

## **Abstract**

### **“Transition to Adult Health Care for Youth with Autism Spectrum Disorders”**

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Descriptive data and anecdotal reports indicate that few adolescents with special health care needs receive transition services to help them bridge the chasm that exists between the expectations and realities of the pediatric and adult health care systems. This is especially true for youth with Autism Spectrum Disorders (ASD). As a result, youth with ASD are underserved when it comes to health care, either because they remain stuck in the pediatric system, or they fail to receive care because they cannot find an adult provider willing to see them, or have difficulty making independent visits to receive proper care. The lack of transition services may have deleterious impacts on the well-being of youth and young adults with ASD. With the increase in ASD prevalence, the lack of care continuity for youth with ASD will create significant and long-lasting challenges to the health care system and related systems, such as residential care and social services.

We seek to understand barriers to transition for youth with ASD and to uncover current best practices. We will use this information to design and test the feasibility of intervention strategies for improving the health care transition. We will use two networks in this study, 1) the Autism Treatment Network (ATN), which consists of 14 (soon to be 18-20) autism clinics and 2) two pediatric primary care clinics associated with the Partners Healthcare network. We will conduct structured interviews with providers at the sites (phone interviews with all sites and in-person in depth interviews at selected sites), parent/youth surveys at selected sites, and interviews with “autism-friendly” internists and adult specialists. Through this approach, we seek to identify characteristics that could improve the transition process and thus better understand the barriers to care for this underserved population. We will examine: 1) whether and how ATN sites and primary care sites are addressing transition services for youth with ASD; 2) what transition services and supports parents/youth receive and would like to receive, what they do on their own around transition and whether parents/youth are satisfied with transition services, and 3) what characteristics adult medical care providers identify as important in their willingness to care for youth and young adults with ASD. From this information, we will draft informational guides for families and providers. We will use the information obtained and the draft guides to develop a logic model, formulate a transition intervention, and assess its feasibility through a review process with the families and practices we interviewed.