**Title:** *Family Patterns in Diagnosis of Children with Autism Spectrum Disorders (ASD)*

**Topic:** Families **Grant Year:** 2013

**Principal Investigator(s):** Nachum Sicherman, Ph.D. **Funding:** $30,000.00

 Joseph Buxbaum, Ph.D.

 George Loewenstein, Ph.D.

**Institution:** Columbia University, New York, New York **Duration:** Two Years

**Purpose:** To study the family structure’s involvement in the early diagnosis of autism spectrum disorder (ASD) because of its importance for earlier intervention and the improvement of treatment efficacy.

**Objectives:** The objective of this study is to look at the effects of the presence and severity of symptoms on the age of diagnosis of children with ASD. It is based on an online survey of parents of children diagnosed with ASD designed to identify potential causes of late diagnosis within the family structure.

**Study:** An online survey was completed by 1,815 parents of children (83.1% male) who were previously diagnosed with ASD. Parents were asked to rate the symptoms exhibited by their child around the time of diagnosis based on severity. The survey asked parents to provide up to five e-mail addresses of friends and/or extended family members, who were then contacted and asked to complete a complementary survey. This allowed the research team to study the role played by various individuals in affecting the time of diagnosis. It also allowed a comparison between answers provided by the parents with those provided by others, enhancing the quantitative analysis.

**Results:** Different approaches lead to substantially different conclusions. Using univariate regressions, researchers examined the relationship between each symptom and age of diagnosis. It was found that for most symptoms, the more severe the symptom is, the earlier the age of diagnosis is. The regression tree analysis identified speech delay, lack of gestures and delayed response to name as the key symptoms leading to early diagnosis. The regression tree and factor analysis approaches provide different results, in part because they are designed to solve different problems. Whereas the factor analysis shows the effect of independent factors on age of diagnosis, the regression trees shows the effects of various symptoms only after accounting for the effects of other, more significant, symptoms. One of the main findings was that symptoms that most strongly predict early diagnosis are not necessarily specific to autism, but more likely indicate what parents expect are deviations of normal development in the home in the first 2 years of life.

**Significance and Implications:** The timing of interventions can have a large impact on ASD trajectories. Family members, caretakers, and healthcare professionals, who are typically the first to raise concerns, necessarily rely on natural observations of symptoms to inform diagnosis and treatment. Identifying specific demographic groups, family configurations, or other factors that predict late diagnosis can aid the effort in diagnosing children with ASD as early as possible.

**Practical Relevance:** This research project provides recommendations to primary care providers, as well as preschool and early education teachers, to enhance the early detection of ASD. The project findings encourage the integration of surveys of extended families’ and friends’ views in further ASD screening mechanisms.