

## Autism Registry and Early Intervention Analysis

While some children with autism can be diagnosed as young as two years old, most children are diagnosed between the ages of three and five. The 2010 CDC's Autism and Developmental Disabilities Monitoring (ADDM) study<sup>1</sup> showed a median age at diagnosis of 3.7 years of age across the 11 state study sites (n= 363,749) and the New Jersey study site (Essex, Hudson, Ocean and Union Counties) had a mean age of 4.1 (n=696). The New Jersey Autism Registry has a median age at diagnosis of 3.4 years and a mean age of 4.5 (n=12,194). Factors that affect the age of first diagnosis include the child's own development, when the parent or caregiver first notices symptoms, the primary care provider's ASD screening efforts, the availability of qualified diagnosticians, and the type of ASD diagnosis (Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, and Asperger's Disorder). While obtaining a formal diagnosis is a process that is dependent on many factors, services and supports for the child and family are available as soon as concerns are raised regarding the child's development and are not contingent on a diagnosis.

One important way very young children ages zero to age three may be eligible to receive services is through the New Jersey Early Intervention System (NJEIS). Through NJEIS, children are provided developmental evaluation by qualified professionals. The evaluation provides information in six developmental areas: gross motor, fine motor, cognition, and communication, social-emotional and adaptive skills. Following the evaluation/assessment, an Individualized Family Service Plan (IFSP) is developed for eligible children which describe the services and supports that are needed by the child and family and how they will be implemented. Services are provided by qualified practitioners in natural environments, settings in which children without special needs ordinarily participate and that are most convenient for the family such as: home, a community agency, or child care setting. Developmental Intervention, discipline-specific therapies and family support services are incorporated into IFSPs based on the child and family's assessment information.

To determine how many children received services and supports through the NJEIS prior to a formal diagnosis, this brief addresses the question: Are children receiving early intervention services prior to obtaining an Autism Spectrum Disorder (ASD) diagnosis?

### Methods

To determine if children diagnosed with Autism received services through the NJEIS, data from the Autism Registry and the NJEIS data system were matched and analyzed. Staff matched eight birth cohorts (2001 to 2008). These birth cohorts were selected because the children would have been old enough to be diagnosed (age range: 5.5 to 13.5 years old) and registered (the Autism Registry rules went into effect on Sept 22, 2009).

The Autism Registry includes demographic data about the child as well as information about the autism diagnosis. Demographic information includes date of birth, birth weight and gestational age, parent's age, and race/ethnicity. The autism-specific data includes type of diagnosis, age at first diagnosis, age when symptoms were first noticed and type of diagnostician.

The NJEIS data system has significant data for participating children including date of birth, county of residence, race/ethnicity, specific diagnosis or eligibility by general developmental delay, age at referral,

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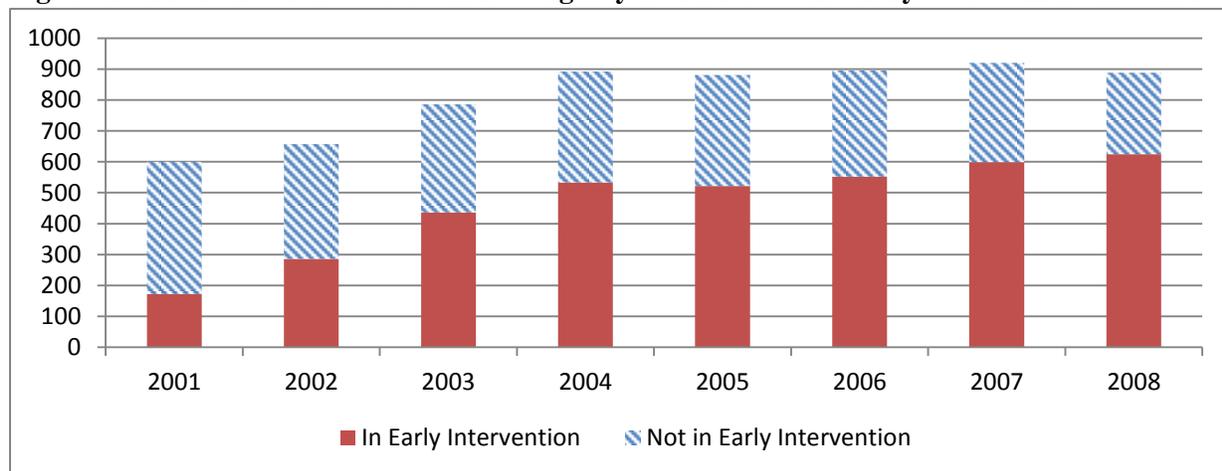
<sup>1</sup> Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *MMWR Surveillance Summaries* / Vol. 63 / No. 2

service delivery information, child progress based on standardized testing and family income information. The NJEIS data included both children that were diagnosed with autism while enrolled in the NJEIS system, and those enrolled for other diagnoses and later registered with the Autism Registry with an autism diagnosis.

## Results

The Autism Registry provided data for 6521 children born between 2001 and 2008 who are registered with the Autism Registry. Of these children diagnosed and registered with an ASD, 3712 or 57.2% were found to have participated in the NJEIS. Since the Autism Registry rules were promulgated in September of 2009, staff has been educating providers regarding their mandate to register children they either diagnose or follow for autism. In this way, we assure both the newly diagnosed and the previously diagnosed are registered. In 2009 when the registry began, the earliest cohort (2001) would have been 8 years old. These children would have already aged out of NJEIS and were probably diagnosed a few years before the Registry began. In contrast, the youngest cohort (2008) would have been approximately one year of age, eligible by age for NJEIS, and most likely not yet diagnosed for autism when the Registry began. As the Registry staff educated diagnosticians and medical home providers, the registry grew in volume, potentially accounting for the overall increase in registrations seen in the size of the columns (see Fig 1). Registry staff began their education efforts with the pediatric specialists who would have more children with autism than with the many more primary care providers who would only have a few children in their caseload with autism. Additionally the newly diagnosed are more likely to be registered, because there are a limited number of specialists who focus on diagnosing children with developmental disorders. The percentage of children registered with autism AND who received NJEIS services dramatically increased over time from 28.7% to 70.4%. There may be a number of reasons for this increase: better awareness of the Autism Registry over time, and improved linkage between providers, NJEIS, and the Autism Registry. For example, the cohort born in 2001 would have been diagnosed between 2004 and 2006, several years before the registry was created. These children, while not in NJEIS were registered by their primary care providers and then referred to special case management. This is one reason the Registry rules extend to medical home providers and previously diagnosed children. In contrast for the cohort born in 2008 that were most likely diagnosed and registered with autism from 2011 to 2013, 70% had already received services and support through NJEIS.

**Fig 1. Number of Children in the Autism Registry who were in NJEIS by Birth Year: 2001-2008**



These rates did vary by county as see in Table 1 which is sorted by percent in NJEIS. More than 60% of children in Warren, Bergen, Ocean, Burlington, and Monmouth had received NJEIS services, while about 50% of children in Essex, Cumberland and Salem had received services.

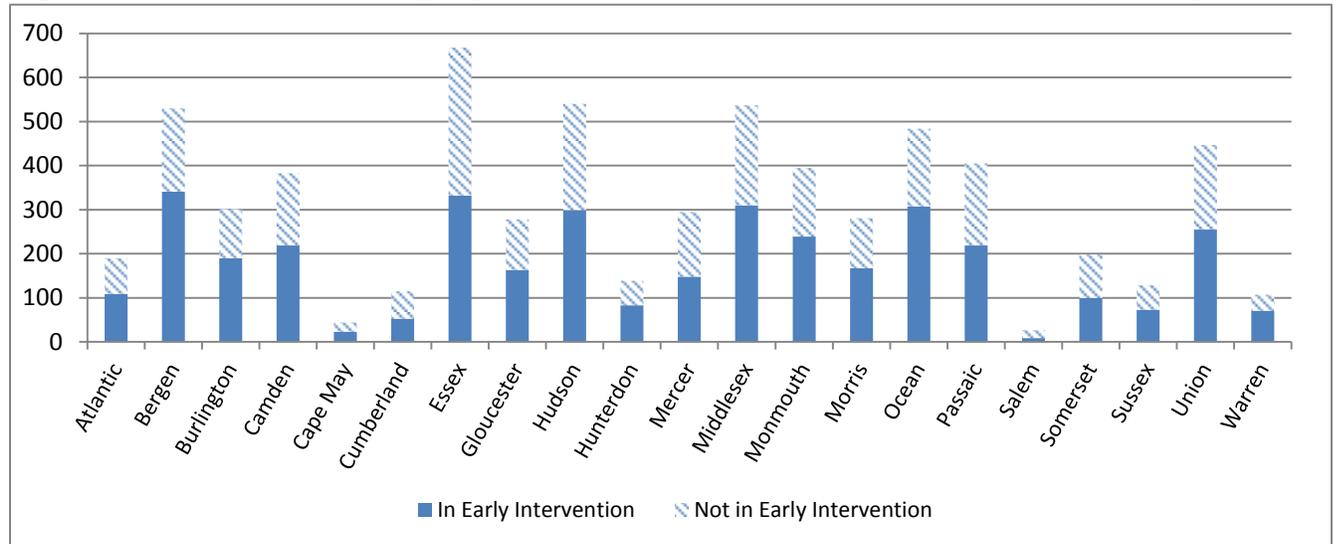
**Table 1. Children in the Autism Registry who were in NJEIS for Birth Years 2001-2008 by County\***

<b>County</b>	<b>In Early Intervention</b>	<b>Not In Early Intervention</b>	<b>% In Early Intervention</b>	<b>Total in the Autism Registry</b>
Warren	71	36	66.4%	107
Bergen	341	189	64.3%	530
Ocean	308	176	63.6%	484
Burlington	190	111	63.1%	301
Monmouth	239	156	60.5%	395
Morris	168	113	59.8%	281
Hunterdon	83	56	59.7%	139
Gloucester	163	115	58.6%	278
Middlesex	310	227	57.7%	537
Atlantic	109	81	57.4%	190
Camden	219	164	57.2%	383
Union	255	192	57.0%	447
Sussex	73	56	56.6%	129
Hudson	299	241	55.4%	540
Passaic	219	186	54.1%	405
Cape May	23	21	52.3%	44
Somerset	100	98	50.5%	198
Mercer	148	147	50.2%	295
Essex	332	336	49.7%	668
Cumberland	53	62	46.1%	115
Salem	9	18	33.3%	27
<b>State Total</b>	<b>3712</b>	<b>2781</b>	<b>57.2%</b>	<b>6493</b>

\*excludes 28 children with unknown County Information

These counties also varied significantly by the number of children (see Fig. 2). As expected the more populated counties of Bergen, Essex, Hudson, and Middlesex had the most children registered (537-668), while the least populated counties of Cape May, Cumberland, Salem, and Warren had the least (27-115).

**Fig 2. Children in the Autism Registry who were in NJEIS for Birth Years 2001-2008 by County**



## Discussion

Overall, children are receiving services through the NJEIS prior to obtaining an Autism Spectrum Disorder (ASD) diagnosis. The trend of children registered with autism AND who have been in the NJEIS is increasing. There are several explanations, however, why all children with autism do not receive services through the NJEIS. First, some children with autism are diagnosed later in childhood because their particular deficits appear later in childhood. For example, children with Asperger’s disorder are usually diagnosed later because their social deficits are not recognized until the demands of a formal school environment are placed upon them. Also children who are considered to be on the “milder” end of the spectrum (more cognitively able, have verbal speech) may not be referred until they are older and their deficits become more apparent to their parent/caregiver. This analysis did not consider the subtype of ASD, but a more in-depth examination is possible. Second, some children with autism may not receive services through NJEIS because their families choose not to participate with the NJEIS. All children referred to NJEIS must be evaluated and must meet a threshold criterion for services; however, children with a diagnosis of autism are considered presumptively eligible for NJEIS and children at-risk for autism would typically show delays that would qualify them for the NJEIS (e.g. significant communication issues). Families do have to consent to participate in NJEIS and there is a Family Cost Participation component for some families. Some families may select private services and therefore, although eligible, choose not to receive NJEIS services. As the Autism Registry grows, Registry and NJEIS staff could continue to match their data and explore not only if children had received NJEIS services, but more about the types of services they received.

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