

CLINICAL PRACTICE GUIDELINES

Quick Reference Guide
for Parents and Professionals

AUTISM/
PERVASIVE DEVELOPMENTAL
DISORDERS

ASSESSMENT AND INTERVENTION
FOR
YOUNG CHILDREN (AGE 0-3 YEARS)



SPONSORED BY
NEW YORK STATE DEPARTMENT OF HEALTH
EARLY INTERVENTION PROGRAM

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NEW YORK STATE DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH
BUREAU OF EARLY INTERVENTION

This guideline was developed by an independent panel of professionals and parents sponsored by the New York State Department of Health. The recommendations presented in this document have been developed by the panel, and do not necessarily represent the position of the Department of Health.

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1. *Clinical Practice Guideline: Report of the Recommendations.* Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years). 5 1/2" x 8 1/2", 322 pages, 1999. Publication No. 4215.
2. *Clinical Practice Guideline: Quick Reference Guide.* Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years). 5 1/2" x 8 1/2", 108 pages, 1999. Publication No. 4216. Reprinted 2006, 2008, 2009.
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**AUTISM /
PERVASIVE DEVELOPMENTAL DISORDERS**

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PREFACE:

WHY THE EARLY INTERVENTION PROGRAM IS DEVELOPING CLINICAL PRACTICE GUIDELINES

In 1996, the New York State Department of Health (NYSDOH) initiated a multiyear effort to develop clinical practice guidelines to support the efforts of the statewide Early Intervention Program. As lead agency for the Early Intervention Program in New York State, the NYSDOH is committed to ensuring that the Early Intervention Program provides consistent, high quality, cost-effective, and appropriate early intervention services that result in measurable outcomes for eligible children and their families.

The guidelines are not standards nor are they policies. The guidelines are tools to help ensure that infants and young children with disabilities receive early intervention services consistent with their individual needs and consistent with the resources, priorities, and concerns of their families.

The guidelines are intended to help families, service providers, and public officials make informed choices about early intervention services by offering recommendations based on scientific evidence and expert clinical opinion on effective practices.

The impact of clinical practice guidelines for the Early Intervention Program will depend on their credibility with families, service providers, and public officials. To ensure a credible product, the NYSDOH elected to use an evidence-based, multidisciplinary consensus panel approach. The methodology used for this guideline was established by the Agency for Health Care Policy and Research (AHCPR), and was selected for this effort because it is an effective, scientific, and well-tested approach to guideline development.

The NYSDOH has worked closely with the State Early Intervention Coordinating Council throughout the guideline development process. A state-level steering committee comprised of early intervention officials, representatives of service providers, and parents was also established to advise the department regarding this initiative. A national advisory group of experts in early intervention has been available to the department to review and to provide feedback on the methodology and the guideline. Their efforts have been crucial to the successful development of this guideline.



When this symbol appears, it indicates that there is information in Appendix B about relevant Early Intervention Program (EIP) policy.

It is intended that the NYSDOH clinical practice guidelines for developmental disabilities in children from birth to age 3 be dynamic documents that are updated periodically as new scientific information becomes available. This guideline reflects the state of knowledge at the time of development. However, given the inevitable evolution of scientific information and technology, it is the intention of the NYSDOH that periodic review, updating, and revision will be incorporated into an ongoing guideline development process.

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This *Quick Reference Guide* provides only summary information. For the full text of the recommendations and a summary of the evidence supporting the recommendations, see *Clinical Practice Guideline: Report of the Recommendations*.

INTRODUCTION

The guideline recommendations suggest “best practices,” not policy or regulation

The Clinical Practice Guideline on which this *Quick Reference Guide* is based was developed by a multidisciplinary panel of clinicians and parents. The development of guidelines for the Early Intervention Program was sponsored by the New York State Department of Health as a part of its mission to make a positive contribution to the quality of care for children with disabilities. The guideline is intended to provide parents, professionals, and others with recommendations based on the best scientific evidence available about “best practices” for assessment and intervention for young children with autism/pervasive developmental disorders.

- ◆ The guideline is not a required standard of practice for the Early Intervention Program administered by the State of New York.
- ◆ This guideline document is a tool to help providers and families make informed decisions.
- ◆ Providers and families are encouraged to use this guideline, recognizing that the care provided should always be tailored to the individual. The decision to follow any particular recommendations should be made by the provider and the family based on the circumstances presented by individual children and their families.

SCOPE OF THE GUIDELINE

Focus of the Guideline

The focus of the guideline on which this *Quick Reference Guide* is based is assessment and intervention for **young children with autism**, with a primary focus on children under 3 years of age. However, age 3 is not an absolute cutoff, and many of the recommendations in the guideline are also applicable in somewhat older children.

Defining “autism” as it is used in this guideline

The definition of *autism* as used in this *Quick Reference Guide* is based on the diagnostic criteria that define autism as presented in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition*, commonly referred to as the **DSM-IV**.



EIP 1

Operational Definition

In this *Quick Reference Guide*, the term “pervasive developmental disorder (PDD)/autism” is abbreviated throughout as “autism.” *Wherever there is a reference to autism, it is intended to mean both PDD and autistic disorder.*

DEFINITIONS OF OTHER TERMS

Definitions are given below for some major terms as they are used in this *Quick Reference Guide*.

<i>Assessment</i>	The entire process of evaluating the child, including the activities and tools used to measure level of functioning, establish eligibility for services, determine a diagnosis, plan intervention, and measure treatment outcomes.
<i>Family</i>	The child’s primary caregivers, which might include one or both parents, siblings, grandparents, foster care parents, or others usually in the child’s home environment(s).
<i>Parents</i>	The primary caregiver(s) or other person(s) who has (have) significant responsibility for the welfare of the child.
<i>Professional</i>	Any provider of professional services who is qualified to provide the intended service. Qualifications generally include training, experience, licensure, and/or other state requirements. The term is not intended to imply any specific professional degree or qualifications other than appropriate training and credentials. (It is beyond the scope of this guideline to address professional practice issues.)
<i>Screening</i>	The early stages of the assessment process. Screening may include parent interviews or questionnaires, observation of the child, or use of specific screening tests. Screening is used to identify children who need more in-depth evaluation.
<i>Target Population</i>	A study group selected according to specific characteristics. For this guideline, the <i>target population</i> is children with possible autism from birth to age 3 years. Throughout this document, the term <u>young children</u> is used to describe this target age group.
<i>Young Children</i>	Term used in this guideline to describe the target age group (children from birth to age 3 years.) Although children from birth to age 3 is the intended focus of the guideline, the term young children may also include somewhat older children.



WHY THE GUIDELINE WAS DEVELOPED

THE IMPORTANCE OF USING SCIENTIFIC EVIDENCE TO HELP SHAPE CLINICAL PRACTICE

Every professional discipline today is being called upon to document its effectiveness. Current questions often asked of professionals are:

- ◆ “How do we know if current professional practices are effective in bringing about the desired results?”
- ◆ “Are there other approaches, or modifications of existing approaches, that might produce better results or similar outcomes at less cost?”

The difficulty in answering these questions is that many times the methods used in current professional practice have not been studied extensively or rigorously.

Evidence-based clinical practice guidelines are intended to help professionals, parents, and others learn what scientific evidence exists about the effectiveness of specific clinical methods. This information can be used as the basis for informed decisions.

This guideline represents the panel’s attempt to interpret the available scientific evidence in a systematic and unbiased fashion and to use this interpretation as the basis for developing guideline recommendations. It is hoped that by this process, the guideline offers a set of recommendations that reflects current best practices and will lead to the best results for children with developmental problems.

HOW THE GUIDELINE WAS DEVELOPED

This guideline was developed using standard research methods for evidence-based guidelines. The process involved establishing specific criteria for acceptable evidence and reviewing the scientific literature to find such evidence. Relatively rigorous criteria were used to select studies that would provide adequate evidence about the effectiveness of assessment and intervention methods of interest.

Studies meeting these criteria for evidence were then used as the primary basis for developing the recommendations. In addition, there were numerous articles in the scientific literature that did not meet the evidence criteria, yet still contained information that may be useful in clinical practice. In many cases, information from these other articles and studies was also used by the panel, but was not given as much weight in making the guideline recommendations.

When no studies were found that focused on children in the target age group (from birth to age 3), generalizations were made from evidence found in the studies of somewhat older children.

In the full-text versions of this guideline, each recommendation is followed by a “strength of evidence” rating indicating the amount, general quality, and clinical applicability (to the guideline topic) of the evidence that was used as the basis for the recommendation.

For more information about the process used to develop the guideline recommendations, as well as a summary of the evidence that supports them, see Clinical Practice Guideline: Report of the Recommendations.

A full description of the methodology, the recommendations, and the supporting evidence can be found in Clinical Practice Guideline: The Technical Report.

**GUIDELINE
VERSIONS**

There are three versions of this clinical practice guideline published by the Department of Health. The versions differ in their length and level of detail in describing the methods and the evidence that support the recommendations.

*The Report of the
Recommendations*

- ◆ full text of all the recommendations
- ◆ background information
- ◆ summary of the supporting evidence

The Quick Reference Guide

- ◆ summary of major recommendations
- ◆ summary of background information

The Technical Report

- ◆ full text of all the recommendations
- ◆ background information
- ◆ full report of the research process and the evidence reviewed

**WHERE CAN I GET MORE
INFORMATION**

There are many ways to learn more about autism and pervasive developmental disorders. Several resources are listed in the back of this booklet. When reviewing this list of resources, families and professionals should be aware that the information provided by these resources has not been specifically reviewed by the guideline panel.

Caution is advised when considering assessment or treatment options that have not been studied using a good scientific research methodology.

It is important to consider whether or not there is good scientific evidence that the approach being considered is effective for young children with autism/PDD.

BACKGROUND: UNDERSTANDING AUTISM

Since the 1980s, we have gained a better understanding of the broad diagnostic category that includes autism and autism-like disorders. Autistic Disorder (autism) is now believed to represent only one part of a clinical spectrum or group of disorders termed *pervasive developmental disorders*.

What is autism?

Autism is a neuro-behavioral syndrome caused by problems in the central nervous system that affect the child's development. The onset of autistic symptoms occurs within the first 3 years of life and includes three general categories of behavioral impairment common to all persons who have autism:

1. *Qualitative impairments in social interaction*
2. *Qualitative impairments in communication*
3. *Restricted, repetitive, and stereotyped patterns of behavior, interest, and activities*

Qualitative impairments in social interaction

Sometimes this deficit in social relatedness is noticeable during the first months of life; parents may report that their child has poor eye contact, lacks interest in being held, or stiffens when held. Young children who have autism often do not initiate or sustain play with their peers and often do not take part in groups. They may lack the ability to judge appropriate reactions in social situations; they may not feel anxiety around strangers, or not be aware of how close to stand to someone.

Qualitative impairments in communication

When language is present in the younger child with autism, it tends to be rote, repetitive, and lacking in apparent communicative intent.

Restricted, repetitive, and stereotyped patterns of behavior, interest, and activities

Most young children who have autism will demonstrate repetitive motor or verbal actions. Children may, for example, flap their hands, bang their heads, rock, pace, spin on their feet, or use repetitive finger movements. In some children, these stereotyped behaviors tend to occur primarily when the child is excited, stressed, or upset. Children with autism also have a tendency to be preoccupied with a small number of activities, interests, or objects. The nature of their play tends to be restricted or repetitive.

Several other common findings in children who are autistic do not fit easily into the symptoms described above. Those findings may include the following:

- ◆ *Unusual responses to sensory stimuli*
- ◆ *Behavior disturbances*
- ◆ *Cognitive characteristics*

How common is autism?

Autism may be more common than previously thought, particularly if defined as a spectrum disorder.

Earlier studies suggest that about 3 to 4 children in 10,000 have autism. More recent studies suggest as many as 20 or more children in 10,000 have autism. A range of 10 to 15 children per 10,000 is a commonly accepted “middle range” estimate.

Who can make a diagnosis of autism?

Based on the medical practice acts of New York State, licensed psychologists and physicians are the only individuals qualified to make a diagnosis of autism. Since making an accurate diagnosis of autism is complex, particularly in children under 3 years of age, it is important that physicians and psychologists who make the diagnosis have experience and expertise in assessing young children with autism.

What causes autism?

Many different types of research support the concept that autism is a biologically based developmental disorder. However, no specific cause has yet been identified.

Is there a cure?

Given that autism is a spectrum disorder with a wide range of presentations and no known specific cause, it seems unlikely that any single cure will be found. Although there is no known cure, there are interventions that show promise for treating some of the symptoms of autism.

What is the prognosis for children with autism?

The prognosis for children with autism varies considerably. Traditional estimates suggest that about two-thirds of cases have an overall poor outcome (as defined by social adjustment), ability to work, and ability to function independently.

The more recent, broader definitions of autism and PDD include many children with milder symptoms for whom the long-term prognosis may be better.

Currently, the majority of children with autism can be expected to continue to need some degree of assistance as adults. A much smaller group, perhaps 10% of cases, may actually seem to “outgrow” their autism and return to near “normal” functioning. Some data suggest that recent behavioral approaches, applied early and intensively, may significantly improve the outcome for at least some children with autism.

WHAT ARE SOME COMMON MISCONCEPTIONS ABOUT AUTISM?

Although much has been learned about autism in recent years, there are still some commonly held misconceptions. Common **misconceptions** may include the following:

Misconception: *Autism is a mental illness.*

Fact: Autism is a neurologically based disorder of development. It is not considered a mental illness.

Misconception: *Children with autism are mentally retarded.*

Fact: Although mental retardation may frequently coexist with autism, not all children with autism are mentally retarded. The intelligence quotients of children with autism span a range from very low to very high.

Misconception: *Children with autism are unruly kids who choose not to behave.*

Fact: Certain aggressive behaviors may be symptoms associated with autism. There may be many reasons why certain children with autism sometimes demonstrate disruptive or aggressive behaviors (confusion due to language deficits, sensory sensitivities, high anxiety, and low tolerance for change, to name a few). However, these behaviors are generally not “chosen” by the child.

Misconception: *Bad parenting causes autism.*

Fact: There is no credible evidence that autism can be caused by deficient or improper parenting, contrary to what may have been believed in the past.

ASSESSMENT METHODS

It is important to identify children with autism as early as possible. It is often possible to recognize autism within the first 3 years of life.



EIP 4, 5, 6

There is no single way that autism is first identified in young children. The sequence of the assessment process may vary from one child to the next. Therefore, the order of the assessment components presented in this *Quick Reference Guide* is not necessarily the order in which the assessment process will occur for a particular child. Regardless of the order in which the process occurs, all the general elements of the assessment process are important for professionals and parents to consider when assessing young children with possible autism.

Frequently, the first indication that there may be a problem is a parent's concern that some aspect of the child's development is delayed or that something is abnormal about the child's behavior. The concern may also be identified by a healthcare provider or other professional at the time of a regular health exam or when the child is being evaluated for some other health concern or developmental problem.

Since autism is relatively rare, it is not practical to screen the general population of young children for autism using a specific screening test. A more useful approach for identifying children with possible autism is to look for certain inappropriate behaviors or lack of certain age-appropriate behaviors that may be "clinical clues" of a possible problem. These clinical clues are identified in TABLE 2.

***Establishing a Specific
Diagnosis of Autism***

While tests specifically designed to assess autism in younger children can be useful in assisting with the diagnosis, no single test provides enough information to be used as the sole basis for the diagnosis of autism.

It is recommended that the diagnosis of autism be based on the criteria in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)*, or the most current edition of this manual.

DSM-IV vs. Other Criteria

The DSM-IV criteria were determined through an extensive process of consensus building and field testing, and they represent the most widely accepted and utilized diagnostic model across the country. An alternative diagnostic model has been proposed by *ZERO TO THREE: National Center for Infants, Toddlers, and Families*. However, to date, that model lacks a formal research base and has not yet gained broad acceptance among developmental specialists. Thus, it is not felt to be appropriate as a basis for the diagnosis of autism at this time.

Cultural Considerations

In evaluating a child with possible autism, it is important to recognize that there may be cultural and familial differences in expectations about such things as eye contact, play and social interaction, and pragmatic use of language.

If English is not the primary language of the family, it is important for professionals to look for ways to communicate effectively with the family and the child including finding professionals and/or translators who speak the child's family's language(s).



EIP 7

EARLY IDENTIFICATION OF POSSIBLE AUTISM

Developmental surveillance is the term that most accurately describes the approach currently practiced by many healthcare providers and other professionals for the early detection of developmental problems.

Developmental surveillance is a flexible, continuous process in which knowledgeable professionals monitor a child's developmental status during the provision of health care services.

Developmental surveillance at specific ages is important for all young children. The periodic exams at 15, 18, and 24 months are particularly useful in evaluating concerns about possible autism.

Developmental surveillance may be done using either parent questionnaires and/or formal screening tests of general development. The information gathered is then reviewed by professionals and discussed with the child's parents.

During the course of surveillance, the professionals may note certain behavioral characteristics that increase concerns that the child may have a specific developmental problem. These concerns may be based on observations made during the exam, information about risk factors, and/or parental concerns.

One method of developmental surveillance is for the professional to look for certain age-specific developmental milestones. Normal developmental milestones in the social and communicative behavior that may provide clinical clues about possible autism are listed in TABLE 1.

This table lists developmental milestones for communication and social skills, two of the developmental areas that define autism. The items listed are developmental milestones that children following a typical developmental sequence should exhibit by the time they reach the specified age. Failure to achieve a developmental milestone is a clinical clue that raises concerns that the child may have autism or some other developmental delay or disorder.

TABLE 1
DEVELOPMENTAL MILESTONES
FOR COMMUNICATION AND SOCIAL SKILLS

15-month developmental milestones

- ◆ Makes eye contact when spoken to
- ◆ Reaches to anticipate being picked up
- ◆ Shows joint attention (shared interest in object or activity)
- ◆ Displays social imitation (e.g., reciprocal smile)
- ◆ Waves “bye-bye”
- ◆ Responds to spoken name consistently
- ◆ Responds to simple verbal request
- ◆ Says “Mama,” “Dada,”

18-month developmental milestones

(All of the above, plus the following)

- ◆ Points to body parts
- ◆ Speaks some words
- ◆ Has pretend play (e.g., symbolic play with doll or telephone)
- ◆ Points out objects
- ◆ Responds when examiner points out object

24-month developmental milestones

(All of the above, plus the following)

- ◆ Uses two-word phrases
- ◆ Imitates household work
- ◆ Shows interest in other children

Adapted from Siegel (1991) and from Table III-5 in *Clinical Practice Guideline: The Technical Report*.

Identifying Clinical Clues and Parental/Caregiver Concerns of Possible Autism

Clinical clues, sometimes referred to as “red flags,” are historical facts and current observations which, if present, increase concern about possible autism in a young child. Clinical clues may be noticed by the parents, others familiar with the child, or a professional as part of routine development surveillance or during health care visits for some other reason.

Clinical clues of autism can include historical information about the child obtained from the parents (for example, the child has no peer friends) or current observations made by the professional at the time of evaluation (for example, unusual repetitive hand movements). Clinical clues of possible autism are listed in TABLE 2.

The clinical clues listed in TABLE 2 represent delayed or abnormal behaviors that are seen in children with autism (although some of these findings may also be seen in children who have a developmental delay or a disorder other than autism).

If clinical clues of possible autism are identified by either parents or professionals, it is important to follow up with appropriate screening tests. For children with suspected autism, it is important to do both a diagnostic evaluation (to determine the specific diagnosis) and a functional assessment (to evaluate the child’s strengths and needs in various developmental domains).

The clinical clues listed below represent delayed or abnormal behaviors that are seen in children with autism (although some of these findings may also be seen in children who have a developmental delay or disorder other than autism). If any of these clinical clues are present, further assessment may be needed to evaluate the possibility of autism or other developmental disorder.

TABLE 2

CLINICAL CLUES OF POSSIBLE AUTISM

- ◆ Delay or absence of spoken language
- ◆ Looks through people; not aware of others
- ◆ Not responsive to other people's facial expressions/feelings
- ◆ Lack of pretend play; little or no imagination
- ◆ Does not show typical interest in or play near peers purposefully
- ◆ Lack of turn-taking
- ◆ Unable to share pleasure
- ◆ Qualitative impairment in nonverbal communication
- ◆ Does not point at an object to direct another person to look at it
- ◆ Lack of gaze monitoring
- ◆ Lack of initiation of activity or social play
- ◆ Unusual or repetitive hand and finger mannerisms
- ◆ Unusual reactions or lack of reaction to sensory stimuli

Source: This table is derived from Table III-5 in *Clinical Practice Guideline: The Technical Report*.

SCREENING TESTS AND ASSESSMENT INSTRUMENTS***Screening Tests for Autism***

Screening tests for autism are often used if there is an increased concern about possible autism or the child's development. Screening for autism is a preliminary assessment method intended to lead to a decision that autism either is unlikely, or is possible and requires further evaluation. Most screening tests are designed to be brief and easy to administer.

Many simple screening tests for autism are available to the public through a variety of sources and claim to be useful in identifying children with autism. Most of these tests have not been evaluated using standard research methods. Only one screening test for autism in young children, the Checklist for Autism in Toddlers (CHAT), was evaluated in research studies meeting criteria for adequate evidence about effectiveness.

The CHAT takes only about 5 to 10 minutes to administer and score. The examiner does not need specific training, and the test can be administered by a variety of individuals. The CHAT is designed to be used with toddlers as young as 18 months of age.

The CHAT consists of nine "yes/no" questions to be answered by the child's parent. The CHAT includes questions about whether the child exhibits specific behaviors such as social play, social interest in other children, pretend play, pointing to ask for something, pointing to indicate interest in something, rough and tumble play, motor development, and functional play. The CHAT also includes observations of five brief interactions between the child and the examiner.

The CHAT is a useful first-level screening method for children 18 to 36 months of age in whom there is any level of concern about possible autism.

If the CHAT screening suggests possible autism, further assessment is needed to determine a diagnosis. If the CHAT screening suggests autism is unlikely, it is still important to assess the child for other developmental or medical problems that may have initiated the concern, and to continue regular periodic surveillance for problems that may be related to the initial concern.



EIP 8

It is important to remember that not all children with autism can be identified early. Because the time of onset and severity of symptoms vary, it is recommended that screenings be repeated at various ages when concerns for autism persist.

Autism Assessment Instruments

Several standardized tests and checklists have been developed to help assess the behavior of children with possible autism. These tests are also intended to further evaluate children in whom autism is considered possible (due to parent concerns, clinical clues, and/or positive screening test results).

These assessment instruments can be used in various ways in assessing children with possible autism. Sometimes these instruments can be used to determine if autism is likely so that a decision can be made to seek a specific diagnosis. At other times, these assessment instruments may be used as part of the formal diagnostic process.

Some of the instruments may be used to rate the severity of symptoms, which may be useful in determining interventions, periodic monitoring of the child's progress, and assessing outcomes.

The autism assessment instruments reviewed in the full text of the guideline include the following:

The *Autism Behavior Checklist (ABC)*: a behavior checklist completed by a parent. The accuracy of the ABC for identifying children with autism is relatively low when compared to other autism assessment instruments. In addition, the content of the test items appears more appropriate to children over age 3. Therefore, the ABC is considered to be of limited usefulness in identifying young children with autism.

The *Autism Diagnostic Interview-Revised (ADI-R)*: a structured interview. The ADI-R is a relatively new test that has demonstrated good accuracy in identifying young children with autism. However, because the ADI-R requires extensive time and training to administer, it may be most useful as part of a more in-depth assessment of children for whom there is a fairly high level of concern for possible autism.

The *Childhood Autism Rating Scale (CARS)*: a test combining parent reports and direct observation by the professional. Among the autism assessment instruments reviewed, the CARS appears to possess an acceptable

combination of practicality and research support. The CARS may be useful as part of the assessment of children with possible autism in a variety of settings, including early intervention programs, preschool developmental programs, and developmental diagnostic centers. Because it gives a symptom severity rating, the CARS may be useful for periodic monitoring of children with autism and for assessing long-term outcomes. It is very important that professionals using the CARS have adequate training in administering and interpreting the CARS.

The *Pre-Linguistic Autism Diagnostic Observation Schedule (PL-ADOS)*: a test using direct observation of the child's behavior as elicited by the examiner. The PL-ADOS has adequate accuracy in identifying children with autism. Since extensive training is needed to learn how to administer the PL-ADOS, it may not be a practical assessment method in certain clinical situations. However, the PL-ADOS may be useful as part of a multi-disciplinary intake assessment in diagnosing young children with autism.

THE DEVELOPMENTAL ASSESSMENT

When there is sufficient evidence to suggest the possibility of autism, it is very important to do a general assessment of the child's development (if this has not already been done).

A developmental assessment for children under age 3 is an attempt to assess various aspects of the child's functioning, including areas such as communication, behavior, social interaction, motor skills, sensory abilities, adaptive skills, and cognition. Assessment of the family and the child's environment also provides important information.



EIP 9, 10, 11

An age-appropriate developmental assessment may include evaluation of such areas as cognition, communication, behavior, social interaction, motor and sensory abilities, and adaptive skills.

It is important that the developmental assessment be individualized to the child by using age-appropriate testing and scoring methods, and focusing on the child's presenting problems. An assessment of the child's specific areas of strength and weakness is also important.

Important components of a developmental assessment include the following:

- ◆ *an objective test of hearing (standardized testing may be less reliable in children under the age of 2)*
- ◆ *standardized testing of*
 - *cognitive ability*
 - *communication*
 - *motor/physical skills*
 - *adaptive skills*
 - *social, emotional, and behavioral functioning*
- ◆ *sensory processing*
- ◆ *curriculum-based assessments*
- ◆ *observation of the child at informal or structured play, and of parent-child interactions*

- ◆ *parental interview to elicit their concerns, obtain a history of the child's early development, and gather information about the child's current level of functioning*
- ◆ *review of the child's records (health, education, day care, etc.) and family medical history*

In some cases, a developmental assessment to evaluate a suspected developmental problem may provide professionals with the first indication that a child may have autism.

It is important to follow up on questionable abnormal findings in the developmental assessment of any young child. This might include adding elements to the developmental assessment and/or referring the child to other professionals for more detailed evaluation and specific diagnosis.

It is important that the findings of the developmental assessment be used in developing any intervention plans and for monitoring the child's progress.

Assessing Cognition

It is important to assess cognitive ability in children with possible autism. However, accurate assessment is often difficult in children with autism because of their uneven levels of skills and limited language. Young children with autism may have difficulty participating in the assessment process. Nevertheless, it is important to assess as accurately as possible the child's verbal and nonverbal cognitive skills as well as the child's skills in everyday environments.



EIP 12

Although mental retardation and autism commonly coexist, it is important not to prematurely label the child as having mental retardation until appropriate standardized and nonstandardized testing of cognition has been done. It is also important that professionals not infer that the child has a higher cognitive level than can actually be observed and measured.

Assessing Communication

Communication is one of the critical clinical clues in identifying autism. It is important to evaluate both nonverbal communication (such as gestures) and verbal aspects of communication (speech and language).



EIP 13

Assessing communication in children with autism is also important because of its impact on intervention decisions and its implications for outcome. It provides a baseline for monitoring progress. It is important to evaluate all of the following:

- ◆ *hearing status*
- ◆ *ability to use nonverbal communication strategies (such as pointing to show or request an item)*
- ◆ *atypical or delayed nonverbal communicative behaviors (such as atypical eye gaze and gestures)*
- ◆ *functional use of spoken language (how children use words and sounds to get what they want)*
- ◆ *significant delays in onset of spoken language or loss of language*

- ◆ *atypical communication patterns (such as persistent repetition of words and use of words without communicative intent)*

Assessing Social Interactions and Relationships

Assessment of social interactions and relationships is important because the inability to form social relationships is one of the characteristics of autism.

Assessment of social interactions and relationships includes the following:

- ◆ *social initiation (such as showing or giving objects to others for social purposes)*
- ◆ *social imitation (such as imitating actions of others)*
- ◆ *age-expected reciprocity (turn-taking during play)*
- ◆ *the child's attachment patterns in the presence of a caregiver (such as neutrality, excessive clinging, or avoidance of parent)*
- ◆ *the child's tendency for social isolation or preference to be alone*

- ◆ *the child's use of people as tools to obtain desired ends (such as taking an adult's hand to reach for a toy)*
- ◆ *social interactions with familiar as well as unfamiliar adults and peers*

Assessing Behavior and Responses to the Environment

Assessing a child's behavior and responses to the environment is important because these factors may affect intervention decisions and provide baselines for monitoring progress.

Assessment of a child's behavior patterns, relative strengths, and problem areas may include:

- ◆ *behavior patterns and problem behaviors*
- ◆ *unusual responses to sensory experiences*
- ◆ *motor skills*
- ◆ *play skills*
- ◆ *adaptive behaviors*
- ◆ *self-help skills*

Assessing the Family and the Child's Environment

It is important for the family of a young child with autism to participate in a family assessment because factors relating to the family can affect intervention and management decisions, and may have implications for outcomes.



EIP 14

Assessment of the strengths and limitations of the family and the child's environment may include observation and/or discussion of:

- ◆ *the family's stressors, tolerance for stress, and coping mechanisms*
- ◆ *the family's current support systems*
- ◆ *education experiences of family members*
- ◆ *family composition, demographics, and specific circumstances*
- ◆ *family interaction and patterns of discipline*
- ◆ *emotional expression of family members*
- ◆ *caregiving skills and sharing of caregiving responsibilities*
- ◆ *knowledge about autism*

THE HEALTH EVALUATION

It is important that all children with suspected developmental problems, including possible autism, have a complete health evaluation.



EIP 15, 16

There are three important reasons for doing health evaluations in children with autism:

1. to provide a general assessment of the child’s health status
2. to identify other conditions that may be confused with autism
3. to identify and assess medical conditions or genetic syndromes that are sometimes associated with autism

It is important to remember that children with autism are susceptible to all the same health problems as children without autism. These medical problems in children with autism may present special challenges for healthcare providers and parents.

Although it is generally accepted that autism is a biologically based condition affecting the central nervous system, extensive biological research has not yet identified any specific anatomical or biochemical findings considered to cause autism.

There are no specific medical tests that can be used to establish the diagnosis of autism. Rather, the diagnosis is made based on **historical information** and **direct observation** of a child’s behavior—specifically, communication, social interactions, and maladaptive behaviors.

Other more controversial assessment methods are also sometimes proposed, such as the use of specific immune, allergic, or metabolic tests. The reasons for such testing are based on various controversial theories about the cause of autism.

General Strategies for the Health Evaluation

It is important that all children with suspected developmental problems have a comprehensive health evaluation and that it include at least the following:

- ◆ *assessment of hearing and vision*
- ◆ *a neurological evaluation*
- ◆ *a skin exam (for signs of conditions such as tuberous sclerosis or neurofibromatosis)*
- ◆ *a search for medical conditions, genetic syndromes, or other developmental problems that are sometimes associated with autism*
- ◆ *assessment of other current health problems*
- ◆ *elements of routine developmental surveillance and general health screening appropriate for the child's age*
- ◆ *addressing any other health concerns expressed by the parents*

Other Related Assessments

It is recommended that professionals assessing the health status of children with autism actively look for associated health conditions seen more commonly in children with autism than in typically developing children.

It is extremely important to establish the **hearing status** in a child with suspected or diagnosed autism to rule out hearing impairment as a factor in the child's communication problems.



EIP 17

If there is any indication that a child has a hearing problem, it is important to refer the child for a hearing evaluation by an audiologist (including the use of brainstem evoked response testing if appropriate).

In most children with suspected or diagnosed autism, it is useful to do an appropriate laboratory test for *Fragile X Syndrome*, a genetic condition found in some children with autism.

When there is an increased likelihood or suspicion of possible seizures in a child with suspected or diagnosed autism, electroencephalograms (EEGs), including possibly a sleep EEG, may be useful.

Magnetic Resonance Imaging (MRI)

MRI scans provide detailed cross-sectional computerized images of the head and brain. MRI scans do not involve the use of radiation. MRI scans are generally used to detect abnormal anatomical structures, tumors, infections, traumatic injuries, and other changes in the brain.

MRI scans may provide useful information in certain clinical situations when there is heightened concern about specific neurological problems, such as seizures.

MRI scans may also be useful in assessing some children at risk for certain neurological problems, such as children with a history of perinatal problems (medical problems that occurred around the time of birth).

MRI scans are not useful in diagnosing autism and they are not generally used in the routine assessment of children with possible autism.

There are minimal risks associated with the use of MRI scans except for those related to sedation for the procedure.

***Single Photon Emission
Computerized Tomography
(SPECT)***

Single photon emission computerized tomography (SPECT) is a nuclear medicine technique that has been used to evaluate regional blood flow within the brain. SPECT involves the use of a small amount of radioactive tracer materials (radioisotopes). These may be either injected or inhaled.

The radioisotopes travel via the bloodstream to the brain, and images of cerebral blood flow are obtained using a special camera that measures photon emissions from the radioisotopes. Subjects must remain still for 4 to 5 minutes while images are being recorded, so sedation is often needed to perform SPECT in younger children and uncooperative subjects.

No adequate evidence has been found to support the use of SPECT scans in the assessment of children with autism. Therefore, the use of SPECT scans is ***not recommended.***

Assessment of Immune Status

A major function of the immune system is to identify foreign materials in the body that might be harmful (such as viruses or bacteria) and to defend the body against these foreign elements. One controversial theory suggests that autism may be caused or aggravated by immune reactions either to foreign elements in the body (such as viruses) or to a person's own tissues (known as an autoimmune response).

No studies were found that produced adequate evidence that autism is caused or otherwise related to the immune system.

No adequate evidence has been found indicating that immunologic testing is useful in any way for helping to diagnose autism, for planning treatment, or for assessing outcomes of interventions. Therefore, the use of immunologic testing is ***not recommended*** for the routine assessment of young children with possible autism.

Food Allergy and Diet Assessment

Testing for allergies is sometimes proposed for children with autism. An allergy is a reaction of the immune system to specific foreign material in the environment.

Allergies are not inherited but are acquired. Upon exposure to certain materials, a person can become sensitized and then later develop allergic reactions when re-exposed to that substance.

The most common types of allergic conditions are allergic rhinitis (hay fever) and allergic asthma. Allergic reactions can also occur to a variety of foods. However, in young children, food allergies are much less common than hay fever or allergic asthma.

Elimination diets are sometimes proposed as a method for detecting food allergies. These involve eliminating certain foods from the diet that are suspected of possibly causing allergic problems. After

these foods have been eliminated for several weeks, each of the eliminated foods is added back into the diet one at a time (referred to as a food challenge).

Testing for food allergies may be useful in some children if there is an increased concern about allergies. However, there is no clear evidence that children with autism are any more likely to have food or other allergies than children without autism.

No adequate evidence has been found indicating that autism is either caused or made worse by allergies or any specific foods, such as milk lactose or wheat gluten. Therefore, testing for food allergies is ***not recommended*** in the routine assessment of children with possible autism.

It is recommended that children with possible autism be treated no differently than other children in the assessment of food allergies.

Assessment of Organic Acid Metabolites (Yeast)

This assessment method involves laboratory analysis of a urine specimen for specific organic acids. The proposed rationale for such testing is based on the controversial theory that in some persons an overgrowth of yeast in the intestinal tract can cause or aggravate autism. Proponents suggest that in these individuals, anti-fungal therapy may bring about an improvement in autism.

No adequate evidence has been found to support the theory that an overgrowth of yeast in the intestinal tract can either cause or aggravate autism. Therefore, testing for specific organic acids in the urine (or any other test claiming to identify an overgrowth of yeast in the intestinal tract) is ***not recommended*** as part of the routine assessment of children with possible autism.

INTERVENTION METHODS

Children with autism may have a greater chance for successful outcomes if interventions are started at an early age.



E P 18, 19, 20, 21

Linking Interventions to Assessment of the Child

It is important to:

- ◆ identify children with autism and begin appropriate interventions as soon as possible since early intervention may help speed the child's overall development, reduce inappropriate behaviors, and lead to better long-term functional outcomes
- ◆ individualize interventions based on an assessment of the specific strengths and needs of the child and family
- ◆ tie interventions to ongoing monitoring of the child's progress

General Considerations for Implementing Interventions

In selecting interventions for children with autism, two important considerations are:

- ◆ scientific evidence that the intervention is effective
- ◆ evidence that the intervention is safe

Role of the Parents and Family in Interventions

It is important that parents be actively involved in all aspects of the child's assessment and intervention process to the extent of their interests, resources, and abilities.

If English is not the family's primary language, it is important for professionals to find a way to communicate effectively with the family. It may be helpful to use translators familiar with the culture and language of the family.

PARENT INTERVENTION GUIDE: QUESTIONS TO ASK PROVIDERS

The following are questions that may be helpful to parents when interviewing potential intervention providers.

1. What kinds of intervention, therapy, and services do you provide?
2. Do you have a particular philosophy for working with children with autism/PDD?
3. How many hours per week do these services require, and how much of this is one-on-one time with the child?
4. How would you describe a typical day or session?
5. What experience do the teachers and/or therapists have in working with children with autism?
6. What experience does the person who supervises the program have? How closely does the program supervisor work with the therapists, teachers, and parents?
7. What kinds of ongoing training do your full and part time staffs participate in?
8. Are parents involved with planning as part of the intervention team?
9. Do you provide a parent training program?
10. How much and what kinds of involvement are expected of parents and family members?
11. Are parents welcome to participate in or observe therapy and/or group sessions?
12. What techniques do you use to manage difficult behaviors?
13. Do you ever use physical aversive techniques or any physically intrusive procedures? If yes, please describe them.
14. Please describe your program for communication and language development. Do you use a picture communication system, sign language, other kinds of communication systems, or all of these?
15. Are there opportunities for integration with typical and/or higher functioning children?
16. How do you evaluate the child's progress, and how often?
17. How do you keep parents informed of the child's progress?

Common Elements of Effective Interventions

Over the last 25 years, a small number of programs have worked intensively on researching interventions for young children with autism and their families. Although these programs vary in their philosophical approach and strategies, they include several common elements.

Dawson and Osterling (1997) recently reviewed eight model early intervention programs for children with autism and described the following six elements that seemed to be common to effective intervention programs.

- (1) A **curriculum content** emphasizing five basic skills: to attend to elements of the environment that are essential for learning; to imitate others; to understand and use language; to play appropriately with toys; and to interact socially.
- (2) A supportive and **structured environment** that includes strategies for **generalization** to more complex, natural environments.
- (3) **Predictability and routine** to assist the child with transitions from one activity to another.
- (4) A **functional approach** to problem behaviors that includes recording the behavior, developing a hypothesis about the function of the behavior for the child, changing the environment to support appropriate behavior, and teaching appropriate behaviors to replace problem behaviors.
- (5) **Plans for transition** from preschool classroom by teaching “survival” skills that children will need later.
- (6) **Family involvement** as a critical component in the overall program.

BEHAVIORAL AND EDUCATIONAL APPROACHES

Behavioral and educational interventions have become the dominant approach for treating children and adults with autism.

In recent years, several intensive intervention programs for children with autism have been developed using a systematic behavioral approach, often referred to as *applied behavioral analysis* (ABA). Many of the current forms of speech and language therapy and many other educational interventions for young children with autism are based upon somewhat similar behavioral principles.

It is recommended that principles of applied behavior analysis (ABA) and behavior intervention strategies be included as important elements in any intervention program for young children with autism.

Basic Principles of Behavioral and Educational Intervention Approaches

Behavioral techniques include specific approaches to help individuals acquire or change behaviors. Behavioral therapies are sometimes called *behavioral modification methods*.

As used here, the term “*behavioral techniques*” refers to specific procedures aimed at teaching new skills and behavior. Intensive behavioral intervention programs use an array of behavioral techniques that change over time as the child progresses and as different skill areas are addressed.

Behavioral and educational interventions can be divided into three general approaches:

- (1) *operant conditioning*
- (2) *respondent (Pavlovian) conditioning*
- (3) *cognitive approaches*

Operant conditioning approaches are typically used in treating children with autism. At the most basic level, operant conditioning involves presenting a *stimulus* and then providing a *consequence* based on the child's response. For example, the therapist might show the child ten pictures (this would be the stimulus) and then give a reinforcing consequence each time the child responds correctly.

- ◆ A *reinforcer* is a consequence that increases the probability of appropriate responses.

Examples of possible reinforcers for young children include verbal praise, an edible treat, or a desired toy.

Consequences may also be used to decrease the probability of inappropriate responses. Examples include verbal disapproval or withholding a desired object or activity.

Effective consequences are different for each child and may be determined through a formal assessment process.

Intensive Behavioral and Educational Intervention Programs

The three basic elements of intensive behavioral and educational intervention programs include:

- ◆ systematic use of behavioral teaching techniques and intervention procedures
- ◆ intensive direct instruction by the therapist, usually on a one-to-one basis
- ◆ extensive parent training and support so that parents can provide additional hours of intervention

It is recommended that intensive behavioral programs include a *minimum* of approximately 20 hours per week of individualized behavioral intervention using ABA techniques (not including time spent by parents).

The precise number of hours of behavioral intervention may vary depending on a variety of child and family characteristics.



Considerations in determining the frequency and intensity of intervention include:

- ◆ age of the child
- ◆ severity of autistic symptoms
- ◆ rate of progress
- ◆ other health considerations
- ◆ tolerance of the child for the intervention
- ◆ family participation

It is important to monitor the child's progress on a regular basis. Monitoring the child's progress may lead to a conclusion that intervention times need to be increased or decreased.

To ensure consistency in the intervention approach, it is important that parents be trained in behavioral techniques and be encouraged to provide additional hours of instruction to the child.

Basic Principles of Specific Behavioral Intervention Techniques

It is important to clearly identify *target behaviors* that need to be addressed for each child and to individualize intervention strategies.

A continuum of behavioral strategies may be important as the child progresses. Strategies generally progress from more individualized (structured one-to-one sessions) to more general interactions (such as with peers in social groups).

As the child's skills progress, it is important to use behavioral techniques that facilitate generalization of new behaviors from structured environments to more natural settings.

It is important to conduct a reinforcer assessment to determine which items will serve as reinforcers for a particular child. It is important to recognize that there are several types of potential reinforcers, such as sensory, edible, and social (such as verbal praise).

Techniques for Reducing Maladaptive Behaviors

Maladaptive behaviors are a defining core characteristic of autism and may include stereotypic behavior, aggression, disruptive behavior, and noncompliance.

Reducing inappropriate behaviors is often one of the highest priorities for parents and one of the first targets for interventions. Some maladaptive behaviors may interfere with learning or socialization, while others may represent hazards to the child or others.

As a first step, a functional analysis is often conducted to determine the function of particular inappropriate behaviors for the child. Then behavioral strategies are devised to reduce maladaptive behavior by using differential consequences for appropriate behavior and inappropriate behaviors. In some cases, this may involve reinforcement of a substitute appropriate behavior that is incompatible with the maladaptive behavior.

Techniques to Improve Communication

Because communication deficits are a second core element defining autism, specific language and communication training is an important component of the intervention programs for children with autism.

Basic communication training for a child with autism often emphasizes functional use of language such as the use of language in everyday settings, nonverbal communication, and social aspects of communication such as turn-taking. Many behavioral techniques are used in teaching communication and language skills to young children with autism.

Since many young children with autism are functionally mute, many clinicians have tried approaches such as manual signing or visual communication systems in an effort to improve communication and language skills. The specific techniques will vary with the needs of the child.

Techniques to Improve Social Interactions

The third core characteristic defining autism is impaired social interactions. Behavioral techniques are often applied to improve the child’s social initiations and appropriate responses.

Techniques may include prompting the child to respond appropriately and reinforcing reciprocal social interactions and responses, particularly with other children. Peers with age-appropriate development who are able to work with or provide peer modeling for children with autism are sometimes given training in behavioral procedures.

In developing strategies to improve social interactions, it is important to consider:

- ◆ the child’s skills and abilities
- ◆ developmentally appropriate interventions
- ◆ the child’s environment
- ◆ the child’s need for social interaction

Parent Training

Behavioral intervention programs often include a specific parent training component. Many preschools also include parent training as a part of their programs.

It is recommended that parent training programs be included as an important part of comprehensive intervention programs for children with autism. These programs are useful because they:

- ◆ help support the family in caring for the child
- ◆ provide an opportunity to include the parents in the intervention
- ◆ help the family to use the intervention strategies in the daily routines of the child

The specific behavioral strategies taught to parents vary depending upon the particular program. It may be useful to teach behavioral principles to siblings.

OTHER EXPERIENTIAL APPROACHES

Other intervention approaches for young children with autism include a diverse collection of therapeutic models and approaches. Some of these approaches form the basis for intensive intervention programs, while others are more limited in scope. Some of the approaches are commonly used, others are less commonly used, and some are controversial. The approaches reviewed include:

- ◆ the Developmental, Individual-Difference, Relationship-Based (DIR) Model (sometimes referred to as “floor time”)
- ◆ sensory integration therapy
- ◆ music therapy
- ◆ touch therapy
- ◆ auditory integration therapy
- ◆ facilitated communication

The Developmental, Individual Difference, Relationship (DIR) model

The Developmental, Individual-Difference, Relationship-Based (DIR) Model (Greenspan, 1997), emphasizes the child’s

- (1) affect and relationships
- (2) developmental level
- (3) individual differences (in motor, sensory, affective, cognitive, and language functioning).

The intervention strategy based on the DIR model is sometimes informally referred to as “*floor time*” because the approach usually includes a component that encourages the therapist and parent to spend a great deal of time on the floor interacting with the child. At home, parents are asked to spend from six to ten daily sessions lasting 20 to 30 minutes. The focus of these sessions is working on the child’s ability for affective-based interactions using the child’s individual differences and developmental level as a starting point.

The specific approach used in the DIR model is difficult to define because it is individualized for the child. However, there seem to be some aspects of the DIR model that may be consistent with the previously described common elements of effective interventions for young children with autism. These common elements include:

- ◆ the importance of child-specific assessment
- ◆ individualizing the intervention to the child’s strengths and needs
- ◆ involving the family in the interventions

No adequate evidence has been found that interventions based on the DIR model are effective for treating autism. Therefore, the DIR model is ***not recommended as a primary intervention*** for young children with autism.

It is important to remember that approaches based on the DIR model can be time-intensive and may take time away from other effective therapies.

If interventions based on the DIR model are being considered, it is important that parents and professionals together make an informed decision based on the following information:

- ◆ there is not adequate research evidence to support the effectiveness of the DIR model
- ◆ interventions based on the DIR model may interfere with other intensive intervention programs unless steps are taken to coordinate the intervention programs
- ◆ interventions based on the DIR model are time-intensive and may take time away from other interventions that have been shown to be effective

If interventions based on the DIR model are considered, it is essential that they:

- ◆ be compatible with the approach and goals of the primary interventions
- ◆ set defined treatment goals and objective outcome measures for the DIR intervention

AUTISM/PERVASIVE DEVELOPMENTAL DISORDERS

- ◆ define treatment goals appropriate for the individual child (such as improving social interactions)
- ◆ provide for baseline and ongoing assessment of behaviors
- ◆ include appropriate modification of the DIR interventions based on the child's progress

Sensory Integration Therapy

Sensory integration therapy is based on an approach that evaluates children for sensory processing disturbances and provides them with the appropriate sensory stimulation. Sensory processing may occur through sight, hearing, smell, taste, touch, and sense of position.

The techniques used to provide the sensory stimulation are individualized based on evaluating the child's responsiveness to specific stimuli.

Based on the needs of the child, sensory experiences such as touch, controlled movement, and balance are used to elicit adaptive responses to these stimuli.

The sensory experiences used generally include play activities that offer opportunities for enhanced sensory intake.

The physical activity that is a part of sensory integration therapy is often pleasurable for the child and may be beneficial for some children with autism.

No adequate evidence has been found that supports the effectiveness of sensory integration therapy for treating autism. Therefore, sensory integration therapy is ***not recommended as a primary intervention*** for young children with autism.

If sensory integration is being considered, it is essential that the therapy be coordinated with the other interventions the child is receiving to avoid any potential conflicts in establishing and achieving the goals for the interventions.

If sensory integration therapy is being considered, it is essential that it:

- ◆ be compatible with the approach and goals of the primary intervention

- ◆ set defined treatment goals and objective outcome measures for the sensory integration therapy
- ◆ define treatment goals appropriate for the individual child (such as reduction in the child’s stereotyped behaviors or aversion to touch)
- ◆ provide for baseline and ongoing assessment of the problem behaviors
- ◆ include appropriate modification of the sensory integration therapy based on the child’s progress

Music Therapy

While music activities are often included as a part of an intervention approach, there are some who advocate for a separate, discrete intervention referred to as “music therapy.” For children with autism, music therapy (as a separate, discrete therapy) involves using some aspect of music, although the particular procedures used in music therapy vary and are not well defined in the literature. Proponents of music therapy suggest it may lead to improvements in social interaction and language development in children with autism.

No adequate evidence has been found to support the effectiveness of using music therapy as a separate, discrete therapy for children with autism. Therefore, music therapy is ***not recommended*** as an intervention method for young children with autism.



Touch Therapy

Touch therapy is a particular method of massage that involves specific sequences of rubbing the body using moderate pressure and smooth, stroking movements.

Touch therapy is performed on individuals who are fully clothed except for their socks and shoes. Areas of the bodies rubbed may include the head, neck, arms, hands, torso, legs, and feet.

Proponents of touch therapy suggest it may be beneficial for children with autism who often have problems with touch aversion, withdrawal, and inattentiveness.

No adequate evidence has been found to support the effectiveness of touch therapy as an intervention for children with autism. Therefore, touch therapy is ***not recommended*** as an intervention for children with autism.

Auditory Integration Training (AIT)

RECOMMENDED NOT TO BE USED

Auditory integration training involves obtaining an audiogram to test the child's hearing. Based on audiogram results, music played through headphones is modified by filtering those frequencies that the child hears the best.

Research on this type of intervention found no difference in children receiving AIT compared to children listening to unmodified music.

Because research has demonstrated that this intervention is not effective, it is recommended that AIT ***not be used*** as an intervention method for young children with autism.

Facilitated Communication

RECOMMENDED NOT TO BE USED

Facilitated communication involves a “facilitator” who supports the child’s hand on a keyboard or letter board while the child types or spells messages. Proponents of this therapy suggest that the messages are communications coming from the child.

Several controlled studies have evaluated components of facilitated communication for children with autism. The messages typed are often beyond the abilities of the child as evidenced by the child’s behavior or language. These studies suggest that communication that exceeds the abilities of the child originates from the facilitator, not the child.

There have been cases where messages produced with facilitated communication have resulted in legal proceedings.

Because no adequate evidence has been found supporting effectiveness, and because possible serious harms have been associated with this intervention, it is strongly recommended that facilitated communication ***not be used*** as an intervention method for young children with autism.

MEDICATIONS AND DIET THERAPIES

As research on autism has expanded in recent years, most researchers have come to agree that there is a biological basis for autism. There has also been a great expansion in knowledge over the past few decades about the underlying chemical and physiological basis for a variety of neurological and psychiatric conditions. This new knowledge has led to the development of a large number of new medications to treat these conditions. All of these factors have contributed to an increased interest in the use of medications and diet as possible interventions for autism.

A number of medications and diet therapies have been suggested as possible treatments for autism. These proposed intervention methods are quite different in terms of the amount of scientific evidence supporting their use.

Psychoactive medications

Psychoactive medications primarily affect a person's behavior, moods, or thought processes. Many psychoactive medications that have been used to treat other neurological or psychiatric conditions have also been tried as treatments for autism.

Other medical treatments

Other treatments, in addition to psychoactive medications, that have been proposed for autism include:

- ◆ hormone medications (growth hormone and secretin)
- ◆ immunologic agents (immune globulin)
- ◆ anti-yeast medications
- ◆ therapeutic vitamins
- ◆ special diets



EIP 24, 25

The use of these other treatments for autism is controversial and generally not accepted by the scientific community because either they have been shown to be ineffective or they have not been sufficiently evaluated.

General Approach for Considering Medication or Diet Therapies as Interventions for Autism

It is recommended that careful consideration be given to the potential benefits and risks of using medication or a special diet to treat symptoms of autism in young children.

In general, medication and diet interventions are not recommended as treatments for autism in young children until the intervention method is shown to be effective and safe for use in this age group.

When discussing the use of medications or special diets for autism, it is important that professionals explain the potential harms and benefits to the child's parents.

It is recommended that a decision to use a medication or special diet be guided by evidence of its effectiveness and safety in scientific studies that use adequate research designs.

If professionals prescribe a medication or recommend a special diet to treat autism in a young child, it is important that they regularly monitor the child to:

- ◆ assess the effectiveness of the medication or special diet
- ◆ look for signs of adverse behavioral or health effects that may be related to the use of the medication or special diet

If a child is receiving medication or using a special diet for autism, it is important that parents and others caring for the child be able to recognize signs of potential side effects (including possible medication toxicity or nutritional imbalance). It is important to instruct the parents about what to do if these side effects occur.

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After an adequate trial period for a medication or special diet, it is recommended that its continued use be periodically reevaluated. It is also recommended that a decision to continue the medication or special diet or not be based on its demonstrated effectiveness when balanced against concerns about side effects.

Psychoactive Medications

It is recommended that the use of psychoactive medication to treat maladaptive behaviors, social withdrawal, or other symptoms of autism in young children be considered only for children with severe or difficult behavior problems, and only if other interventions have been ineffective.

It is important that physicians prescribing psychoactive medication for symptoms of autism in a young child discuss the potential risks and benefits with the child's parents.

Psychoactive medication may be useful in some young children with autism who have severe behavioral problems that have not responded to behavioral techniques (such as applied behavioral analysis).

Types of medications that can sometimes be useful include:

- ◆ mood stabilizers
- ◆ neuroleptics
- ◆ opiate antagonists
- ◆ sedatives
- ◆ selective serotonin reuptake inhibitors (SSRIs)
- ◆ stimulants

For some young children with autism who have severe sleep problems, a trial of sedating medications may be useful for inducing sleep.

For children with autism who regress in their level of development, psychoactive medication may sometimes be useful for treating the associated medical conditions that may be related to the regression.

Hormone Therapies

Hormones are complex chemicals naturally produced in the human body that aid in regulating many normal physiological functions, including metabolism, digestion, growth, body temperature, and immune functions.

Some hormone replacement therapies have been proposed as possible treatments for autism. In particular, adrenocorticotropin hormone (ACTH) and secretin (a hormone that helps regulate digestion) have been promoted as treatments for autism.

ACTH, one of several hormones produced in the pituitary gland, is also referred to as the “growth hormone” because it is involved in regulating growth and a variety of other processes in a normally growing child. A deficiency of ACTH results in stunted physical growth. This can be treated with ACTH replacement therapy.

Secretin, a hormone secreted by the pancreas, plays a role in digestion.

Secretin causes increased production of bicarbonate in the small intestine to help neutralize acid from the stomach.

A pharmaceutical preparation of secretin has been available for several years. The only approved medical use for secretin is as a diagnostic aid to evaluate normal functioning of the pancreas and digestive tract. At this time, secretin has not been approved as a treatment for any medical conditions such as autism.

No adequate evidence has been found to support the effectiveness and safety of hormone therapies (such as ACTH or secretin) as a treatment for autism in young children. Therefore, the use of hormone therapies is ***not recommended*** as a treatment for autism in young children.

Immunologic Therapies

RECOMMENDED NOT TO BE USED

Immune or immunologic therapies, including treatment with intravenous immune globulin (IVIG), have been suggested as a possible treatment for children with autism. Proponents of these therapies suggest that some children with autism have abnormalities of their immune systems and believe that immunologic therapy may be useful for these individuals.

The only immunological therapy that is described in detail in the scientific literature as a treatment for autism is the use of IVIG. Immune globulin is prepared by separating immunoglobulin from pooled human blood specimens. Several steps in the process are added to ensure that any live viruses or bacteria in the specimens are inactive so that these infections are not transmitted when IVIG is given.

It is strongly recommended that intravenous immune globulin therapy ***not be used*** as a treatment for autism in children because of substantial risks and lack of proven benefit associated with this intervention.

Immunological testing is not useful for guiding interventions for autism in children. Immunological tests provide no information that is helpful in determining appropriate treatment for autism, and they are not useful for predicting or measuring functional outcomes for children with autism.

Anti-Yeast Therapies

Various anti-yeast therapies have been proposed as interventions for children with autism. These interventions typically involve administration of oral anti-fungal medication or special diets that include foods purported to have anti-fungal properties (such as garlic and grapefruit seed extract).

Yeast, a type of fungus, is a common microorganism found widely in the environment, including on the skin, in the mouth, and in the intestinal tract (where it is considered part of the normal intestinal flora, along with certain bacteria). In healthy individuals, there is a balance between the yeast and other bacteria in the intestinal tract and mouth, so that these microorganisms do not cause any adverse health effects.

When individuals take antibiotics for bacterial infections, this can sometimes lead to an imbalance of the normal microorganisms in the body. This imbalance can lead to an overgrowth of yeast. This kind of overgrowth of yeast in the intestinal tract of children can have some temporary effects, such as diarrhea, but the normal microbial balance usually returns on its own after a few days.

Typically, adverse health effects from yeast or fungal infections are not common in children who are otherwise healthy. The use of anti-fungal therapies for autism is based on a theory that symptoms of autism in some children are either caused or aggravated by an overgrowth of yeast in the intestinal tract. The theory also suggests that yeast overgrowth in the intestines occurs after a child has been treated with antibiotics.

No adequate evidence has been found to support anti-yeast therapies, including the use of oral anti-fungal medications and special diets, as a treatment for autism. Therefore, the use of anti-yeast therapies is ***not recommended*** for the treatment of autism in children.

Additionally, testing a child for specific organic acids (as an indicator of underlying yeast infection) provides no information that is helpful in determining appropriate treatment for autism. This information is not useful for predicting or measuring functional outcomes for children with autism.

Vitamin Therapies

Oral administration of a high dose of vitamin B₆ (pyridoxine) combined with magnesium has been suggested as a possible treatment for children with autism.

In humans, a deficiency of vitamin B₆ can lead to significant neurological problems, including seizures and peripheral nerve disorders. Documented vitamin B₆ or magnesium deficiencies are typically treated by administering therapeutic doses of vitamin B₆ or magnesium.

No adequate evidence has been found indicating that administering high doses of any type of vitamin or trace mineral (such as magnesium) as an effective treatment for autism. Therefore, vitamin therapies are ***not recommended*** as a treatment for autism in young children.

If a child with autism has a documented vitamin or trace mineral deficiency, it is recommended that this be treated, as appropriate, with vitamin replacement therapy.

Diet Therapies

Diet therapies, especially those that involve the elimination of cow's milk products (containing casein) and/or wheat products (containing gluten) from the diet, have been proposed for the treatment of autism in children. Proponents of these diets suggest that autism in some children is related to allergies to specific foods, and that eliminating these foods from the diet can result in an improvement in the symptoms of autism.

Diet therapies are not generally accepted as standard forms of treatment for autism and are considered experimental by many experts. The theory that food allergies might cause or contribute to autism is controversial. Whether food allergies are more common in children with autism compared to children without autism is also controversial.

No adequate evidence has been found to support the effectiveness of the use of special diets (elimination of milk, gluten, or other specific food products) as a treatment for autism. Therefore, special diets are ***not recommended*** for the treatment of autism in children.

If food allergies are documented in a child using standard allergy testing methods, then appropriate dietary changes or other treatment may be needed. However, this would be unrelated to the child's autism.

Allergy testing provides no information that is helpful in determining appropriate treatment for autism, and it is not useful for predicting or measuring functional outcomes for children with autism.

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APPENDIX A

**ARTICLES THAT
MEET CRITERIA FOR EVIDENCE**

AUTISM/PERVASIVE DEVELOPMENTAL DISORDERS

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APPENDIX B

NEW YORK STATE EARLY INTERVENTION PROGRAM

- B-1 EARLY INTERVENTION PROGRAM:
RELEVANT POLICY INFORMATION**
- B-2 EARLY INTERVENTION PROGRAM:
DESCRIPTION**
- B-3 OFFICIAL EARLY INTERVENTION PROGRAM
DEFINITIONS**
- B-4 TELEPHONE NUMBERS OF MUNICIPAL
EARLY INTERVENTION PROGRAMS**

B-1 EARLY INTERVENTION PROGRAM: RELEVANT POLICY INFORMATION

- EIP ❖ 1 In New York State, children with diagnosed conditions that are highly likely to affect development are eligible for early intervention services. Children with autism are eligible for the Early Intervention Program on this basis. Some children who are eventually diagnosed with autism are initially found eligible for the Early Intervention Program because of developmental delays that meet the NYS definition of developmental delay. This definition is given in Appendix B-2.
- (page 2)
- EIP ❖ 2 The terms *assessment*, *parents*, and *screening* are also defined in regulations that apply to the NYS Early Intervention Program. These definitions are included in Appendix B-2.
- (page 3)
- EIP ❖ 3 In New York State, the term used for professionals who are qualified to deliver early intervention services is “qualified personnel.” *Qualified personnel* are those individuals who are (1) approved to deliver services to eligible children to the extent authorized by their licensure, certification, or registration, and (2) have appropriate licensure, certification, or registration in the area in which they are providing services. See Appendix B-3 for the list of qualified personnel included in program regulations.
- (page 3)
- EIP ❖ 4 Under the NYS Early Intervention Program, physicians and other professionals are considered “primary referral sources.” When primary referral sources suspect possible autism or a developmental delay in cognitive, communication, physical, social-emotional, or adaptive development, they must refer the child to the Early Intervention Official in the child’s county of residence unless the parent objects to the referral. See Appendix B-4 for a list of Local Numbers for County Early Intervention Programs.
- (page 11)

AUTISM/PERVASIVE DEVELOPMENTAL DISORDERS

EIP ❖ 5 Parents can refer their children directly to the NYS Early Intervention Official in their county of residence if they suspect possible autism or a developmental delay.

(page 11)

EIP ❖ 6 Primary referral sources, including physicians and other professionals, are required to inform parents about the Early Intervention Program and the benefits of early intervention services for children and their families.

(page 11)

EIP ❖ 7 The child's multidisciplinary evaluation for the Early Intervention Program must be conducted in the child's dominant language, whenever feasible.

(page 12)

EIP ❖ 8 If the CHAT is used by a physician or other professional before the child is referred to the NYS Early Intervention Program and autism is suspected, the physician or professional must inform the parents about the program and the benefits of early intervention services. If the CHAT is used by the multidisciplinary evaluation team after a child has been referred and autism is suspected, the child's multidisciplinary evaluation should include an assessment for autism by professionals qualified to make a diagnosis.

(page 18)

EIP ❖ 9 Under the NYS Early Intervention Program, the multidisciplinary evaluation team is responsible for informing the parent(s) about the results of the child's evaluation.

(page 20)

EIP ❖ 10 Under the Early Intervention Program, a multidisciplinary evaluation must assess all five areas of development (cognitive, communication, physical, social-emotional, and adaptive). The multidisciplinary evaluation team can use a combination of standardized instruments and procedures and informed clinical opinion to determine a child's eligibility for services. The multidisciplinary evaluation is provided at no cost to parents.

(page 20)

- EIP ❖ 11 Under the NYS Early Intervention Program, if the core component of the child’s multidisciplinary evaluation suggests possible autism, a supplemental evaluation by personnel qualified to diagnose autism may be conducted to confirm or rule out the diagnosis.
(page 20)
- EIP ❖ 12 An assessment of cognitive development is a required component of the multidisciplinary evaluation under the NYS Early Intervention Program.
(page 21)
- EIP ❖ 13 An assessment of communication development is a required component of the multidisciplinary evaluation under the NYS Early Intervention Program.
(page 22)
- EIP ❖ 14 A family assessment is an optional part of the multidisciplinary evaluation for the NYS Early Intervention Program.
(page 23)
- EIP ❖ 15 An assessment of physical development, including a health assessment, is a required component of the multidisciplinary evaluation under the NYS Early Intervention Program. Whenever possible, the health assessment should be completed by the child’s primary healthcare provider.
(page 24)
- EIP ❖ 16 Medical tests, including genetic tests, MRIs, SPECTs, immune system evaluation, and food allergy and diet assessment are not considered early intervention evaluations or services under the NYS Early Intervention Program. The service coordinator should help families access appropriate services, as needed, through the child’s primary healthcare provider.
(page 24)
- EIP ❖ 17 Audiological services are covered under the NYS Early Intervention Program.
(page 25)

AUTISM/PERVASIVE DEVELOPMENTAL DISORDERS

- EIP ❖ 18 Under the NYS Early Intervention Program, early intervention services must be included in a child and family’s Individualized Family Service Plan (IFSP) and provided at no cost to parents, under the public supervision of Early Intervention Officials and the State Department of Health by qualified personnel, as defined in State regulation. (See Appendix B-4 for a list of Local Numbers for County Early Intervention Programs and Appendix B-3 for the definition of *qualified personnel*.) (page 30)
- EIP ❖ 19 Under the NYS Early Intervention Program, early intervention services can be delivered in a wide variety of home- and community-based settings. Early intervention services can be provided to an individual child, to a child and parent or other family member or caregiver, to parents and children in groups, and to groups of eligible children. (These groups can also include typically developing peers.) Family support groups are also available. (page 30)
- EIP ❖ 20 Under the NYS Early Intervention Program, an IFSP must be in place for children within 45 days of referral to the Early Intervention Official. The IFSP must include a statement of the major outcomes expected for the child and family, and the services needed by the child and family. The IFSP must be reviewed every 6 months and evaluated annually. Information from ongoing assessments should be used in IFSP reviews and annual evaluations. (page 30)
- EIP ❖ 21 An IFSP may be amended any time the parent(s) and the Early Intervention Official agree that a change is needed to better meet the needs of the child and family. (page 30)
- EIP ❖ 22 The type, intensity, frequency, and duration of early intervention services provided to a child and family under the NYS Early Intervention Program are determined through the IFSP process. All services in the IFSP must be agreed to by the parent and the Early Intervention Official. If disagreements arise about what should be included in the IFSP, parents can seek due process through mediation and/or an impartial hearing. (page 34)

EIP ❖ 23 Music therapy is not an early intervention service under the NYS Early Intervention Program.

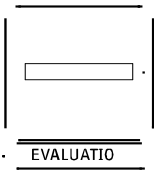
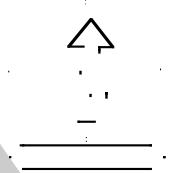
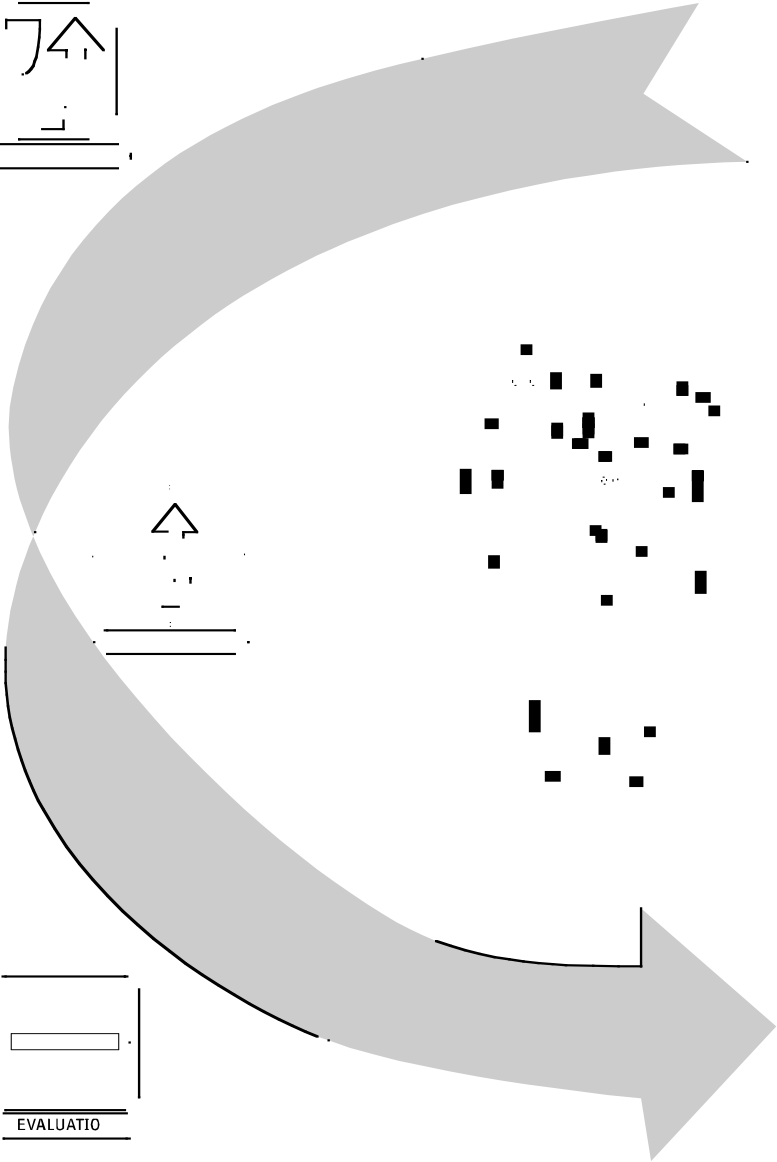
(page 41)

EIP ❖ 24 Drugs, hormone therapies, immunological therapies, vitamin therapies, and medical treatments are not included in the definition of early intervention services in New York State law or regulation pertaining to the Early Intervention Program. Service coordinators may assist families in accessing primary and specialty healthcare services outside the scope of the Early Intervention Program.

(page 44)

EIP ❖ 25 Nutrition services are considered early intervention services under the NYS Early Intervention Program. However, the program does not cover or reimburse for special foods or dietary supplements.

(page 44)



6. Transition

- Plan for transition included in IFSP
- Transition to:
 - services under Section 4410 of Education Law (3-5 system)
- OR
- other early childhood services, as needed

Areas of Development

- cognitive
- physical (including vision and hearing)
- communication
- social/emotional
- adaptive development



REVIEW AHEAD

5. IFSP – Review Six Months /Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies, and/or services
- If parent requests, may review sooner:
 - If parent requests an increase in services, EIO may ask for independent evaluation

Early Intervention Services*

- assistive technology devices and services
- audiology
- family training, counseling, home visits and parent support groups
- medical services only for diagnostic or evaluation purposes
- nursing services
- nutrition services
- occupational therapy
- physical therapy
- psychological services
- service coordination
- social work services
- special instruction
- speech-language pathology
- vision services
- health services
- transportation and related costs

Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.



Revised 12/04

B-2 EARLY INTERVENTION PROGRAM: DESCRIPTION

The Early Intervention Program is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead state agency responsible for the Early Intervention Program.

Early Intervention services can help families:

- ◆ Learn the best ways to care for their child.
- ◆ Support and promote their child's development.
- ◆ Include their child in family and community life.

Early Intervention services can be provided anywhere in the community, including:

- ◆ A child's home.
- ◆ A child care center or family day care home.
- ◆ Recreational centers, play groups, playgrounds, libraries, or any place parents and children go for fun and support.
- ◆ Early childhood programs and centers.

Parents help decide:

- ◆ What are appropriate early intervention services for their child and family.
- ◆ The outcomes of early intervention that are important for their child and family.
- ◆ When and where their child and family will get early intervention services.
- ◆ Who will provide services to their child and family.

Early Intervention Officials (EIO)

In New York State, all counties and the City of New York are required by public health law to appoint a public official as their Early Intervention Official.

The EIO is the person in the county responsible for:

- ◆ Finding eligible children.
- ◆ Making sure eligible children have a multidisciplinary evaluation.
- ◆ Appointing an initial service coordinator to help families with their child’s multidisciplinary evaluation and Individualized Family Service Plan (IFSP).
- ◆ Making sure children and families get the early intervention services listed in their IFSPs.
- ◆ Safeguarding child and family rights under the Program.

The EIO is the “single point of entry” for children into the Program. This means that all children under three years of age who may need early intervention services must be referred to the EIO. In practice, Early Intervention Officials have staff who are assigned to take child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the Early Intervention Official. (See Step 1 of Early Intervention Steps.) Sometimes, someone else will be the first to raise a concern about a child’s development. New York State public health law requires certain professionals, primary referral sources, to refer infants and toddlers to the Early Intervention Official if a problem with development is suspected. However, no professional can refer a child to the EIO if the child’s parent refuses or declines the referral.

Service Coordinators

There are two types of service coordinators in New York State: an initial service coordinator and an ongoing service coordinator. The initial service coordinator is appointed by the Early Intervention Official. The initial service coordinator helps with all the steps necessary to get services — from the child’s multidisciplinary evaluation to the first Individualized Family Service Plan (IFSP).

Parents are asked to choose an ongoing service coordinator as part of the first IFSP. The main job of the ongoing service coordinator is to make sure the child and family get the services listed in the IFSP. The ongoing service coordinator will also help change the IFSP when necessary and make sure the IFSP is reviewed on a regular basis. Parents may choose to keep the initial service coordinator or can choose a new person to be the ongoing service coordinator.

Eligibility

Children are eligible for the Early Intervention Program if they are under three years old AND have a disability OR developmental delay. A disability means that a child has a diagnosed physical or mental condition that often leads to problems in development (such as Down syndrome, autism, cerebral palsy, vision impairment, hearing impairment).

A developmental delay means that a child is behind in at least one area of development, including:

- ◆ Physical development (growth, gross and fine motor abilities).
- ◆ Cognitive development (learning and thinking).
- ◆ Communication (understanding and using words).
- ◆ Social-emotional development (relating to others).
- ◆ Adaptive development (self-help skills, such as feeding).

A child does not need to be a U.S. citizen to be eligible for services, and there is no income “test” for the Program. The child and family do have to be New York State residents to participate in the Early Intervention Program.

How is eligibility decided?

All children referred to the Early Intervention Official have the right to a free multidisciplinary evaluation to determine if they are eligible for services. The multidisciplinary evaluation also helps parents to better understand their child’s strengths and needs and how early intervention can help. A child who is referred because of a diagnosed condition that often leads to developmental delay—like Down syndrome—will always be eligible for early intervention services. If a child has a diagnosed condition, he or she will still need a multidisciplinary evaluation to help plan for services. If a child has a delay in development and no diagnosed condition, the multidisciplinary evaluation is needed to find out if the child is eligible for the Program. A child’s development will be measured according to the “definition of developmental delay” set by New York State.

Services

The Early Intervention Program offers many types of services. Early intervention services are:

- ◆ Aimed at meeting children’s developmental needs and helping parents take care of their children.
- ◆ Included in an Individualized Family Service Plan (IFSP) agreed to by the parent and the Early Intervention Official.

Early intervention services include:

- ◆ Assistive technology services and devices.
- ◆ Audiology.
- ◆ Family training, counseling, home visits, and parent support groups.
- ◆ Medical services only for diagnostic or evaluation purposes.
- ◆ Nursing services.
- ◆ Nutrition services.
- ◆ Occupational therapy.
- ◆ Physical therapy.
- ◆ Psychological services.
- ◆ Service coordination services.
- ◆ Social work services.
- ◆ Special instruction.
- ◆ Speech-language pathology.
- ◆ Vision services.
- ◆ Health services needed for children to benefit from other early intervention services.
- ◆ Transportation to and from early intervention services.

Provision of services

Only qualified professionals—individuals who are licensed, certified, or registered in their discipline and approved by New York State—can deliver early intervention services. All services can be provided using any of the following service models:

- ◆ Home- and community-based visits. In this model, services are given to a child and/or parent or other family member or caregiver at home or in the community (such as a relative’s home, child care center, family day care home, play group, library story hour, or other places parents go with their children).
- ◆ Facility or center-based visits. In this model, services are given to a child and/or parent or other family member or caregiver where the service provider works (such as an office, a hospital, a clinic, or early intervention center).
- ◆ Parent-child groups. In this model, parents and children receive services together in a group led by a service provider. A parent-child group can take place anywhere in the community.
- ◆ Family support groups. In this model, parents, grandparents, siblings, or other relatives of the child get together in a group led by a service provider for help and support, and to share concerns and information.
- ◆ Group developmental intervention. In this model, children receive services without parents or caregivers in a group setting led by a service provider or providers. A group means two or more children who are eligible for early intervention services. The group can include children without disabilities and can happen anywhere in the community.

Reimbursement

All services are at no cost to families. The program accesses Medicaid and commercial third party insurance when parents' policies are regulated by the state. County and state funds cover the costs of services not covered by other payers.

For more information about New York State laws and regulations that apply to early intervention services, contact the Bureau of Early Intervention.

New York State Department of Health
Bureau of Early Intervention
Corning Tower, Room 287
Empire State Plaza
Albany, NY 12237-0660

518/473-7016

http://www.health.ny.gov/community/infants_children/early_intervention/

bei@health.state.ny.us

B-3 OFFICIAL EARLY INTERVENTION PROGRAM DEFINITIONS

These definitions are excerpted from New York State Code of Rules and Regulations, §69-4.1 and §69-4.10. For a complete set of the regulations governing the Early Intervention Program, contact the New York State Department of Health, Bureau of Early Intervention at (518) 473-7016 or visit the Bureau's Web page:

www.health.ny.gov/community/infants_children/early_intervention/index.htm

Sec. 69-4.10 Service Model Options

- (a) The Department of Health, state early intervention service agencies, and early intervention officials shall make reasonable efforts to ensure the full range of early intervention service options are available to eligible children and their families.
- (1) The following models of early intervention service delivery shall be available:
- (i) home- and community-based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at the child's home or any other natural environment in which children under three years of age are typically found (including day care centers and family day care homes);
 - (ii) facility-based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at an approved early intervention provider's site;
 - (iii) parent-child groups: a group comprised of parents or caregivers, children, and a minimum of one appropriate qualified provider of early intervention services at an early intervention provider's site or a community-based site (e.g. day care center, family day care, or other community settings);
 - (iv) group developmental intervention: the provision of early intervention services by appropriate qualified personnel to a group of eligible children at an approved early intervention provider's site or in a community-based setting where children

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under three years of age are typically found (this group may also include children without disabilities); and

- (v) family/caregiver support group: the provision of early intervention services to a group of parents, caregivers (foster parents, day care staff, etc.) and/or siblings of eligible children for the purposes of:
 - (a) enhancing their capacity to care for and/or enhance the development of the eligible child; and
 - (b) providing support, education, and guidance to such individuals relative to the child's unique developmental needs.

Sec. 69-4.1 Definitions

- (b) *Assessment* means ongoing procedures used to identify:
 - (1) the child's unique needs and strengths and the services appropriate to meet those needs; and
 - (2) the resources, priorities and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability.
- (g) *Developmental delay* means that a child has not attained developmental milestones expected for the child's chronological age adjusted for prematurity in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social/emotional, or adaptive development.
 - (1) A developmental delay for purposes of the Early Intervention Program is a developmental delay that has been measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures and/or instruments and documented as:
 - (i) a twelve month delay in one functional area; or
 - (ii) a 33% delay in one functional area or a 25% delay in each of two areas; or
 - (iii) if appropriate standardized instruments are individually administered in the evaluation process, a score of at least 2.0 standard deviations below the mean in one functional area or score of at least 1.5 standard deviation below the mean in each of two functional areas.

- (ag) *Parent* means a parent by birth or adoption, or person in parental relation to the child. With respect to a child who is a ward of the state, or a child who is not a ward of the state but whose parents by birth or adoption are unknown or unavailable and the child has no person in parental relation, the term “parent” means a person who has been appointed as a surrogate parent for the child in accordance with Section 69-4.16 of this subpart. This term does not include the state if the child is a ward of the state.
- (aj) *Qualified personnel* are those individuals who are approved as required by this subpart to deliver services to the extent authorized by their licensure, certification or registration, to eligible children and have appropriate licensure, certification, or registration in the area in which they are providing services, including:
- (1) audiologists;
 - (2) certified occupational therapy assistants;
 - (3) licensed practical nurses, registered nurses and nurse practitioners;
 - (4) certified low vision specialists;
 - (5) occupational therapists;
 - (6) orientation and mobility specialists;
 - (7) physical therapists;
 - (8) physical therapy assistants;
 - (9) pediatricians and other physicians;
 - (10) physician assistants;
 - (11) psychologists;
 - (12) registered dietitians;
 - (13) school psychologists;
 - (14) social workers;
 - (15) special education teachers;
 - (16) speech and language pathologists and audiologists;
 - (17) teachers of the blind and partially sighted;
 - (18) teachers of the deaf and hearing handicapped;

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- (19) teachers of the speech and hearing handicapped;
 - (20) other categories of personnel as designated by the Commissioner.
- (al) *Screening* means a process involving those instruments, procedures, family information and observations, and clinical observations used by an approved evaluator to assess a child's developmental status to indicate what type of evaluation, if any, is warranted.

B-4 TELEPHONE NUMBERS OF MUNICIPAL EARLY INTERVENTION PROGRAMS

Please visit our Web page

http://www.health.ny.gov/community/infants_children/early_intervention/

APPENDIX C

ADDITIONAL RESOURCES

ADDITIONAL RESOURCES

Autism Society of America (ASA) (800) 3-AUTISM
 7910 Woodmont Avenue
 Bethesda, MD 20814

Website: <http://www.autism-society.org/>

Call the national ASA office for information about local ASA chapters.

The Parent Network of WNY (866) 277-4762
 1000 Main Street
 Buffalo, NY 14202

Website: <http://www.parentnetworkwny.org>

Parent to Parent Network of New York State (800) 305-8817
 500 Balltown Road
 Schenectady, NY 12304

Website: <http://www.parenttoparentnys.org>

New York Autism Network (NYAN) – Regional Offices

- New York City and Lower Hudson Valley Regional Center (914) 493-NYAN
- Long Island Regional Center (516) 366-2960
- Western New York Regional Center (716) 275-6605
- Eastern New York Regional Center (518) 442-5132

Website: <http://www.albany.edu/psy/autism/autism.html>

Families for Early Autism Treatment (315) 265-6312
 (FEAT of NNY)
 PO Box 544
 Potsdam, NY 13676

Email: featofnny@aol.com

ADDITIONAL RESOURCES

BOOKS

Autism: The Facts. Simon Baron-Cohen & Patrick Bolton. New York, NY: Oxford University Press, 1993.

Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals. Catherine Maurice, Gina Green and Stephen Luce, eds. Austin, TX: Pro-Ed, 1996.

Children with Autism: A Parent's Guide. Michael D. Powers, et al., eds. Bethesda, MD: Woodbine House, 1989.

Right from the Start: Behavioral Interventions for Young Children with Autism, A Guide for Parents and Professionals. Sandra L. Harris and Mary Jane Weiss. Bethesda, MD: Woodbine House, 1998.

Topics in Autism: Siblings of Children with Autism, A Guide for Families. Sandra L. Harris and Michael Powers. Bethesda, MD: Woodbine House, 1994.

Understanding and Teaching Children with Autism. Rita Jordan & Stuart Powell. New York, NY: John Wiley & Sons, 1995.

The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorders, 2nd edition. Bryna Siegel, ed. New York, NY: Oxford University Press, 1998.

NOTE: Inclusion of these resources is not intended to imply an endorsement by the guideline panel or the NYSDOH. The guideline panel has not specifically reviewed either the books or the information provided by these organizations.

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GUIDELINE VERSIONS

There are three versions of each clinical practice guideline published by the Department of Health. All versions of the guideline contain the same basic recommendations specific to the assessment and intervention methods evaluated by the guideline panel, but with different levels of detail describing the methods, and the evidence that supports the recommendations.

The three versions are:

The Clinical Practice Guideline:

Report of the Recommendations

- ◆ full text of all the recommendations
- ◆ background information
- ◆ summary of the supporting evidence

Quick Reference Guide

- ◆ summary of major recommendations
- ◆ summary of background information

The Guideline Technical Report

- ◆ full text of all the recommendations
- ◆ background information
- ◆ full report of the research process and the evidence

For more information contact:

New York State Department of Health
Early Intervention Program
Corning Tower Building, Room 287
Albany, New York 12237-0618

(518) 473-7016

www.health.ny.gov/community/infants_children/early_intervention/eip@health.state.ny.us