



Early Identification of
Autism Spectrum Disorders:

Guidelines for Healthcare Professionals in New Jersey



Jon S. Corzine
Governor



Heather Howard
Commissioner



A Message from Commissioner Howard

In September 2007, New Jersey Governor Corzine signed into law P.L. 2007, c.172 directing the Department of Health and Senior Services (DHSS) to disseminate guidelines for health care professionals to use in evaluating infants and toddlers for health care professionals to use in commonly called autism. The goals of this legislation are 1) the early and accurate identification of children with Autism Spectrum Disorders (ASDs), and 2) the referral of identified children to appropriate services in a timely manner.

If you are reading this document you are most likely a healthcare professional committed to the well being of children in New Jersey; welcome. As a part of the cadre of professionals caring for children and families in hospitals, clinics, private practices, community settings and homes, you are the audience these guidelines are intended to reach. You are a professional whom parents trust with the physical and developmental health of their child. You are also a key partner in helping children with autism grow, learn and flourish by being in a position to give them an early start to appropriate interventions and treatment. By collaborating with parents and families, educators and schools, community organizations, early intervention staff, therapists, and advocacy organizations you can help put the puzzle pieces of the life of a child with autism into place. Putting the pieces together starts with early identification and referral. This guide will help you in that endeavor.

I want to thank you for your hard work and dedication to improving the health of the residents of our State.

With Best Wishes

A handwritten signature in blue ink that reads "Heather Howard".

Heather Howard

Autism Spectrum Disorders

Guidelines for Healthcare Professionals in New Jersey

Table of Contents	i
Purpose and Scope	1
About Autism	2
Signs and Symptoms	2
Prevalence	3
Developmental Surveillance and Screening	5
Role of the Physician and Healthcare Professional	7
Figure 1: Practice Parameter Medical Home Providers	9
Making Referrals in New Jersey	10
Diagnostic Evaluations	11
Child Evaluation Centers	11
Clinical Enhancement Centers	11
Autism Specialty Schools and University Based Clinics	11
Private Practice Physicians/ Professionals	12
The New Jersey Early Intervention System	13
The New Jersey Autism Registry	14
Appendices	
A. Sample Screening Tools	15
B. Child Evaluation Centers	17
C. Clinical Enhancement Centers	18
D. Autism Specialty Schools and University Based Clinics	19
References	20





Acknowledgements

The DHSS appreciates the organizations and persons who participated in the stakeholder meeting which took place during the initial planning stages of these guidelines. The Department would like to thank them for their engagement, advice and review of materials.

Denise Aloisio, MD
Jersey Shore Medical Center

Jennifer Blanchette-McConnell, Ph.D.
Regional Early Intervention Collaborative

Marilyn Dunning, MA
Early Childhood Consultant

Caroline Eggerding, MD
Bancroft NeuroHealth

Randy Huron, MD
Hackensack University Medical Center

Yvette Janvier, MD
Children's Specialized Hospital

Walter Kalman, MSW, LSW
National Association of Social Workers\New Jersey Chapter

Audrey Mars, MD
Hunterdon Medical Center

Mark Mintz, MD
The Center for Neurological and Neurodevelopmental Health

Janice Pronnicki, MD, MPH FAAP
American Academy of Pediatrics/New Jersey Chapter

Grace Reilly, RN, MSN, APNC
New Jersey State Nursing Association

Barbara Tkach, M.Ed.
New Jersey Department of Education

Barbie Zimmerman-Bier, MD
University of Medicine and Dentistry of New Jersey
New Jersey Medical School

Autism New Jersey
Autism Speaks/
Central New Jersey Chapter
Statewide Parent Advocacy Network, Inc.

The New Jersey Department of Health and Senior Services (DHSS) is responsible for the information contained in this document. This report was prepared by a core team at the DHSS comprising:

Susan Evans, Ed.D
Autism Project Specialist
Special Child Health and Early Intervention Services

Marilyn Gorney-Daley, DO, MPH
Medical Director
Special Child Health and Early Intervention Services

Gloria M. Rodriguez, DSW
Director
Special Child Health and Early Intervention Services

Terry Harrison, M.Ed.
Part C Coordinator
Special Child Health and Early Intervention Services

Additionally, the DHSS thanks the following staff within Special Child Health and Early Intervention for their contributions:

Celeste Andriot-Wood, MA

Leslie Beres-Sochka, MS

Betsy Collins, RN MSN

Michael Gallo, Ph.D.

Sandra Howell, Ph.D.

Mary Knapp, RN MSN

Pauline Lisciotto, RN MSN

Karen Melzer, M.ED.

Purpose & Scope

The Department of Health and Senior Services (DHSS) has published this guide for Medical and Healthcare Professionals* as one method of disseminating and promoting best practices concerning the early identification, screening, and referral of children suspected of having autism within New Jersey. The term autism is herein used in an inclusive manner to mean any one of the three disorders (Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Asperger's Disorder) described in the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revised, 2000*¹ under the category of Pervasive Developmental Disorder and commonly referred to as Autism Spectrum Disorders (ASD). This guide does not specifically address the Pervasive Developmental Disorders of Rett Syndrome or Childhood Disintegrative Disorder (CDD) as these disorders have unique developmental profiles and etiologies. However, the basic recommendations are appropriate for children with these developmental disorders as well.

In 2006, the American Academy of Pediatrics (AAP) published the policy statement *Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening*.²

The AAP policy statement *Identification and Evaluation of Children with Autism Spectrum Disorders*³ followed in 2007 and built upon the 2006 paper by including specific recommendations for surveillance and screening for the early identification of autism. It is important for healthcare

professionals to be able to recognize signs and symptoms of autism in children and have a plan for assessing, screening and referring children to the appropriate resources in their New Jersey communities.

* State statute defines a Healthcare Professional as:
“ A person licensed or otherwise authorized and pursuant to Title 45 of Title 52 of the Revised Statutes, to practice a health care profession that is regulated by the Director of the Division of Consumer Affairs by one of the following boards: the State Board of Medical Examiners, board of Nursing, the New Jersey State Board of Dentistry, the New Jersey State Board of Optometrists, the New Jersey State Board of Pharmacy, The State Board of Chiropractic Examiners, The Acupuncture Examining Board, The State Board of Physical Therapy, The State Board of Respiratory Care, The Orthotics and Prosthetics Boards of Examiners, The State Board of Psychological Examiners, The State Board of Social Work Examiners..., The Audiology and Speech-Language Pathology Advisory Committee..., the Occupational Therapy Advisory Council and the Certified Psychoanalysts Advisory Committee.”





The New Jersey Department of Health and Senior Services endorses the recommendations contained in both the 2006 and 2007 policy statements of the American Academy of Pediatrics and encourages the adoption of the recommended practices by all medical home professionals involved in the routine care of young children.

A third policy statement *Management of Children with Autism Spectrum Disorders*⁴ was also released by the AAP in 2007, however the content of that paper is beyond the scope of these guidelines. The reader is directed to the source document for further information on interventions, treatment and management options for children diagnosed with autism. The clinical reports of the AAP can be accessed via the AAP website: www.aap.org. In addition, the document *Technical Assistance: Part C Early Intervention Services for Children with Autism Spectrum Disorders in New Jersey 2009*⁵ is a helpful resource for understanding the New Jersey Early Intervention System (NJEIS) and how services may be provided to families of children with autism, under the age of three. The guidelines are available on line at www.state.nj.us/health/fhs/eis/index.shtml

Presented here is the information and resources needed by New Jersey's health care community to meet the AAP recommendations and to further fulfill their obligations to the health and well being of the young children in the state.

About Autism

Autism is a complex and pervasive developmental disorder characterized by varying degrees of impairment in communication skills, social interactions and the presence of restricted, repetitive and stereotyped behaviors, interests and activities. The medical cause or causes of autism is currently unknown; therefore the condition is identified and diagnosed based upon behavioral testing and clinical observation with the symptom presentation compared against the criteria found in the *Diagnostic and Statistical Manual of Mental Disorders-Fourth edition Text Revised*.

Signs & Symptoms

The National Research Council in its 2001 report [Educating Children with Autism](#) explained that "the manifestations of autism vary considerably across children and within an individual child over time. There is no single behavior that is always typical of autism and no behavior that would automatically exclude an individual child from a diagnosis of autism, even though there are strong and consistent commonalities, especially relative to social deficit."⁶ While there is recognized heterogeneity and differences in onset of symptoms in autism, there are several behavioral indicators that have been identified as consistent indicators of autism.

The Child Neurology Society has identified that any of these red flags in young children are signs for **immediate** referral⁷:

1. **No babbling by 12 months;**
2. **No pointing or gesturing by 12 months;**
3. **No single words by 16 months;**
4. **No two word phrases by 24 months; and**
5. **Loss of previously acquired skills, especially language.**

Additionally, the presence or absence of any of these behaviors or a combination of these behaviors should also trigger a referral:

- ❖ Lack of joint attention (Child does not draw other's attention to objects in the environment);
- ❖ Child does not respond to his/her name;
- ❖ Lack of pretend, imitative and functional play appropriate to developmental age;
- ❖ Failure to develop peer relationships appropriate to developmental age;
- ❖ Child does not imitate others' behaviors;
- ❖ Child is rigid in routines or has very difficult transitions;
- ❖ Child engages in repetitive or stereotypical behavior;
- ❖ Child has unusual responses to sensory stimuli;

- ❖ Child has trouble relating to others or not have an interest in other people at all;
- ❖ Child avoids eye contact and wants to be alone;
- ❖ Child appears to be unaware when other people talk to them but responds to other sounds;
- ❖ Child repeats or echoes words or phrases said to them, or repeat words or phrases in place of normal language (echolalia); and
- ❖ Persistent family concerns.

Prevalence

Autism is not rare. In 2007, the Centers for Disease Control and Prevention (CDC) established a prevalence rate in 8 year old children as 1 in 150 in the fourteen states studied.* NJ had the highest rate among all the study states with an established rate of 1 in 94 children.⁹ The Interagency Autism Coordinating Committee, the lead body responsible for coordinating autism activities within the Department of Health and Human Services, recognized that autism has emerged as a national health emergency.¹⁰

* Fourteen states included: Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, West Virginia, & Wisconsin.

About Regression...

Skill loss of any kind, but in particular the loss of language and social communicative behaviors (pointing, waving bye-bye, etc) is a well documented occurrence in approximately 25 percent of children with autism⁸. Parental report or clinical observation of skill loss always indicates the need for further evaluation of the child. Healthcare providers should be cautious about attributing concerns of regression to a variable outside of the child (i.e. birth of a sibling, divorce, etc.)



Autism is four times more likely to appear in boys than in girls. It is more common among children than cancer, diabetes, and AIDS combined and occurs in all racial, ethnic, and social groups. Currently, there are no clear answers to the question of “*why*” the current prevalence rate has changed dramatically over the past decade. Changes in the criteria used to diagnose autism, an increased recognition of the disorder by

professionals and the public, and an increase in the disorder among children may all be contributing factors to the rates now being reported. While scientific research continues to examine the causal factors in autism, an abundance of clinical research has provided guidance on “what to do” with children who display the signs and symptoms of autism, the success of which all rely on early detection measures and appropriate intervention.

Autism can be detected early and trained professionals can make a reliable and stable diagnosis by age two,^{11, 6} yet the national average age of diagnosis remains between the age of four and five.⁹ Parents consistently report having concerns about their child’s development before the third birthday^{12, 13, 14} but find barriers to diagnosis

beginning with physicians delays in referral^{15, 16}. Delays between parental concerns and an accurate diagnosis can result in potentially deleterious effects on the child’s development as typically there are accompanying delays in the start of appropriate interventions which may ultimately improve the child’s functioning.

According to the CDC, 17 percent of children in the United States have a developmental or behavioral disability and many more have delays in language or other areas, which can impact eventual school readiness. Less than 50 percent of these children are identified as having a problem before starting school, increasing the likelihood of more significant delays and missed opportunities for specialized interventions.¹⁷ Research consistently demonstrates that the initiation of appropriate interventions as soon as autism is suspected improves long-term outcomes with those interventions begun at earlier ages being more effective than those begun at later ages.¹⁸⁻²¹

Given the state of the science regarding the ability to detect and intervene in developmental delays and in particular autism, the “wait and see” approach applied in the past can no longer be considered the appropriate course of action.

Developmental Surveillance and Screening

Developmental surveillance and screening are distinct processes that work in tandem to ensure healthcare providers are properly identifying those children who may be at risk for developmental delays. **Surveillance**, the systematic collection, analysis and interpretation of developmental information, is done on a continuous basis while **screening** uses standardized measure(s) to detect the presence or absence of delays and to refine the risk.

Both surveillance and screening are vital to identifying developmental delays in children and in particular, children with possible autism.

Healthcare providers carry out **surveillance** activities related to a child’s development by:

- ❖ Maintaining an updated family history;
- ❖ Asking open ended, age-appropriate questions about a child’s development which include topics beyond physical growth measures;
- ❖ Listening to parental concerns;
- ❖ Observing a child’s behavior during visits including:
 - Back and forth social interactions between child & caregiver
 - Presence of babbling (4+ months)
 - Presence of spoken or approximation of spoken words (12+ months);

- ❖ Interacting with the child during the visits with attempts to elicit
 - Response to name (12+ months)
 - Following a point (12 +months)
 - Social interactions appropriate to age.

Using an appropriate, standardized screening tool in conjunction with surveillance

activities increases the accuracy of identification of children with and without delays. Glascoe has shown that clinical judgment alone without the aid of a standardized measure, detects fewer than 30 percent of children who have developmental disabilities²³. Therefore, screening should be expected for all children under a provider’s care. In recognizing the limitations of clinical judgment alone, the AAP recommends the administration of a standardized developmental screening tool at 9, 18 and 24 or/30 month visits in primary care settings and DHSS also endorses this practice for providers in New Jersey.

The AAP and DHSS further recommend the use of an autism-specific screening tool at 18 and 24 months for all children. For children with potential autism, the





information from an autism-specific screening tool can provide clearer direction to a family and to the follow-up evaluation team.

To meet these recommendations an array of developmental screening tools are available and healthcare professionals are encouraged to become familiar with them. Tools designed to assess developmental milestones are sufficient to detect delays in language and/or cognitive skills which are often part of the autism diagnosis, however, the specificity of these tools is not sufficient to distinguish between potential autism and other delays and disabilities such as hearing impairment.

A screening measure for use at the universal level is dependent on several features. The measure needs to be psychometrically sound, developmentally appropriate for the patient's age range, easy to administer within the context of the professional practice and be

economically feasible relative to time, cost and other resources. A sample list of appropriate general and autism-specific screening tools is listed in Appendix A of this document.

The Commonwealth Fund, a private foundation concerned with health care issues, has published a manual for pediatric practices entitled Pediatric Developmental Screening: Understanding and Selecting Screening Instruments²³ which may be downloaded from their website: www.commonwealthfund.org.



Age in Months	Surveillance Activities	Formal Screening
2	X	
4	X	
6	X	
9	X	Standardized tool for general development
12	X	
15	X	
18	X	Standardized tool for general development + ASD specific screener
24	X	Standardized tool for general development + ASD specific screener
36	X	
48	X	
60	X	

Role of the Physician and Healthcare Professional

By preparing these guidelines, the DHSS is reaffirming to physicians and healthcare providers the importance of early detection, referral and intervention for children suspected of developmental delays, particularly autism. For families, having a diagnosis is important to understanding their child's developmental differences and delays, and can be helpful in accessing necessary resources for intervention. Even the youngest of children have supports and services available to them and interventions started early can result in considerable cost savings to both the family and the systems that serve them. Medically, diagnostic information allows for counseling regarding recurrent risk for siblings and for etiologic investigation.³

A comprehensive evaluation for autism by a multi-disciplinary team should include clinical observation of the behavioral presentation, the completion of one or more autism diagnostic instruments, parent interview, developmental and familial history, plus an assessment of



cognitive and communication skills. Medical considerations are dependent on individual symptom presentation but may include metabolic testing to rule out untreated metabolic disorders, tests for genetic disorders and investigation for epilepsy if seizures are suspected clinically or if there is a history of regression.^{3,6}



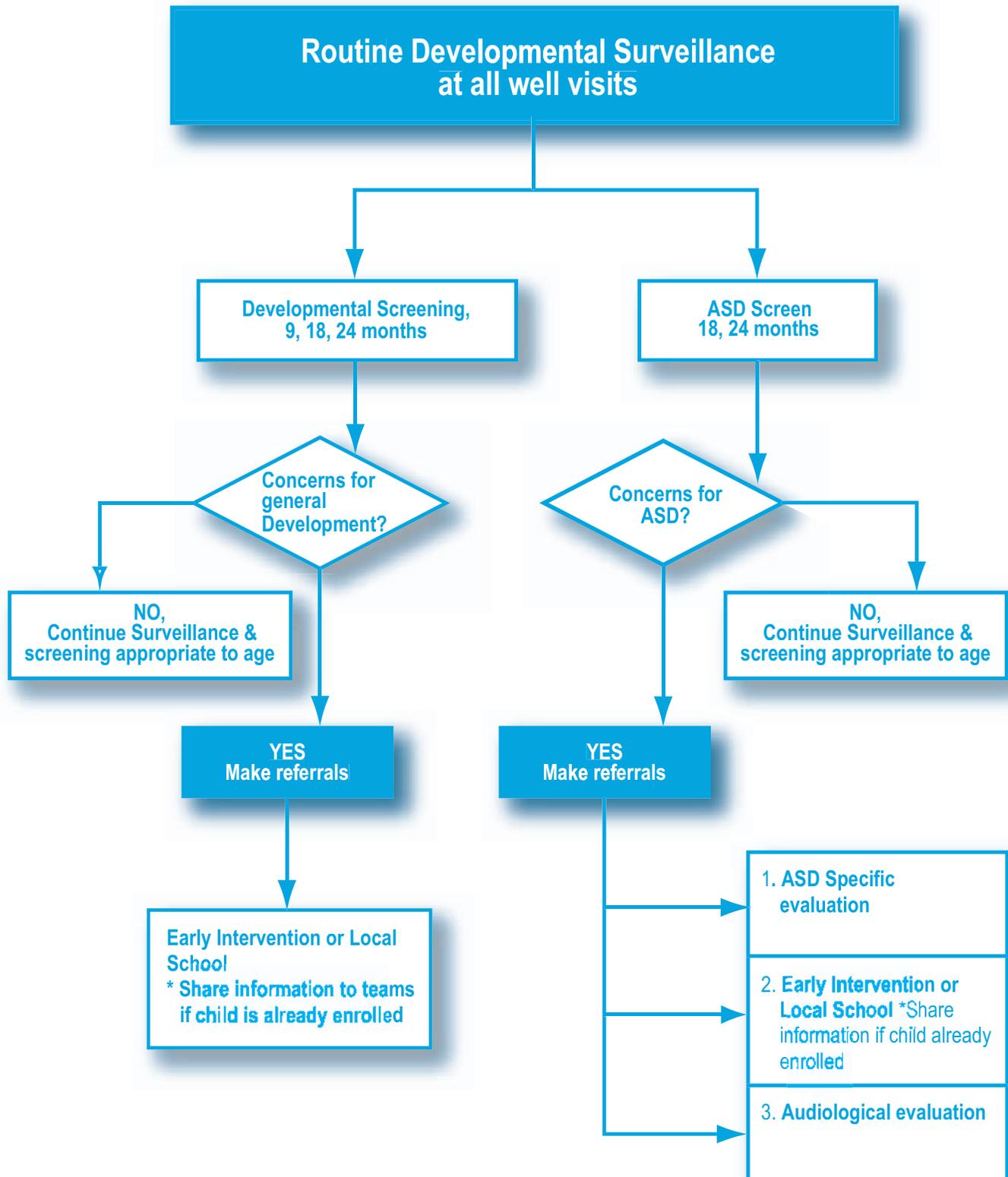
Specifically, **Medical Home Professionals** in New Jersey should:

1. Provide routine developmental surveillance of children during all well-child care visits;
2. Conduct developmental screening tests at the 9, 18 and 24 or/30 month visits or at any time a parent expresses concerns, to identify those at risk of atypical development;
3. Administer an autism-specific screening for children at 18 & 24 months (regardless of risk-factors);
4. Immediately refer when surveillance and screening results indicate possible autism. Referrals should be made for:
 - a. A comprehensive autism evaluation (NJ resources listed in Appendices);
 - b. Evaluation by the New Jersey Early Intervention System (birth to age three) or the Local Education Authority (over age three); and
 - c. An audiological evaluation.

Specifically, **Healthcare Professionals** in New Jersey should:

1. Know the signs and symptoms of autism; (described herein)
2. Be familiar with at least one autism-specific screening tool appropriate for children over the age of 18 months (found in Appendix A);
3. Know the resources available for families in the public, private and medical sectors found in the appendices of this guide; and
4. Should recommend to families of children where there is concern for autism:
 - a. Follow-up visit with medical home
 - b. Comprehensive autism evaluation
 - c. An evaluation by the New Jersey Early Intervention System (birth to age three) or the Local Education Authority (over age three)
 - d. Audiological Evaluation

Figure 1
Practice Parameter Medical Home Providers





Making Referrals in New Jersey

When surveillance and screening activities result in concerns for possible autism, (or developmental delay) the healthcare provider's next steps are dependent on several factors.

1. Are these results from within the Primary Care Physician's office or Medical Home?
 - a. Yes - **REFER** to sub-specialty for full autism evaluation
 - b. No - **REFER** to Primary Care Physician AND sub -specialty for full autism evaluation



2. Has the child recently had audiological evaluation? (within 3 months)
 - a. Yes - investigate results of recent testing
 - b. No - **REFER** for audiological evaluation to rule out hearing difficulties
3. Is the child currently enrolled in an intervention program?
 - a. Yes - provide current information regarding concerns to parents to share with program staff
 - b. No - **REFER** to New Jersey Early Intervention System for eligibility evaluation (children 0-3) or **REFER** to the Local Educational Agency (school district) for children ages 3+.

Diagnostic Evaluations

New Jersey offers multiple resources for families in need of a complete diagnostic evaluation for autism.

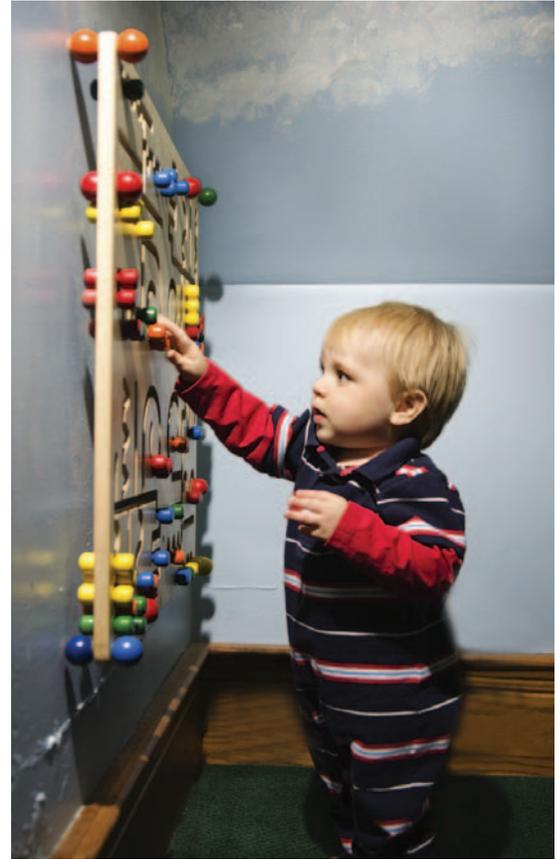
Child Evaluation Centers

Through a statewide network, New Jersey has eleven **Child Evaluation Centers** which provide comprehensive, multidisciplinary evaluations of children with congenital or acquired neuro-developmental and behavioral disorders and the development of an individualized service plan. Cost of a diagnostic evaluation is the responsibility of the patient and each clinical site varies in their fees, however no child shall be denied access to these services due to the absence of third party coverage or inability to pay. Families should contact the evaluation team directly to determine their options regarding insurance, sliding scale fees, private pay or other funding sources. Contact information is listed in Appendix B.

Clinical Enhancement Centers

The Governor's Council for Medical Research and Treatment of Autism has awarded grants to six programs throughout the state in order to provide for supplementary resources and expertise in the diagnosis of children with autism. Cost of a diagnostic evaluation is the responsibility of the patient and each clinical site varies in their fees, however no child shall be denied access to these

services due to the absence of third party coverage or inability to pay. Families should contact the evaluation team directly to determine their options regarding insurance, sliding scale fees, private pay or other funding sources. Contact information is listed in Appendix C.



Autism Specialty Schools & University-Based Clinics

New Jersey has a few private schools and university-based clinics that provide diagnostic services through their outreach/community divisions. Diagnosticians associated with private schools and/or university-based programs are limited by scope of practice to their expertise and training in the diagnosis of autism and are unable to prescribe or execute medical testing such as blood work, EKGs, or other medical work-ups that may otherwise be available under a medical setting. As diagnostic services are not conducted in a medical setting, use of



insurance may be more limited. Those limitations aside, these programs are a valuable resource for diagnostic services. Cost of a diagnostic evaluation is the responsibility of the patient and fees vary by site. Families should contact the program directly to determine their options regarding insurance, sliding scale fees, private pay or other funding sources. Contact information is listed in Appendix D.

Private Practice Physicians/ Professionals

A Developmental Pediatrician, Pediatric Neurologist, Child Psychologist or Psychiatrist may be another resource for diagnostic evaluations for autism. However, while these professionals can be excellent resources in many instances, not all have specific training or expertise in the diagnosis of autism. Families and referring physicians should indicate the reason for referral is concern for autism. Cost of a diagnostic evaluation is the responsibility of the patient and each practice varies in fees and insurance requirements. Families should contact the professional directly to determine options regarding insurance,

sliding scale fees, private pay or other funding sources. These state and national advocacy organizations keep a list of contact information for physicians that specialized in the diagnosis of autism and the geographic area in which they are located:

Autism New Jersey, New Jersey-based resources for diagnostic services www.autismnj.org

Autism Society of America, resources listed under the “Autism Source” section. Search nationwide autism-related services and supports by location or service type. www.autism-society.org

Autism Speaks, national resources indexed by state under the “Community” section www.autismspeaks.org

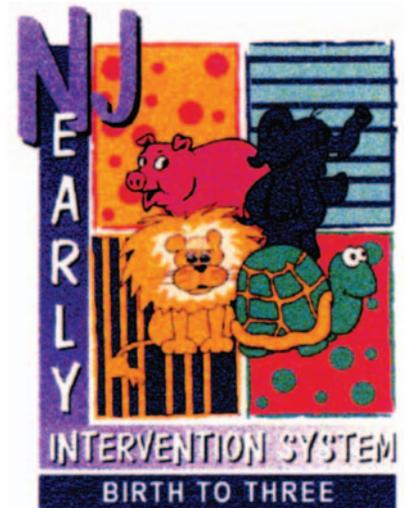


The New Jersey Early Intervention System

Referral to the New Jersey Early Intervention System (NJEIS) can and should be initiated as soon as developmental delay and/or autism is suspected by the medical home, health care professional or parent. The DHSS is the lead agency for the Early Intervention System in New Jersey.

NJEIS does not require a diagnosis of autism for entry into the program. Upon referral, the child's information is gathered and a team of evaluators is charged with determining the child's eligibility for the system. NJEIS eligibility criteria are 1) a 25 percent delays in two or more developmental areas or a 33 percent delay in one area or 2) a score of at least 2.0 standard deviations below the mean in one area or 1.5 standard deviations below the mean in 2 areas when evaluated with

an appropriate standardized instrument. Children are evaluated by a multi-disciplinary team that uses a standardized developmental tool(s), observation, parent interview and clinical opinion to determine eligibility. **Eligibility evaluations are conducted at public expense.** Once a child is determined eligible for NJEIS, the team conducts additional assessment as needed and develops an Individualized Family Service Plan, according to the regulations of N.J.A.C. 8:17., consistent with Part C of the Individuals with Disabilities Education Act (IDEA), 34 CFR Part 303.



The initial evaluation by the NJEIS team is to:

- 1) determine eligibility for NJEIS; and
- 2) determine developmental status of a child for IFSP development

NJEIS evaluation teams do not diagnose children

To make a referral to the NJEIS use the statewide toll-free number:
1-888-653-4463



For questions about the Registry, please contact DHSS at 609-292-5676

New Jersey's Autism Registry

In 2007, the New Jersey State Legislature and Governor Corzine enacted a law that requires the Department to maintain a registry of reported autism diagnoses. Licensed New Jersey health care professionals are required to register any child that they serve who has or meets criteria for a diagnosis of Autism. The child must be a New Jersey resident and be under the age of twenty-two. Registration forms will be available online at: <http://www.state.nj.us/health/fhs/sch/schr.shtml>.

The purpose of the registry is to connect children with special needs to services in their community. Maintaining data on the number of children with autism, will allow DHSS to better understand the extent of autism in New Jersey, enable more comprehensive needs analysis and help plan for services to children and families affected by autism. All information is gathered in complete compliance with the Health Information Portability and Accountability Act of 1996 (HIPAA) and the Department of Health and Senior Service's own Internal Review Board office. The registry collects information on:

- ❖ Demographic information such as the date of birth, gender, and race
- ❖ Contact information such as name and address so that potential services can be offered
- ❖ Diagnosis information
- ❖ Diagnostician's information and information on the person submitting the form.

Once a child is registered, a letter and informational pamphlets are sent to the parent or legal guardian named on the registration, notifying them of the registration and that a Health Services Case Management Unit will also contact them to offer access to family-centered coordinated services.

Families may request that their health care professional not report the personal identifying information about the child such as their name and address. The child's non-identifying information such as sex, month and year of birth, and county of residence will be registered. However, parents that do not allow a child's identifying information to be included the DHSS may be unable to receive referrals from DHSS to important services and resources.

Appendix A

The DHSS has included this sample of appropriate general developmental and autism-specific screening tools as

guidance for individual professional practices to consider.

Screening tool	Age group	Administration	Availability
(Autism Specific) Modified Checklist for Autism In Toddlers (M-CHAT) Robins, Fein & Barton 1999	16-30 months	23 item check-list can be completed by parents alone or administered by staff. Easy to score, Available in Spanish. Follow-up interview required when a positive screen is obtained.	www2.gsu.edu/~wwwpsy/faculty/robins.htm
(Autism-Specific) Social Communication Questionnaire (SCQ)	Over age 4	Parent questionnaire with 40 yes-or-no items. @10 minutes to administer	www.wpspublish.com
Ages & Stages	0-60 months	Pass/fail for four domains, @ 10-15 minutes to administer, parents can complete independently	www.agesandstages.com
Parents Evaluation of Developmental Status (PEDS)	0- 8 years	Screening & surveillance tool completed by parents. @ 2 minutes to score Multiple languages available	www.pedstest.com
Brigance Screens – II	0-90 months	Screens use direct elicitation and observation. The Infant and Toddler Screen can be administered by parent report @10 minutes to administer	www.curriculumassociates.com
Battelle Developmental Inventory Screening Test (BDIST), 2nd Edition	0 - 8 years	Combination of direct assessment, observation, and parental interview. Administration 15-35 minutes. English & Spanish versions available.	www.riverpub.com



The CDC suggests the following information be considered in the choice of a screening tool.

1. **Domain or domains** the screening tool covers. What are the questions that need to be answered? What types of delays or conditions do you want to detect?
2. **Psychometric properties.** The ability of the test to do what it is meant to do.
 - a. The sensitivity of a screening tool is the probability that it will correctly identify children who exhibit developmental delays or disorders.
 - b. The specificity of a screening tool is the probability that it will correctly identify children who are developing normally.

3. **Characteristics of the children.** For example, age and presence of risk factors.
4. **Setting** where the screening tools will be administered. (E.g. physician office, daycare setting, community screening). Screening can be performed by professionals, such as nurses, or teachers or by trained paraprofessionals.

The Commonwealth Fund, a private foundation concerned with health care issues, has published a manual for pediatric practices entitled: [Pediatric Developmental Screening: Understanding and Selecting Screening Instruments](#)²³ which is available on their website at: www.commonwealthfund.org/content/publications



Appendix B

Listed here are the **Child Evaluation Centers** operated in part by DHSS funding.

Cooper University Hospital

Child Evaluation Center
Three Cooper Plaza
Camden, New Jersey 08103-1489
Phone: (856) 342-2257

Jersey City Medical Center

Center for Children with Special Needs
953 Garfield Avenue, 1st Floor
Jersey City, New Jersey 07304
Phone: (201) 915-2059

Jersey Shore University Medical Center

FAS Diagnostic Center
Child Evaluation Center
Medical Arts Building
1944 Rt. 33 Suite 101 A
Neptune, New Jersey 07753
Phone: (732) 776-4178 ext. 2

John F. Kennedy Medical Center

Child Evaluation Center
2050 Oak Tree Road
Edison, New Jersey 08820
Phone: (732) 548-7610

South Jersey Healthcare

FAS Diagnostic Center
Child Evaluation Center
1138 East Chestnut Ave., 3B
Vineland, New Jersey 08360-4893
Phone: (856) 696-1014 or 1035

St. Joseph's Children's Hospital

Child Evaluation Center
703 Main Street
Paterson, New Jersey 07503
Phone: (973) 754-2500

Morristown Memorial Hospital

Child Evaluation Center
100 Madison Avenue
Morristown, New Jersey 07960-6095
Phone: (973) 971-5227

Children's Seashore House of the Children's Hospital of Philadelphia

FAS Diagnostic Center
Child Evaluation Center
4009 Black Horse Pike
Mays Landing, NJ 08330
Phone: (609) 677-7895 ext. 33463

Children's Hospital of New Jersey at Newark Beth Israel

FAS Diagnostic Center
Child Evaluation Center
201 Lyons Avenue
Newark, New Jersey 07112
Phone: (973) 926-4544

Children's Specialized Hospital

FAS Diagnostic Center
Phone: (908) 301-5511
Child Evaluation Center
150 New Providence Rd.
Mountainside, New Jersey 07092
Phone: (888) 244-5373 or (908) 233-3720

UMDNJ New Jersey/ New Jersey Medical School

FAS Diagnostic Center
Child Evaluation Center
185 South Orange Avenue, F509
Newark, New Jersey 07107
Phone: (973) 972-8930



Appendix C

Listed here are the Clinical Enhancement Centers funded by the Governor's Council for Medical Research and Treatment of Autism through 2010. Some sites are also part of the CEC network listed in Appendix B.

The Autism Center
University of Medicine and Dentistry,
New Jersey Medical School
Behavioral Health Sciences
Building F-level
183 South Orange Avenue
Newark, NJ 07103
(973) 972-8930

Children's Specialized Hospital
Toms River
94 Stevens Road
Toms River, NJ 08755
(732) 914-1100

Mountainside
150 New Providence Road Mountainside,
NJ 07092
(908) 301-5579

Hamilton
3575 Quakerbridge, Road,
Hamilton, NJ 08619
(609) 631-2800

Institute for Child Development
Hackensack University Medical Center
30 Prospect Avenue
Hackensack, NJ 07601
(201) 996-5555

Jersey Shore Medical Center
1945 Route 33
Neptune, NJ 07753
(732) 776-4178

**The Center for Neurological &
Neurodevelopmental Health**
1001 Laurel Oak Road
Suite E2
Voorhees, NJ 08043
856-0346-0005

Hunterdon Medical Center
2100 Wescott Drive
Flemington, NJ 08822
(908) 788-6396

Appendix D

The following private schools and university-based programs include health care professionals who have specific expertise in diagnosing autism. The inclusion or the exclusion of a program here should not be taken as an endorsement by DHSS or the lack thereof.

Bancroft NeuroHealth
425 Kings Highway East
Haddonfield, NJ 08033
(856) 429- 0010

Douglass Developmental Disabilities Center
151 Ryders Lane
New Brunswick, New Jersey 08901-8557
(732) 932 - 3902

Eden Family of Services
One Eden Way
Princeton, NJ 08450
(609) 987 - 0099

Saint Peter's University Hospital
The Children's Hospital at Saint Peter's
254 Easton Ave
New Brunswick, NJ 08903
(732) 339-7045





References

1. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders, 4th Edition, Text Revision (DSM-IV-TR)* Washington DC: American Psychiatric Publishing, 2000
2. American Academy of Pediatrics Council on Children with Disabilities Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics*. 2006; 118 (1): 405-420
3. American Academy of Pediatrics, Plauché Johnson, C., Myers, S.M. and the Council on Children with Disabilities. Identification and Evaluation of Children with Autism Spectrum Disorders. *Pediatrics*. 2007; 120(5): 1183-1215
4. American Academy of Pediatrics, Myers, S.M., Plauché Johnson, C. and the Council on Children with Disabilities. Management of children with autism spectrum disorders. *Pediatrics*. 2007; 105(5): 1162-1182
5. New Jersey Early Intervention System. Technical Assistance: Part C Early Intervention Services for Children with Autism Spectrum Disorders in New Jersey. Available at www.state.nj.us/health/fhs/eis/index.shtml
6. National Research Council, Committee on Interventions for Children with Autism. *Educating Children with Autism*. Washington, DC: National Academies Press; 2001
7. Filipek, PA, Accardo, PJ, Ashwal S, et al. Practice parameter: screening and diagnosis of autism-report of the Quality Standards Subcommittee of the American Academy of Neurology and the child Neurology Society. *Neurology*. 2000; 55: 468-479
8. American Academy of Pediatrics. *Understanding Autism Spectrum Disorders*. Elk Grove Village, IL: American Academy of Pediatrics: 2005
9. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigator: Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder: Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. *MMWR Surveill Summ*. 2007; 56(1)12-28
10. Interagency Autism Coordinating Committee Strategic Plan For Autism Spectrum Disorder Research. Available at: <http://iacc.hhs.gov> Accessed March 5 2009.
11. Lord C, Risi S, DiLavore PS, Shulman C, Thurm A, Pickles A. Autism from 2 to 9 years of age. *Arch Gen Psychiatry*. 2006; 63(6):694-701.
12. Howlin P, Moorf A. Diagnosis in autism: a survey of over 1200 patients in the UK. *Autism*. 1997;1:135-162
13. Howlin, P. Asgharian A. The diagnosis of autism and Asperger's syndrome: Findings from a survey of 770 families. *Developmental Medicine and Child Neurology* 1999;41:834-839

14. Wiggins LD, Baio, J, Rice C. Examination of the time between first evaluation and first autism spectrum diagnosis in a population –based sample. *J Dev Behav Pediatr.* 2006;27:S79-S87
15. Knafl K, Ayres L, Gallo A, Zoeller L, Breitmayer B. Learning from stories: parents; accounts of the pathway to diagnosis. *Pediatric Nursing* 1995;21:411-415
16. Smith B, Chung MC, Vostanis P. The path to care in autism: is it better now? *J Autism Dev Disord.* 1994;24:55-563
17. Center for Disease Control and Prevention. Learn the Signs/Act Early campaign materials. Available: www.cdc.gov/Features/DetectAutism. Accessed March 5 2009.
18. Handleman, JS, Harris, S, eds. *Preschool Education Programs for Children with Autism 2nd ed.* Austin, TX: Pro-Ed; 2000
19. Fenske, B C, Zalenski, S, Krantz, P J, McClannahan, LE. Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. *Analysis and Intervention in Developmental Disabilities* 1985; 5: 49-58
20. Smith T, Groen AD, Wynne JW. Randomized trial of intensive early intervention for children with pervasive developmental disorder. *Am J Ment Retard.* 2000;105:269-285
21. Sallows GO, Graupner TD. Intensive behavioral treatment for children with autism: four year outcome and predictors. *Am J Ment Retard.* 2005;110=417-438
22. Glascoe FP. Early detection of developmental and behavioral problems. *Pediatrics in Review.* 2000;21 272-280
23. Drotar D, Stancin T, Dworkin, P. *Pediatric Developmental Screening: Understanding and Selecting Screening Instruments.* The Commonwealth Fund, 2008. Available at: www.commonwealth-fund.org/Content/Publications



Early Identification of
Autism Spectrum Disorders:

Guidelines for Healthcare Professionals in New Jersey

This booklet is also available
on the DHSS website at:
www.nj.gov.health/fhs/documents/autismguidelines.pdf



Early Identification of
Autism Spectrum Disorders:

Guidelines for Healthcare Professionals in New Jersey

