

The New Jersey Autism Registry and Early Intervention Participation

New Jersey has a long history of public awareness efforts to ensure that parents, guardians, primary care providers and others caring for children recognize the early signs of autism and connect families to our care system. This is important because the earlier that children are identified with autism, the sooner they can be connected to services that can improve outcomes and lead to a better quality of life.

One important source of these services is Early Intervention (IDEA Part C). New Jersey has a very strong Early Intervention Services (NJEIS) program which provides over 1.5 million service hours a year to over 30,000 children from birth to age three. Children are provided developmental evaluations by qualified professionals. The evaluation provides information in six developmental areas: gross motor, fine motor, cognition, communication, social-emotional, and adaptive skills.ⁱ A child experiencing delays in development does not need to have a formal clinical diagnosis to be eligible for Early Intervention; therefore, many children can receive these important early services.

To ensure that all children in New Jersey who are diagnosed with an Autism Spectrum Disorder (ASD) are connected to services, New Jersey created the Autism Registry in 2009, and continues to receive registrations for approximately 3000 children annually. Although the time between when parents and caregivers recognize the early signs of autism and when the child receives a professional diagnosis can be many months. While the March 2020 CDC Morbidity and Mortality Weekly Report (MMWR) Surveillance Summary found that 85% of four-year-old children across three study sites had received a professional evaluation by the age of 36 months and the median age of diagnosis in New Jersey is 3.6 years,ⁱⁱ many of these children may have already been receiving EI or other developmental services.

While obtaining a formal diagnosis is a process that is dependent upon these factors, services and supports for the child and family are available as soon as concerns are raised regarding the child's development. There are several factors that affect the age of first diagnosis. These include:

- The child's individual development
- The presentation and severity of the child's symptoms
- When the parent or caregiver first notices symptoms
- The primary care provider's ASD screening efforts

- The availability of qualified diagnosticians.

To better understand if children are getting services even before a formal diagnosis, a previous multiple-year (2001-2008) comparison of NJEIS and Autism Registry data showed that nearly 60% of children registered with autism had received EI servicesⁱⁱⁱ. As the rate of Autism has continued to increase in New Jersey, this examination builds on the previous work by examining children born from 2007 through 2014, and considers two questions: How many children received Early Intervention services prior to a formal diagnosis, and what factors are related to receiving those early services?

Methods

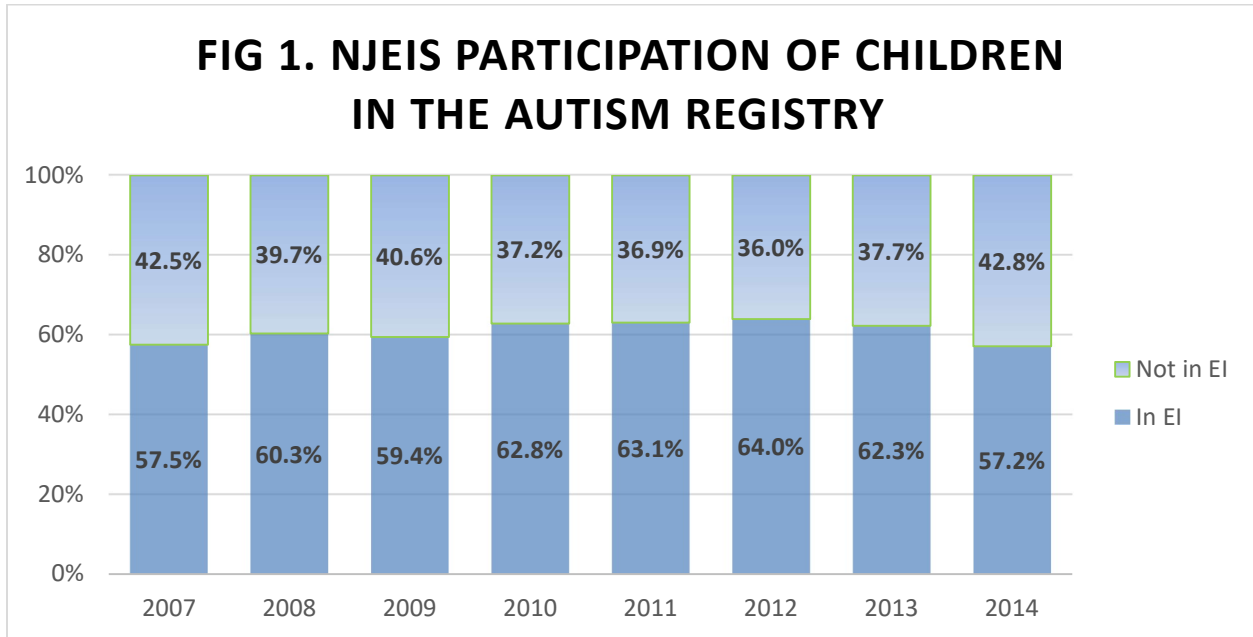
To determine if children diagnosed with autism received EI services, Autism Registry data from children born between 2007-2014 were matched to NJEIS data. Since the Autism Registry rules were promulgated in September of 2009, staff has been educating providers regarding their mandate to register children with autism that they either diagnose or follow. In this way, we assure both the newly diagnosed and the previously diagnosed are registered. In 2009 when the registry began, the earliest cohort (2007) would have been approximately two years of age, eligible by age for NJEIS, and most likely not yet diagnosed for autism. These birth cohorts are most likely to be included in the Registry, as it was well-established by the time they presented for diagnostic evaluations. The match did not include children born after 2014 as these children may not have been diagnosed yet.

The Autism Registry provided 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 included both children that were diagnosed with autism and those without a formal diagnosis. As NJEIS does not require a diagnosis, children are evaluated on the extent of developmental delays.

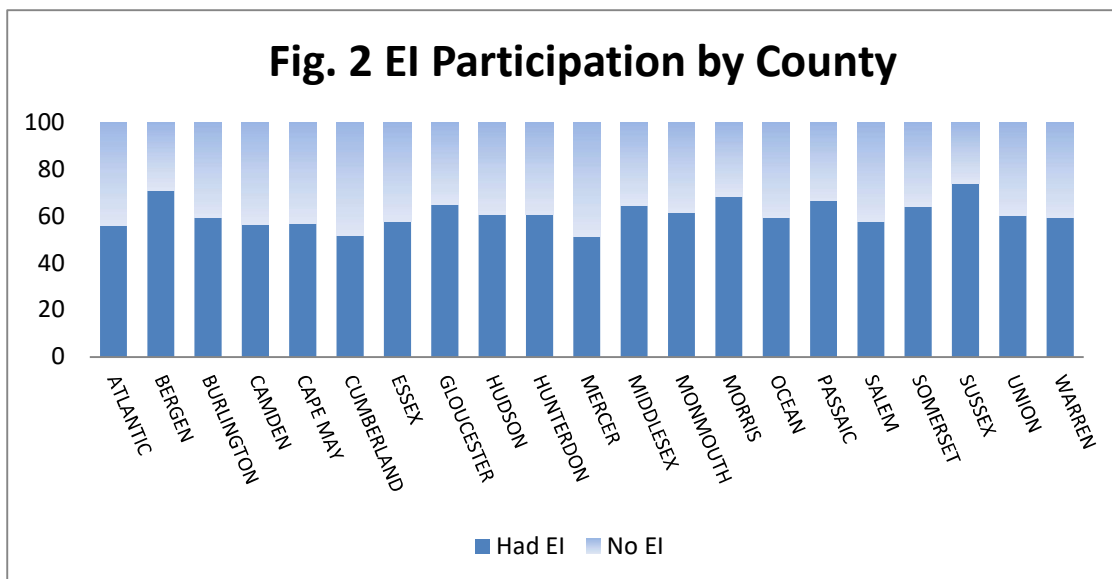
Results

The Autism Registry provided data for 13,682 registered children born between 2007 and 2014. Of these children, 7760 or 56.7% were found to have participated in the NJEIS. The percentage of

children registered with autism AND who received EI services has remained stable over the last 7 years at just under 60% (Fig.1.)



These participation rates significantly vary by county of birth. Bergen, Morris, and Sussex have the highest rates, while Atlantic, Cumberland, and Mercer have the lowest rates (Fig. 2.) As NJEIS participation is voluntary and may include a family cost share, these differences may be attributed to socioeconomic factors.

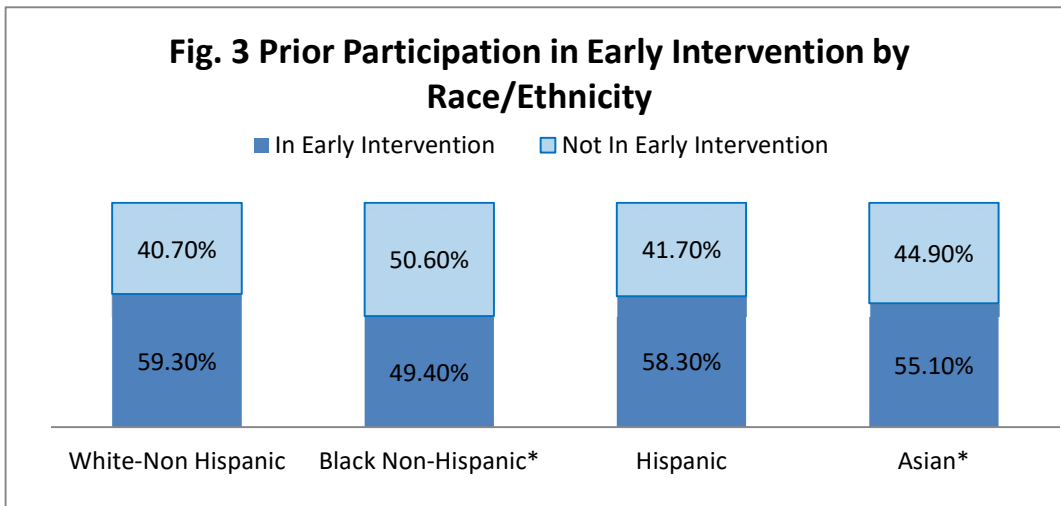


While we cannot provide information for those families who elect not to use NJEIS services, we can compare those children who did receive EIS services to those who did not to better understand what factors are related to receiving NJEIS services. These factors include:

- Race and Ethnicity
- Birth Factors
 - Weight
 - Gestational age
 - Plurality (single birth vs. multiple)
- Other comorbidities such as birth defects

Race and Ethnicity

In terms of race and ethnicity, we see that Black Non-Hispanic and Asian children were significantly less likely to have received NJEIS services (see Figure 3.)



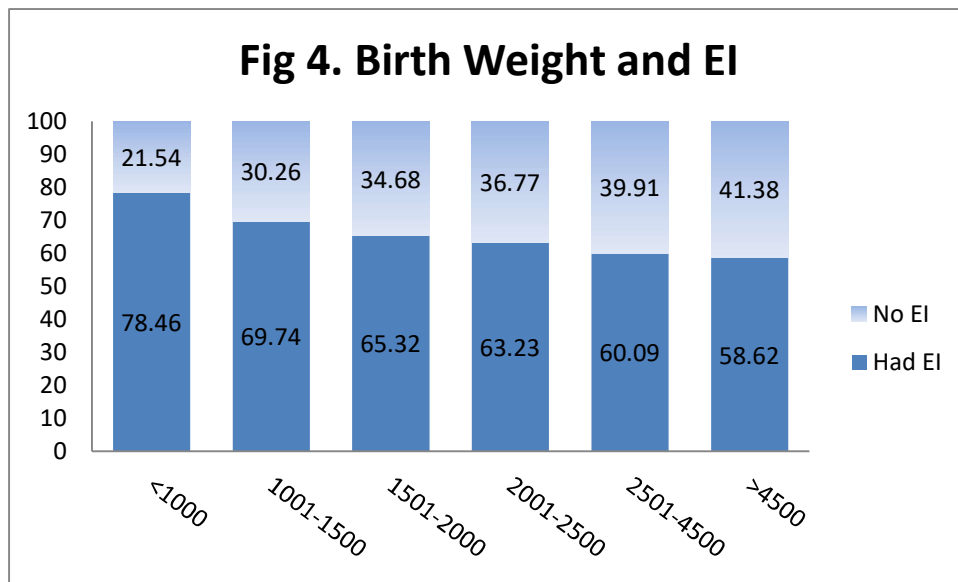
Birth Factors

Premature birth, low birth weight and being a multiple are all risk factors for delayed development. Therefore, babies born with these risk factors may be more likely to be referred to Early Intervention even before autism symptoms might be noticed by caregivers. Moreover, there is an interrelationship between birth weight, gestational age, and plurality (single birth vs. multiple). For

example, twins are more likely to be born prematurely and weigh less than their singleton counterparts.

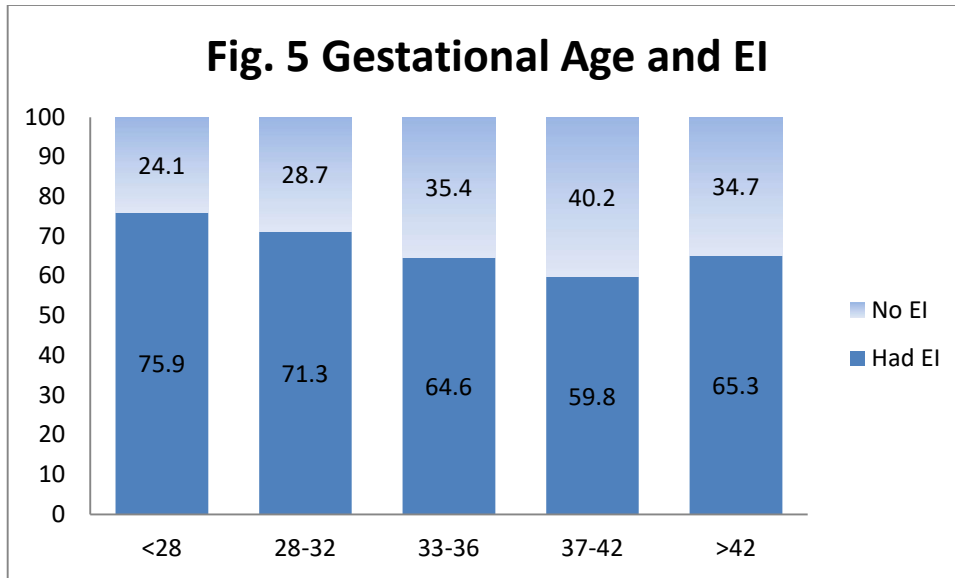
Birth Weight

Among children with autism, lower birth weights were significantly related to receiving NJEIS services (Figure 4.) Those born with very low birth weights (<1500 grams) were much more likely to have received NJEIS.



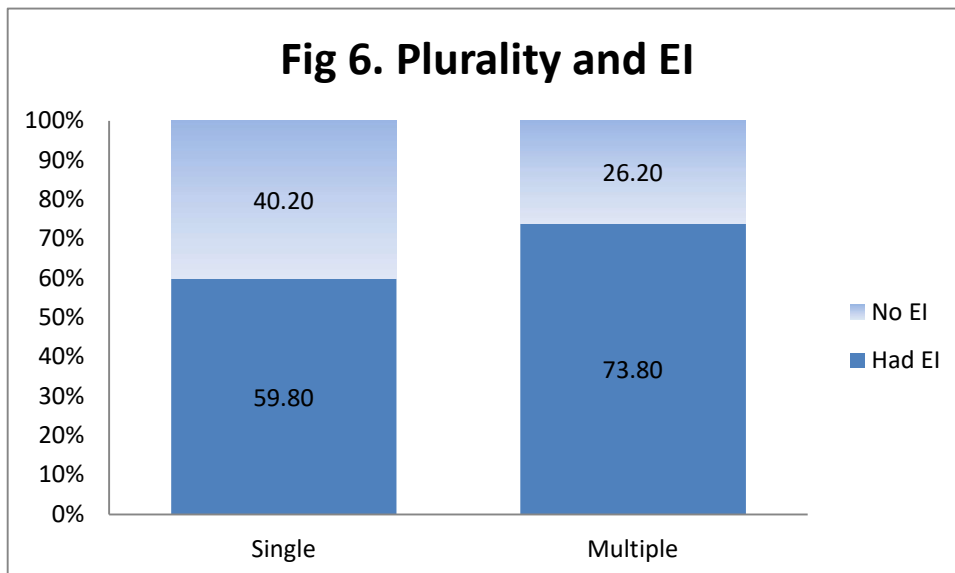
Prematurity

Children born prematurely are also more likely to be referred to NJEIS. Among children with autism, those born before 37 weeks of gestation were significantly related to receiving EI services (Figure 5.). Approximately 73% of those born prior to 33 weeks received EI, in comparison to about 60% who were full-term.



Plurality

Among children with autism, being a twin or triplet is significantly related to being referred to NJEIS. Approximately 75% of twins and triplets received EI, in comparison to about 60 percent who were single births (Figure 6.)

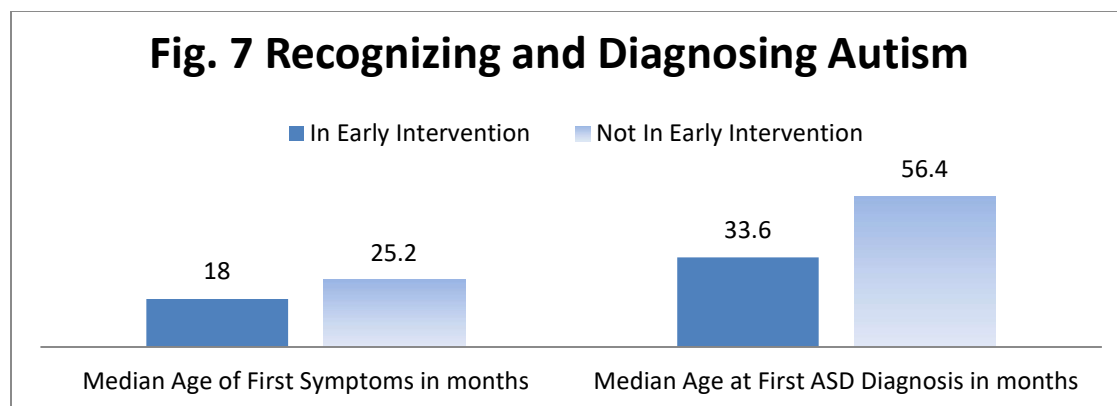


Not unexpectedly, children who were born with a reportable birth defect were significantly more likely to have EI services than children who were not. While only 2% of the children with autism also

had a reportable birth defect, 92% of these children had received NJEIS services. Ear and orofacial birth defects were not significantly ($p=.07$) related to receiving services.

These birth-related risk factors may have increased the likelihood that children who were later diagnosed with autism may have participated in NJEIS, not because of recognizable autism symptoms, but because of developmental delays related to these birth factors. Indeed, many children who were later diagnosed with autism did not have these birth-related risk-factors. Among children who had no birth-related risk factors, early signs of autism are related to increased NJEIS participation. For those children who showed early symptoms noticed by a caregiver or a provider is significantly related to NJEIS participation. In fact, 50% of the children who had NJEIS were noted as having early signs of autism by 18 months. In contrast, among those children who did not have EI services, the median age of symptoms was 25.2 months (Fig 7.)

Although NJEIS does not require a diagnosis for children to receive services, those who had EI were diagnosed significantly earlier than those who did not. The median age of diagnosis for those in NJEIS was 33.6 months, while those who did not participate in EI were diagnosed at 56.4 months. These differences may be related to the severity of the autism, but it could be related to being engaged with the NJEIS system. While EIS providers do not diagnosis children with autism, they are engaging with the families. Moreover, as the children turn three, they receive exit evaluations which may or may not suggest seeking additional services through the specialized preschool programs (Part B of IDEA.) At this time, the children are often evaluated and diagnosed as they move to the school system.



While race/ethnicity, birth-related risk factors, and other comorbidities are related to autism and NJEIS participation, we were interested to see which risk factors were most likely to predict NJEIS use^{iv}. Our

analysis shows that black children were about half (54%) as likely as white children to have participated in NJEIS. Similarly, but to a lesser extent, Hispanic and Asian children were 16% and 17% less likely than white children to participate in NJEIS services. Age at first autism diagnosis was also related, with children who were diagnosed earlier than their peers being 54% more likely to participate in NJEIS. Children born prematurely were also more likely to participate into NJEIS. Specifically, for each week of prematurity, the child was 5% more likely to be in NJEIS. Children who were twins or triplets (multiple vs. single birth) were 35% more likely to be in NJEIS. Children born with a congenital birth defect were almost three times more likely to participate in NJEIS services compared to children who only had an ASD diagnosis.

Effect	Point Estimate	95% Wald CI lower	95% Wald CI upper
Child Race: Black	0.539	0.469	0.618
Child Race: Hispanic	0.841	0.753	0.939
Child Race: Asian	0.826	0.684	0.997
Age of initial Autism Diagnosis	0.541	0.525	0.558
Gestational Age	0.945	0.925	0.967
Plurality: Multiple	1.371	1.098	1.711
Congenital Birth Defect	2.775	2.208	3.486

The birth-related risk factors and the presence of other conditions are related to increased use of NJEIS. Due to these factors, these children would most likely be experiencing more pronounced developmental delays or more likely to be "noticed" or screened for delays. Since these factors are also apparent and recorded at birth, providers and caregivers might be more attuned to monitoring the child for developmental issues which would prompt the need for early intervention. Additionally, children born with these risk-factors might exhibit early and more profound symptoms of autism. This would also explain the why some children are diagnosed earlier than others. In contrast, children with no birth-related risk factors may not be noticed as early, thus missing the opportunity for EI services or they exhibit fewer profound symptoms which delays their diagnosis. For example, speech and language delays are major autism markers, so if a child is not exhibiting significant delays, they may not be referred for EI services. Moreover, it may be that they are not referred for diagnosis until later as the child enters school or preschool settings.

Several factors also contribute to overall use of NJEIS. While families can contact NJEIS directly, most children are referred to NJEIS by their primary care provider or pediatrician. To be eligible for services, children are evaluated in terms of their level of developmental delays by multi-disciplinary teams. NJEIS is also a voluntary program with a family cost share based on the federal poverty level. Most families have a zero or minimal (\$2) cost share per services.

Discussion

Overall, about 60% of children are receiving services through the NJEIS prior to obtaining an Autism Spectrum Disorder (ASD) diagnosis. This percentage has remained very stable over time. There may be several reasons for this stability. First, NJEIS is a voluntary program with a cost share per service based on the family's income. Some families may choose private services instead of NJEIS services. Second, NJEIS services are only available until the child turns three; therefore, if the child is not recognized as having delays, they would miss the window of opportunity. After the age of three, children could receive services through specialized preschool programs (IDEA Part B administered by the Department of Education). Third, some children with autism are diagnosed later in childhood because their deficits are milder and may go unnoticed until later in childhood.

Although all children referred to NJEIS must be evaluated, they must meet a threshold criterion for services. 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 NJEIS (e.g., significant communication issues). In addition, children who present 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. For example, children with level one autism (previously defined as 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.

As expected, children who had risk factors for developmental delays were more likely to have received Early Intervention services. However, these risk factors precede the expression of autism symptoms. Prematurity and being a multiple are associated with early intervention participation. Birth defects, although rare, are also predictive of early intervention. These risk factors would be identified well before the expression of autism. Children who display early signs of autism are also

more likely to benefit from early intervention.

The finding that race is a factor was somewhat surprising as there are no race/ethnic difference in the general NJEIS population, and neither the New Jersey Autism registry nor the CDC New Jersey study site found significant differences between race and ethnic groups for overall prevalence of autism. However, there is a difference for age of diagnosis with non-whites being diagnosed later than their white counterparts. The age of formal diagnoses disparity might explain this finding except, in general, NJEIS does not have a disparity.

In closing, we see that most children in the autism registry had received services before the age of three through our Part C Early Intervention program. Moreover, several birth-risk factors predicted use of NJEIS. These findings will help to inform parents and providers about the importance of risk factors and again underscores the importance of screening and referral to services.

For more information, please contact:

New Jersey Autism Registry
www.nj.gov/health/fhs/autism/
609-292-5676

ⁱ Following the evaluation/assessment, an Individualized Family Service Plan (IFSP) is developed for eligible children which describes 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 childcare setting. Developmental Intervention, discipline-specific therapies and family support services are incorporated into IFSPs based on the child and family's assessment information.

ⁱⁱ For a more detailed look at findings from the Autism Registry, download our report at <https://nj.gov/health/fhs/autism/public/registry/>

ⁱⁱⁱ The previous analysis of Autism and Early Intervention is available at <https://nj.gov/health/fhs/autism/public/registry/>

^{iv} A logistic regression model was used to examine the characteristics of children who participated into EI services versus those who did not participate into EI services.