

Leadership Education in Neurodevelopmental Disabilities (LEND) Program  
Westchester Institute for Human Development  
University Center for Excellence in Developmental Disabilities  
And  
New York Medical College  
*Team Project Abstract*  
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**Title:** Pathways to Identification, Diagnosis, and Treatment of Autism Spectrum Disorder in Young Children

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**Background:** Early detection of Autism Spectrum Disorder (ASD) is crucial so treatment can begin as soon as possible. Recent literature has investigated the age of ASD diagnosis in relation to a number of fairly broad features, such as age of first parental concern, differences among sexes, disparities across geographic regions, and disparities based on socioeconomic and racial/ethnic background. However, no studies have described the age of diagnosis at a community level, taking into account the assessment strategies within the early intervention system and the extent to which caregivers can access expertise within the community at large. The goal of this study was to examine how families accessed community resources (public early intervention program and private practitioners) to obtain a diagnosis of autism spectrum disorder and access treatment.

**Method:** We examined archival charts of 130 children diagnosed with ASD before the age of three who received evaluations through the county EI system; the county studied is relatively resource-rich. The charts contain extensive information about the child's developmental history and assessment and intervention experiences within the EI system, as well as with health and behavioral professionals in the community. A protocol was developed to record a timeline of early intervention program entry, evaluations that identified ASD through descriptions but did not diagnose it, and evaluation yielding an ASD diagnosis. Also recorded were basic demographics and community specialists consulted.

**Results:** Review of charts revealed several distinct basic patterns of access, with the mean Age of Diagnosis as follows: child enters EI with a diagnosis (8%; 25.0 mos.); child enters EI and receives a diagnosis through the initial multidisciplinary evaluation (34%; 25.7 mos.); child enters EI, is identified but not diagnosed until later (24%; 29.5 mos.); child enters EI, is NOT identified but is identified and diagnosed later (17%; 29.6 mos.); child enters EI early (under 12 months) with motor delay and eventually is identified and diagnosed with ASD (12%; 27.6 mos.); child is identified but not diagnosed in EI (7%; 40 mos.).

An analysis of the lag time for obtaining a diagnosis for those who were diagnosed at entry of EI, and those who were not, was 5 months. For those who entered

EI and were diagnosed immediately, this was exclusively because a psychologist was on the evaluating team.

Use of community professionals, primarily for diagnostic purposes, was analyzed. Thirty-five percent of the families consulted one professional; 8 % consulted two, and one family (0.8 %) consulted three. The two most common types consulted were developmental pediatricians and pediatric neurologists. Only a few families consulted psychiatrists, private psychologists, and geneticists.

**Conclusion:** These data provide a valuable base of comparison of the experiences of families in a high-resource county with many parents of relatively high educational background and financial resources. It is notable how young children are being diagnosed (43% by age 24 months) and how effective the EI program appears to be in this regard (72% diagnosed through EI; 93% diagnosed during their time in EI). It will be important to gather similar data in lower-resource counties to understand the difference in experiences.