



# Maine Behavioral Healthcare

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## **Publication Describes New Resource for Studying Individuals Most Severely Affected By Autism**

**Rigorously characterized sample of children will expand the genetic library for autism  
researchers and contribute to targeted treatments**

Westbrook, Maine (Nov. 10, 2015) - The Autism Inpatient Collection (AIC), a repository of phenotypic and biological information, is described in an article [published on-line](#) today in the journal *Molecular Autism*. The data provide key information about an understudied segment of children with autism: those with intellectual disability, expressive language impairment, challenging behaviors and/or low adaptive functioning.

“We have been able to enroll and gather detailed data on those most severely affected by autism, a group that is often missing from current research. This is incredibly important, as our understanding of autism, from the genetic code to the clinical characteristics, can only be as complete as our data are representative,” stated Matthew Siegel, MD, principal investigator for the AIC study who is the director of the Developmental Disorders Program at Maine Behavioral Healthcare and a research scientist with the Maine Medical Center Research Institute.

The AIC project is being performed by the [Autism and Developmental Disorders Inpatient Research Collaborative](#) (ADDIRC), a research network of specialized child psychiatry units that specialize in assessment and treatment of children with autism. ADDIRC members include Bradley Hospital (Brown University), Cincinnati Children’s Hospital (University of Cincinnati), Children’s Hospital Colorado (University of Colorado), Sheppard Pratt Health Systems (University of Maryland), Western Psychiatric Institute and Clinics (University of Pittsburgh) and Maine Behavioral Healthcare/Maine Medical Center Research Institute (Tufts University).

Utilizing the psychiatric hospital setting is a new strategy to study individuals who can be difficult to access in typical outpatient research settings. “We have developed a platform that can systematically assess large numbers of children and adolescents who are severely affected by ASD, which will allow us to contribute to the identification of subtypes and test targeted treatments,” explained Dr. Siegel.

The AIC will ultimately include over 1600 individuals with ASD and their parents. In this paper describing the first 147 subjects, the AIC cohort was found to be 12.6 years old, on average, with a non-verbal IQ of 71 and an Adaptive Behavior Composite score of 56. Over half the sample (52%) is non-verbal or minimally-verbal, 26% are female and 68% have significant challenging behaviors, including 26% who

engage in self-injury. Dr. Susan Santangelo, director of the Center for Psychiatric Research at the Maine Medical Center Research Institute and a co-investigator on the AIC project, explained that “By studying this unique cohort, we hope the AIC will give us a better understanding of the genetic underpinnings of autism, help us identify biologically based autism subtypes, and ultimately provide critical information to the patients and families with some of the greatest need.”

Access to the AIC project data and biosamples can be requested from the [Simons Foundation Autism Research Initiative](#). The availability of these data may accelerate the identification of genetically distinct autism subtypes, and shed more light on a very complex developmental disorder.

The AIC is supported by grant funding from the Simons Foundation and the Nancy Lurie Marks Family Foundation.

The Maine Medical Center Research Institute is the research arm of Maine Medical Center and seeks to enhance the health of our population through excellence in research across the spectrum of the biomedical and health sciences.

Maine Behavioral Healthcare is a leading provider of developmental disorder and mental health services, with over 30 outpatient locations throughout southern, western and mid-coast Maine, as well as Spring Harbor Hospital, providing an integrated continuum of comprehensive, coordinated behavioral healthcare for Maine residents of all ages.

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