

# Physician Transition for Adolescents with Autism Spectrum Disorder



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UNIVERSITY  
SCHOOL OF  
MEDICINE

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## BACKGROUND/ABSTRACT

Pilot project exploring transition to adult healthcare for individuals with Autism Spectrum Disorder (ASD).

Four adolescents and their parents participated

90 minute interview at Emory Autism Center discussing healthcare transition

3 healthcare transition goals created by each adolescent

Existing resources were reviewed and adapted to create new materials

## METHODS

**Recruitment.** Adolescents and their family members were recruited from the clinical contacts of the Emory Autism Center. Participants met the following criteria:

- reside within one of two healthcare regions in the Georgia DPH network
- be between the ages of 14 and 17
- have an ASD diagnosis

### Participants:

- 4 male adolescents (including one set of twins) and their mothers
- 15 or 16 years of age
- all participants possessed verbal communication skills requisite for responding to interview questions

**Interviews:** Each family met to review expectations, sign consent forms, engage in a brief interview, and establish 3 initial goals. Adolescents were interviewed separately from their mothers, and the family met together with staff at the end of the appointment to generate goals.

## PARTICIPANT THEMES

Several themes were identified following participant interviews:

- **Adolescent dependence** on parents for
  1. medication compliance
  2. appointment scheduling
  3. maintenance of records, etc.
- Adolescents had adequate **awareness of basic healthcare knowledge**
- Participation in the project generated **increased awareness and motivation** regarding independence and healthcare transition

## KEY HEALTHCARE SKILLS FOR ASD

**Self Advocacy:** skills that enable an individual with ASD to communicate his goals, challenges, strengths and needs

**Planning & Scheduling:** tasks include scheduling, filling out forms, contacting pharmacists and other providers, arranging/providing transportation

**Self-monitoring/Self-awareness:** knowledge of personal healthcare needs, emotion regulation, behavioral regulation, and basic guidelines for maintaining strong physical and mental health

## CREATION OF SUPPLEMENTAL MATERIALS

Based on a review of existing materials, several new documents were created specifically for ASD:

**Introduction to ASD and Healthcare Transition:** a handout for physicians providing an introduction to ASD including:

1. diagnosis requirements
2. comorbidities and other basic information
3. impact on severity levels within the autism spectrum on healthcare transition

**Transition Timeline:** a handout for providers and families that includes:

1. specific skills required for successful healthcare transition
2. a sample timeline for what healthcare transition might look like for an individual with ASD

**Transition Readiness Assessments:** assessments used during participant interviews, modified from currently available transition resources to include specific questions appropriate for individuals with ASD; separate assessments were developed for adolescents and parents.



## PARTICIPANT GOALS

Increase awareness of **emergency medical care:** recognition of symptoms and procedures

Creation of a **medical home** for records and information

Increase **participation in planning and scheduling** of medical appointments and related medical care

Increase **self advocacy**

## MATERIALS REVIEWED AND OTHER RELEVANT RESOURCES

Health Care Transition from Pediatric to Adult Primary Care: Guide for Physicians to Support Youth and Young Adults with Special Health Care Needs (Georgia Department of Public Health)

Transition to Adulthood: A Health Care Guide for Youth and Families (Autistic Self-Advocacy Network)

New Jersey Action Blueprint for Transition to Adult Health Care (Boggs Center on Developmental Disabilities)

Stepping Up to Adult Care: Developing a Health Care Transition Program for Pediatric Sickle Cell Disease Populations (Georgia Department of Public Health)

Transition Readiness Assessments for Youth and Parents  
(<http://gottransition.org>)  
Autism Speaks Transition Toolkit

## RECOMMENDATIONS AND FUTURE DIRECTIONS

1. Continue assessments with additional participants and families to:
  - learn more about adolescent and family needs
  - expand the ASD severity range among participants
2. Monitor progress on individualized goals
3. Continue to update assessment and other supplemental materials
4. Engage pediatricians and identify procedures for identifying adult healthcare providers
5. Create physician training modules