, have you felt that you could have used extra help arranging or coordinating your child's care among the different health care providers or services?

    ☐ Yes, and usually received it ☐ Yes, and sometimes received it
    ☐ Yes, and never received it ☐ No
24. In the past 12 months, how satisfied were you with the communication between your child's doctors and other health care providers?

    ☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied
    ☐ Somewhat dissatisfied ☐ Very dissatisfied
25. In the past 12 months, did your child's health care provider communicate with the child's school, child care provider, or special education program?

    ☐ Yes ☐ No ☐ Service not needed

If yes, during this time, how satisfied were you with the health care provider's communication with the school, child care provider, or special education program?

☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied
☐ Somewhat dissatisfied ☐ Very dissatisfied

26. In the past 12 months, how satisfied are you with the **health care** provided for your child's ASD?

☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied
☐ Somewhat dissatisfied ☐ Very dissatisfied

27. In the past 12 months, how has this **health care** affected your child's ASD?

☐ Very positively ☐ Somewhat positively ☐ Neither positively nor negatively
☐ Somewhat negatively ☐ Very negatively

28. In the past 12 months, how often did your child's doctors or other health care providers...

	Always	Usually	Sometimes	Never
Spend enough time with your child?	☐	☐	☐	☐
Listen carefully to you/your child?	☐	☐	☐	☐
Show sensitivity to your family's values and customs?	☐	☐	☐	☐
Provide the specific information you/your child needed?	☐	☐	☐	☐
Help you/your child feel like a partner in your child's care?	☐	☐	☐	☐
Discuss with you/your child the range of options to consider for his/her health care or treatment?	☐	☐	☐	☐
Make it easy for you/your child to raise concerns or disagree with recommendations for your child's health care?	☐	☐	☐	☐

	Always	Usually	Sometimes	Never
Work with your child to decide together which health care and treatment choices would be best for your child?	☐	☐	☐	☐
Work with your child to make positive choices about his/her health?	☐	☐	☐	☐
Work with your child to gain skills to manage his/her health and health care?	☐	☐	☐	☐
Work with your child to understand the changes in health care that happen at age 18?	☐	☐	☐	☐

29. Do any of your child's doctors or other health care providers treat only children?

    ☐ Yes ☐ No

    If yes, have they talked with you about when your child will need to see doctors or other health care providers who treat adults?

    ☐ Yes ☐ No

30. Have you and your child received a summary of your child's medical history (medical conditions, allergies, medications, immunizations, etc.) to prepare for a transition of health care providers?

    ☐ Yes ☐ No

31. Have your child's doctors or other health care providers worked with you and your child to create a plan of care to meet his or her health goals and needs in the future?

    ☐ Yes ☐ No

    If yes…

    Do you and your child have access to this plan of care?

    ☐ Yes ☐ No

Does this plan of care address transition to doctors and other health care providers who treat adults?

☐ Yes ☐ No ☐ No, child already sees providers who treat adults

32. Eligibility for health insurance often changes in young adulthood. Do you know how your child will be insured as he/she becomes an adult?

☐ Yes ☐ No

If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult?

☐ Yes ☐ No

33. Do you have any concerns about your child transitioning from pediatric to adult care?

☐ Yes ☐ No

If yes, have you had the opportunity to talk to your child's health care provider about these concerns?

☐ Yes ☐ No

If yes, how helpful has your child's health care provider been with addressing these concerns?

☐ Very helpful ☐ Somewhat helpful ☐ Neither helpful nor unhelpful

☐ Somewhat unhelpful ☐ Very unhelpful

Section 4: Caregiver and Household Information. The following questions are about you and your household.

34. Which of the following best describes you?

☐ Married ☐ Single, never married ☐ Living with partner

☐ Divorced ☐ Separated ☐ Widowed ☐ Prefer not to answer

35. Which of the following describes your race? *Please check all that apply.*

☐ Black/African/African-American ☐ White/Caucasian ☐ Asian/Pacific Islander

☐ Native American ☐ Other ☐ Prefer not to answer

36. Are you of Hispanic or Latin origin? ☐ Yes ☐ No ☐ Prefer not to answer

37. What 5-digit zip code do you live in? _____

38. What was your total household income in 2018?

☐ Less than $20,000	☐ $20,000 - $34,999	☐ $35,000 - $49,999
☐ $50,000 – $74,999	☐ $75,000 - $99,999	☐ $100,000 - $124,999
☐ $125,000 – $149,999	☐ $150,000 or more	☐ Prefer not to answer

39. Please list any **health care resources** that your child has used specifically for their diagnosis in the past 12 months that you believe could be useful to other families in a similar situation:

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40. Please provide any additional information or thoughts that you would like to share:

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Thank you so much for your time and support!

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To show our appreciation, we would like to give you the opportunity to enter a raffle for the chance to win one of three $15 Amazon gift cards. Please provide the best method of contacting you if selected as a winner. Tear along the dotted line, so that your information will not be connected to your survey responses.

Name: ____

Email: ____

Phone Number: __________________________________

Other: ____