Guidelines for Part C
Early Intervention Services for
Infants and Toddlers with Autism

North Carolina Infant Toddler Program
Early Intervention Branch
Women’s and Children’s Health Section
Division of Public Health
North Carolina Department of Health and Human Services

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Guidelines for Part C Early Intervention Services for Infants and Toddlers with Autism

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North Carolina Infant-Toddler Program
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Introduction

North Carolina’s Infant Toddler Program (ITP) is a system of supports and services for children aged birth to three years who have, or are at established risk for, developmental delay. The program serves infants, toddlers, and their families who are referred by community resources or self-referred. Autism is one example of the types of developmental delays or established conditions that make a child eligible for the ITP.

When a family, child care teacher, provider, or pediatrician questions whether a child has autism, the family often needs information, guidance, and support. Both formal and informal supports are critically important to families, including services that may be provided. The purpose of this document is to assist staff of the ITP’s Children’s Developmental Services Agencies (CDSAs), providers, and families in better understanding and designing quality intervention for those children who are suspected of having autism or who are diagnosed with autism.

Description of North Carolina’s Part C Early Intervention Program

The ITP serves children aged birth to three years of age who have, or are at established risk for, developmental disabilities or delays under Part C of the Individuals with Disabilities Act (IDEA). The program is located within the Division of Public Health’s Early Intervention Branch and its 18 regionally-based CDSAs.

Anyone, such as the child’s family, pediatrician or another person who works with the child, may refer an infant or toddler with suspected developmental disability or delay to the CDSA serving the county in which the child resides. When the child is referred, a staff member at the CDSA contacts the family to explain the program and offer assistance. Through the intake process, children and their families also may be referred to other programs for more appropriate or additional support.

If the family has concerns about their child, a developmental evaluation may be provided to determine if the child is eligible for the ITP. Evaluations may be provided for the child at the family’s home or other natural environment such as a child care classroom. Families’ concerns, impressions and ideas are an integral part of this evaluation process. If the child meets the eligibility definition for the ITP, then the family is offered enrollment. If the family decides to enroll the child, an Individualized Family Service Plan (IFSP) is developed and services begin. These policies are described in the North Carolina Infant Toddler Program Manual.

Ongoing communication and collaboration with others who work with the child is also a key element of the early intervention process. For example, if the child’s pediatrician referred the child and family to the CDSAs, feedback about the child’s evaluation results and connection to other supports and services that the child and family may receive are important information for the child’s pediatrician. For children who may have autism, the importance of this relationship has recently been reinforced. The American Academy of Pediatrics (AAP) has developed guidelines for screening all infants and toddlers for autism as part of ongoing well child care and has emphasized the importance of early intervention.
ITP and American Academy of Pediatrics Guidelines

The ITP worked with the North Carolina Pediatric Society and other partners to implement best practices regarding the 2010 AAP guidelines for screening infants and toddlers developmental delays and disorders, including autism. As pediatricians provide developmental screening routinely and incorporate additional autism screening tools into practice, the level of risk identified for any individual child gives rise to specific action steps. The flowchart in Appendix C shows these action steps. In addition, close collaboration and ongoing communication between Children’s Developmental Services Agencies (CDSAs) and community pediatric or family practices is recommended. This helps to assure that the child and family are being supported through their medical home and primary care physician in addition to the support that they receive through the ITP.

Sammy’s parents and his child care teacher are worried about Sammy. He is 22 months old and does not seem to be able to communicate easily with his mom or dad, his teacher, or the other children in his class. He gets upset easily and his behavior seems to be getting worse.

AAP Recommendations on Medical Evaluation and Management

Primary care physicians play a critical role in ensuring that young children at risk for or diagnosed with an autism spectrum disorder (ASD) receive needed services, both during the initial evaluation and diagnostic process, and related to ongoing health management. Recommendations from the American Academy of Pediatrics regarding the role of the pediatrician in serving such children are described below. Although these services are not provided directly through the ITP, Early Intervention Service Coordinators should work to ensure coordination of services between the ITP and the child’s primary care physician and to encourage families to seek needed medical care and consultation as appropriate.

Sammy’s mom and dad decided to ask their pediatrician about Sammy’s behavior at his next well-child check up. Their pediatrician already was planning to conduct routine developmental screening at 24 months as well as an autism screening.
Sammy’s autism screening suggested that he demonstrates several characteristics of autism such as not responding to his name and not pointing to things of interest to him. His developmental screening showed possible delays in social and language development. The pediatrician and Sammy’s parents decided it would be best to refer Sammy to the CDSA for additional evaluation.

**Comprehensive evaluation.** While the child is receiving comprehensive evaluation services necessary for diagnosis and intervention planning, the AAP also recommends medical evaluation that may include:

- Health, developmental, and behavioral histories,
- Physical examination, including an assessment of the presence of dysmorphic features (features suggestive of a congenital disorder, genetic syndrome, or birth defect) and neurological abnormalities,
- Referrals to pediatric sub-specialists, as appropriate, such as a neurologist, geneticist, and/or developmental pediatrician,
- Consideration of laboratory testing to identify etiology or a coexisting condition,
- Consideration of neurological testing, as clinically appropriate.

The AAP does not recommend a standard battery of genetic and neurological testing, but rather recommends targeted studies based on the child’s clinical presentation.

**Audiology evaluation.** The AAP recommends that all children with language delays, including those suspected of having ASDs, have an audiological evaluation, regardless of the results of the child’s newborn hearing screening test.

**Ongoing medical care and management.** The AAP notes that although educational and behavioral interventions are the cornerstones of management of ASDs, optimization of medical care is also likely to have a positive impact on the child’s progress and quality of life. They recommend that medical care of children with ASDs should therefore include:

- Routine preventive care, including immunizations, and treatment of acute illnesses,
- Care for underlying or associated conditions, such as tuberous sclerosis, fragile X syndrome, or epilepsy, and
- Management of sleep dysfunction, coexisting challenging behaviors, and gastrointestinal problems.
The prevalence of epilepsy among people with ASDs ranges from 11 percent to 39 percent, with a higher prevalence associated with severe global developmental delay and motor deficits. Sleep problems are common at all levels of cognitive functioning among people with ASD, and may be associated with an identifiable cause such as obstructive sleep apnea or gastroesophageal reflux. When there is not an identifiable medical cause, behavioral interventions are recommended. Similarly, when the intervention team is addressing challenging behaviors, medical factors that may be causing or exacerbating the behaviors should be considered. Pharmacologic interventions may be considered for people with ASD to treat maladaptive or disruptive behaviors such as aggression, self-injurious behavior, repetitive behavior, sleep disturbance, anxiety, or hyperactivity. However, use of such intervention with children under the age of 3 is rare. Parents should be directed to their primary care physician if they have questions about the appropriate use of medication to address behavioral and/or emotional difficulties in young children with ASD. Although the relationship between gastrointestinal problems and ASDs is not clear, studies have indicated that people with ASDs often have problems such as chronic constipation and/or diarrhea, frequent vomiting, and frequent abdominal pain. Medical evaluation of children with such symptoms is appropriate, but routine specialized gastroenterological testing for children with ASDs who do not have symptoms is not typically recommended. Similarly, medication may be appropriately used for various medical conditions or behavioral issues, in older children for example, but these do not treat autism itself. Positive behavioral supports are necessary and, for very young children, must be considered within natural learning opportunities and routine based interventions.

**Complementary and alternative medicine and the role of the primary care physician.** The AAP notes that the use of complementary and alternative medicine (CAM) with people with ASD is common and that families often request more information about CAM from their primary health care providers. Although there is much information on the Internet about CAM, there is often not enough scientific evidence to support or refute their use as treatment for ASD. Some CAM treatments have been found ineffective or are known to be harmful. The AAP provides recommendations to pediatricians, including the type of scientific evidence needed to support specific treatments, the importance of being knowledgeable about CAM therapies, their patients’ use of such therapies, providing balanced information and advice about treatment options, identifying risks or potential harmful effects, and maintaining open communication with families. Parents of children enrolled in the ITP who have questions about CAM should be referred to their primary care physician for specific information and guidance.

**Overview of Autism**

Autism is a complex neurological and developmental disorder characterized by atypical development across three primary areas: reciprocal social interaction, communication, and restricted interests and repetitive behaviors. Autism typically appears during the first three years of life and can impact individuals differently and in varying degrees; symptom severity can range from mild to severe. Old myths and falsified research still are present in popular literature (e.g., children with autism are not affectionate, cannot communicate, autism/immunization controversy), but professionals working with infants and toddlers and their families are charged to understand and appropriately share current research and evidence-based practice with the children and families they serve. Key information on these items and on new information on signs of autism are available through the American Academy of Pediatrics website (www.aap.org) and the Centers for Disease Control and Prevention “Learn the Signs: Act Early” website (www.cdc.gov/ActEarly).

The fact that autism typically appears during the first three years of life underscores the importance of early screening and identification strategies. Early intervention supports and services should begin as early as possible, reflected in federal indicators for the ITP such as identifying and enrolling children prior to their first birthday, where appropriate, evaluating and determining eligibility and providing...
service planning within 45 days of the child’s referral to the CDSA, and initiating services within 30 days of the service being identified on the child and family’s Individualized Family Service Plan (IFSP). 6

Autism affects boys more often than girls (roughly 4:1) but extends across all racial, ethnic and socioeconomic levels. Approximately 50 percent of all individuals with autism also have some degree of cognitive impairment. Autism is often accompanied by abnormalities in cognitive development, learning, attention, and sensory processing. 7 A minority of individuals (~20-30%) may experience regression of skills in early childhood.

At this time, there are no biological or genetic tests to diagnose autism; therefore, diagnosis is made primarily through clinical observation, parental/caregiver report, and developmental assessment. The DSM-IV-TR 8 provides current diagnostic criteria for a group of disorders known as Pervasive Developmental Disorders (PDD). Autistic Disorder falls under this broad category. To meet criteria for Autistic Disorder, individuals must show a specific number and type of characteristics. Four other diagnoses are currently included under the Pervasive Developmental Disorders umbrella. 8

*Asperger's Disorder* – This disorder is characterized primarily by deficits in social interaction and the development of restricted, repetitive patterns of behavior, interests, and activities. It is not diagnosed in early childhood and is differentially distinguished from Autism by the lack of clinical delay or deviance in early language and cognitive development. However, parents may have concerns about the child prior to age three – sometimes this may be in the form of motor delays or clumsiness. 9 Best estimates suggest a prevalence of 2/10,000 and it is three to four times more likely to occur in boys than girls. This diagnosis is not used if a child meets criteria for Autistic Disorder.

*Rett’s Disorder* – Rett’s Disorder is a neurological disorder caused by gene mutation(s) on the X chromosome and is almost exclusively found in females; it is thought that males with this mutation may be miscarried or not survive. Following an apparently normal prenatal and perinatal period, there may be multiple specific deficits that occur between 5 and 48 months. These include a characteristic pattern of head growth deceleration, loss of previously acquired purposeful hand skills, and the appearance of poorly coordinated gait or trunk movements. Young children, in particular, may exhibit difficulties in social interaction similar to autism but these difficulties may be transient. The prevalence of this disorder is not well understood but is estimated to be 1/10,000 – 23,000. 10

*Childhood Disintegrative Disorder* – The essential feature of this disorder is a distinctive pattern of severe developmental regression in multiple areas of functioning following at least two years of normal development. These areas may include expressive or receptive language, social skills, adaptive behavior, bowel or bladder control, play, or motor skills. This disorder is thought to be very rare and may occur more often in boys than girls.

*Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)* – This diagnosis is used when there is a significant and pervasive impairment in reciprocal social interaction in conjunction with impairment in communication or the presence of stereotyped behavior, interests or activities. Children receiving this diagnosis will not have shown enough symptomatology for a specific Pervasive Development Disorder diagnosis such as Autistic Disorder.

While the DSM-IV-TR provides the definitive diagnostic criteria for each of the pervasive developmental disorders (including autism and PDD-NOS), many parents and professionals may refer to this group of diagnoses as Autism Spectrum Disorders. Use of this term is gaining popularity because it is inclusive of a wide ‘spectrum’ of individuals with similar social, communication, and behavioral differences.
Furthermore, it may be appropriate to use the term ‘autism spectrum disorder’ to refer to younger children because diagnoses of autism or autism spectrum have been found to be quite stable over time, but distinctions within this spectrum are not very reliable at young ages (e.g., PDD-NOS).  

Although many parents report developmental concerns about their children by the age of 12 to 18 months, diagnosis still may not occur, on average, until four years of age. Some sources have even suggested that the median age of diagnosis is nearly 6 years old. Accurate diagnosis is possible, however, by 18 to 24 months of age, using recent research evidence and focusing specifically on those factors which are most likely to be early identification keys in screening and assessment tools, such as the absence of joint attention. Other early indicators of an autism spectrum disorder are highlighted in the Screening and Red Flags sections of this document. When these factors are present and/or screening or surveillance measures indicate a risk for autism, further evaluation should be performed.

Whereas children may not receive diagnoses at younger ages and therefore within the time of enrollment in the ITP, this does not mean that delays and needs do not exist. Similarly, a diagnosis of autism may be present without showing concurrent developmental delay on testing measures. Clearly, supports and services to these very young children and their families are needed, and many children are enrolled in the program under the developmental delay category based on specific delays in one or more developmental areas (communication, cognitive, socio-emotional, physical, and/or adaptive).

It is important to note that revisions are currently being discussed for the next edition of the Diagnostic and Statistical Manual of Mental Disorders leading to a new designation: DSM-V. Possible edits may include subsuming certain current diagnoses (e.g., Asperger Syndrome) into the broader category of Autism Spectrum Disorders. This new category may replace the current umbrella heading of Pervasive Developmental Disorders. Changes to the criteria for autism are also being discussed. Much research, including epidemiological studies, has been completed since the publication of the DSM-IV, and a newly published DSM-V is eagerly awaited, in part because many practitioners believe that characteristics, features, and specific presentation of autism in infants and toddlers will be included. Once the DSM-V is published, please refer to that updated and new information.

Prevalence Estimates

Estimates of the prevalence of autism have increased dramatically over the past two decades. The current estimate is approximately 1/100 -110; this compares to 1/1500 in the early 1990s. The most recent prevalence estimates are based on the results of two separate, large-scale studies, one of which examined children’s health and educational records and one that surveyed parents.

One estimate was generated by the Autism and Developmental Disabilities Monitoring (ADDM) Network, an ongoing surveillance project sponsored by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control, dedicated to better understanding the prevalence

Sammy was evaluated by CDSA staff. The percentage of developmental delay that was present on his language and social emotional evaluations showed that Sammy is eligible for the ITP.
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of autism. Eleven states, including North Carolina, participate in this surveillance effort which involves trained coders reviewing health and educational records for large cohorts of 8 year old children. The most recent data was from a cohort of 307,790 children who were 8 years old in 2006. Results published in December 2009\(^\text{17}\) indicated that approximately 1 percent or 1/110 of children in these 11 states were classified as having an ASD.

The second recent estimate drew on data collected as part of the 2007 U.S. National Survey of Children’s Health\(^\text{16}\) in which 78,037 parents were asked about a diagnosis of ASD via telephone interviews. Specifically, parents were asked whether a doctor or other health-care provider had said their child had autism and whether the child currently had the condition. Children were not assessed independently to verify the parents’ reports. Results suggested an estimate of 1/91 children, or approximately 1%, have an autism spectrum disorder.\(^\text{18}\)

Results of these recent studies indicate a continued increase in the prevalence estimates of autism spectrum disorders as depicted in the graph shown above from the Autism Speaks website (www.autismspeaks.org).\(^\text{63}\) There may be possible explanations for this trend, including a change in study methods to include a wider range of ASD diagnoses, improved screening and diagnostic tools which may allow healthcare providers to identify more cases of ASD and at earlier ages, as well as increased public awareness which may encourage more parents to ask for help for evaluation when they suspect their child has an ASD.\(^\text{18}\) Additionally, it has been suggested that the possibility of “diagnostic substitution” may exist. A study of the rise in prevalence in California suggested that approximately 25 percent of the increased autism caseload is uniquely associated with diagnostic change through a single pathway – individuals previously diagnosed with mental retardation.\(^\text{50}\) Despite these potential explanations, the prevalence of ASD appears to be increasing, suggesting that ASD is an “urgent public health concern.”\(^\text{21}\)
Screening

The importance of early identification of children with autism has been highlighted in recent practice guidelines issued by the American Academy of Pediatrics\(^\text{22}\), the American Academy of Neurology\(^\text{23}\), and the National Academy of Sciences.\(^\text{24}\) As stated earlier in this document, in recognizing the need for earlier identification, the American Academy of Pediatrics\(^\text{22}\) specifically recommends that pediatricians conduct surveillance for ASD symptoms at each preventive care visit, and conduct specific ASD screening at children’s 18- and 24-month visits. The importance of early detection derives from intervention studies demonstrating significant gains in language, social, and cognitive functioning for young children with autism participating in early intervention programs.\(^\text{25, 26, 27}\)

Screening for ASD is one way to facilitate the early identification for toddlers. Screening has been defined as “a brief assessment procedure designed to identify children who, because of the risk of a possible learning problem or handicapping condition, should proceed to a more intensive level of diagnostic assessment.”\(^\text{28}\) Screening can be conducted by a range of professionals, including health care providers and early intervention personnel. As multiple providers or agencies may have an opportunity to screen or observe the child and make a referral to the CDSA after talking with the child’s family, the interagency work on the referral flowchart \(^\text{4}\) was felt to be of extreme importance to the ITP and the children and families it serves. Health care personnel may screen all children who come to their offices for well-child checkups. Early intervention personnel may screen only those children for whom someone has expressed concern. In this context, screening answers the question of whether the concerns are likely to be related to autism or some other developmental delay or disability.

Screenings gather information in different ways, including parental report, through observations of the child, or through direct interactions with the child. Each method has its merits and drawbacks. One advantage of parental reports is the ease and speed of administration, while a disadvantage is the potential sources of reporter bias.\(^\text{29, 30, 31}\) For example, some parents may fail to recognize abnormal behaviors, while others may view developmentally appropriate behaviors as atypical. Interactive methods allow clinicians to directly observe subtle social and communicative deficits that parents might not recognize; however, some behaviors (e.g., peer interactions) may not be observed as easily in clinical settings. In addition, interactive screenings may require more time - and sometimes training - to administer.

Several screening tools are being used in the community- the most popular being the Modified Checklist for Autism in Toddlers (MCHAT).\(^\text{32}\) This questionnaire is designed for parents of 18 to 24-month-old toddlers. A follow-up interview is considered a critical part of the MCHAT screening process. In brief, the interview consists of a few additional questions related to the “red flags” or symptoms endorsed by the parents. The questionnaire and interview are readily available online. When combined with a follow-up questionnaire and used with 2-year-old toddlers, it has been found that 76 percent of toddlers who fail the MCHAT have autism. Accuracy decreases as children’s age decreases and when the follow-up interview is not completed.
Red Flags

In clinical terms, there are a few important “red flags” that indicate a child should be evaluated for autism. These symptoms are not specific to autism - many children with other disabilities may have these or similar symptoms. However, if a child has one or more of these symptoms, autism should be considered as a possible diagnosis and further evaluation pursued. These symptoms are often included in screening measures and can be useful as benchmarks to aid communication with families about autism. These symptoms include but are not limited to:

- No big smiles or other warm, joyful expressions by 6 months of age or thereafter,
- No back-and-forth sharing of sounds, smiles, or other facial expressions by 9 months or thereafter,
- No babbling by 12 months,
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months,
- No words by 16 months,
- No two-word meaningful phrases (without imitating or repeating) by 24 months,
- Any loss of speech or babbling or social skills at any age.

Evaluation and Diagnosis

**Diagnostic Process.** Accurate and appropriately conducted evaluations, for diagnostic and intervention planning purposes, are essential in ensuring that young children at risk for or who have autism get effective intervention and treatment. The diagnostic process provides important information for families and providers and enhances the intervention team’s ability to design an effective intervention plan. Although every intervention plan should be individualized, diagnostic classification provides a critical framework for communication among those working with the child, including the parents and caregivers. The literature on treatment for children with autism has identified key elements of effective intervention, and in some cases traditional intervention for children with developmental disabilities or behavioral disorders may be contraindicated for a child with autism. Diagnostic classification also provides information for the family regarding what to expect, at least in the short-term, and for family planning purposes. Despite the stress and emotions associated with receiving the diagnosis of autism for a child, parents and caregivers may experience relief at being given a framework for understanding their child’s difficulties. Most parents of children with an ASD first notice differences in their child’s development during the first two years of life, usually at about 14, 17, or 19 months, with 30-50 percent reporting concerns in the first year and 80-90 percent reporting concerns by the second birthday.
Diagnosis of Autistic Disorder at age 2 is reliable and stable, and there is increasing evidence for stability for children under 24 months. The diagnosis of PDD-NOS tends to be less stable than that of Autistic Disorder. For those children who lose their ASD diagnosis, most continue to have developmental difficulties that require intervention. The Diagnostic and Statistical Manual, 4th Edition, is considered the “gold standard” criteria for the diagnosis of autism when used by appropriately trained and experienced professionals. The DSM-IV is not a checklist, but rather a tool for organizing and analyzing clinical information, and its use requires specialized training, knowledge, and clinical skills, including the ability to distinguish autism spectrum disorders from other alternative psychiatric or developmental disorders (differential diagnosis). Discipline-specific professions are licensed to diagnose autism. This does not disregard the understanding and knowledge of autism of professionals from other disciplines; however, the diagnosis itself must involve one of the several types of licensed professionals.

A child may also be referred to the CDSA who has already received a diagnosis of autism from his or her pediatrician or community provider/agency.

In the case of diagnosing young children with autism, the professional must rely on knowledge of typical development, especially in terms of communication and social emotional development and behavior, and diagnostic markers especially relevant to young children. Understanding these markers requires a clinician to recognize behaviors which are present and should not be there as well as recognize behaviors which should be present but are not. For very young children, social-communication deficits, including use of another’s body as a tool, impaired use of nonverbal behaviors, lack of social or emotional reciprocity, lack of shared enjoyment, lack of imaginative or imitative play and delays in spoken language tend to be the clearest discriminators.

Retrospective analyses of videotapes from children’s first year of life have demonstrated poor visual orientation and attention, limited response to name, lack of socially directed looking, excessive mouthing of objects, and aversion to social touch.

The presence of restricted and repetitive behaviors are significant for diagnosing autism, but they can be seen in typically developing children as well as children with other disabilities. However, when observed in typically developing children they are usually milder, only one or two specific behaviors are seen, they decrease with age, and the child is more likely to engage others in the activities making them more social and flexible.

Part of the diagnostic process involves distinguishing autism from other possible disorders. Some symptoms may overlap with those of other disorders; additionally, autism may coexist with other disorders. Many of the disorders that may need to be considered for differential diagnosis in older children do not present in children under the age of 3. In most cases, careful assessment of the child’s social-communication skills, especially qualitative skills essential for reciprocal social interactions and functional communication, including nonverbal communication skills, will distinguish autism from other possible disorders. This includes other communication disorders, behavioral disorders such as Attention Deficit Hyperactivity Disorder (ADHD), and anxiety disorders such as Obsessive-Compulsive Disorder (OCD); furthermore, some of these diagnoses may be more appropriately made in older children. In the case of Reactive Attachment Disorder, careful assessment of the nature of the child’s interactions with others, early history, and relationships with caregivers will provide the critical information.
Distinguishing autism from other possible disorders and/or determining that there may be multiple disorders (e.g., intellectual deficit) reflects the critical component of the ITP in requiring multiple evaluators and multiple assessment tools for the infant or toddler, observing and assessing the child in multiple settings, and gaining critical information from the family and caregivers. Multiple settings are very important for appropriate observation of the infant or toddler’s development, skills, and learning opportunities. Parents may note that their children function better in natural environments than in novel settings, and early intervention’s focus on natural learning opportunities helps families understand ways to support their infant or toddler’s development. In addition, observing a child with siblings or in a child care setting will provide critical information about the child’s interest in and interaction and play with other children.

**Evaluation.** An evaluation provides the necessary information on which to base both the diagnosis of autism and the individualized treatment planning, identifying what is developmentally appropriate for a particular child and their pattern of strengths and weaknesses. The most effective approach is one that:

- Is provided by an integrated and coordinated team of professionals who can assess the child’s functioning across all domains, including cognitive, communication, social emotional (including family functioning), and motor development; adaptive functioning, and response to sensory input,
- Is family centered so as to capitalize on the parents’ and caregivers’ knowledge of the child and set the stage for ongoing collaboration and communication between the professionals and the family,
- Identifies the needs, priorities, and resources of the family, and
- Is culturally sensitive, taking into account the family’s cultural values, language, religion, education, and socio-economic factors that may affect the interpretation of the information gained.

**Key Components of the Evaluation Process.** There are several key components of the evaluation process that are critically important for any child referred to the ITP. Developing a relationship with the family of the infant or toddler who is referred to the ITP is essential in understanding the family’s priorities and concerns, and in facilitating the family’s support of their child’s development. Professionals should always describe current research and knowledge as what is currently known (e.g., “as we understand from the current evidence”). In the case of a question of autism, this importance is no less relevant. Reviewing pertinent background information, interviewing parents and other caregivers of the child, observing the child, providing structured evaluations, and sharing the information gained with the family are all part of a necessary process in order to be most effective for the child and for his or her family.
Review of relevant background information. A review of relevant background information helps in providing information about parental and referral source concerns and questions, and should include:

- Records from the referral source and previous medical providers, and others,
- Birth records, and
- Child/family health history
  - Pre- and perinatal history/course,
  - Child health history, including hospitalizations, surgeries, significant injuries, illnesses, medications, seizures,
  - Vision and hearing status,
  - Family history for developmental delays or disabilities,
  - Family history for congenital, psychiatric, and substance abuse disorders; and suicide.

Parent/caregiver interview. Parents are experts on their child and provide key information in any evaluation or assessment process. Their responses and questions should be interpreted in the context of typical child development and the family’s characteristics, cultural norms and values. A comprehensive medical and developmental history provides the information needed to interpret the child’s behavior and should include:

- Concerns and questions, including those of family members or others,
- Developmental and behavioral history
  - Developmental milestones, including social emotional,
  - Current communication skills and strategies, including gestures and facial expressions,
  - Sleeping patterns,
  - Feeding history and any difficulties,
  - Preferred activities and play skills, including typical interactions with peers,
  - Unusual sensory responses,
  - Atypical interests and/or behaviors,
  - Loss of skills,
  - Behavioral difficulties,
  - Emotional responses,
  - Past intervention or treatment.
- Child health history, as noted above
- Family history
  - Extended separations from caregivers,
  - Marital conflict/separation/divorce,
  - Exposure to trauma,
  - Sibling relationships,
  - Child care/preschool history.

Behavioral observation. A behavioral observation is useful for clarifying parent reports or questions, providing follow up for interview questions that were difficult for the parents to answer, providing direct information regarding key diagnostic indicators, and observing interactions between the child and other family members. Because evaluation of the social, communication, and play skills in children suspected of having autism requires identifying the absence of certain behaviors as well as the presence of others, providing prompts or opportunities for these behaviors during an observation can help to determine whether the child has these skills and, if so, the quality of the skills when utilized. In addition, because parents may be compensating for the child’s difficulties without realizing it, direct observation by
professionals can provide an opportunity to begin to help the family understand the nature and significance of the child’s behaviors. The observation may be structured or unstructured.

**Structured evaluation.** The evaluation provides an understanding of the child’s level of functioning in different domains as well as how the pattern of deficits in skill acquisition may affect his or her overall functioning. Structured evaluation also provides information about the child’s problem-solving strategies and his or her ability to adapt to the demands of the formal testing situation.

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<th>Evaluation and assessment should always include observation of a child in natural settings and across settings.</th>
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Evaluation of the child’s cognitive development and adaptive functioning provides the context upon which to assess other areas of development. Children with autism demonstrate a great deal of variability in their functioning in specific domains and developmental trajectories, and understanding the child’s cognitive functioning can aid in distinguishing young children with autism from those who have other developmental delays. Assessment of verbal and nonverbal development and adaptive skills provides a basis for interpretation of specific social and communicative skills. Assessment of the child’s play skills and use of toys and objects, as well as ability to imitate novel acts, is also important. The child’s level of cognitive functioning may also be relevant in choosing intervention strategies. Assessment of the child’s adaptive skills, which typically include acquired conceptual, social, and practical skills that enable the person to function in every day situations, includes assessment of self-help or daily living skills such as those needed for eating, toileting, and dressing. Such an assessment provides information about the child’s typical functioning at home, and his or her ability to translate skills into every day functioning, which is often difficult for people with autism.

Delays in communication development are not specific to autism, and so the evaluation of this domain must include an assessment of the *qualitative* nature of the child’s social and functional communication, or pragmatic ability. Examples of specific areas of social-communicative skills that should be assessed include joint attention, use of communicative vocalizations, social reciprocity, pretend play, sustained interaction, nonverbal communication skills including coordination of eye gaze and use of gestures, spontaneous giving/showing, and ability to have attention directed. A comprehensive analysis of the domains of communication development includes:

- **Language and communication**
  - Expressive language and communication,
  - Gestural means,
  - Vocal repertoire,
  - Verbal means (words, sentences, conversation),
  - Modality strengths and preferences (speech, gestural, visual)
- **Receptive language and communication**
  - Nonlinguistic response strategies,
  - Understanding of conventional meanings,
  - Comprehension of vocabulary, sentences and discourse
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• Sociocommunicative and socioemotional
  o Range of communicative functions expressed,
  o Reciprocity of communication (rate of communicating, use of repair strategies),
  o Social-affective signals for social referencing and to regulate interaction,
  o Comprehension of and expression of emotion in language and play,
  o Self and mutual regulatory strategies to modulate arousal and emotional state

• Language-related cognitive domains
  o Attention in social and nonsocial contexts,
  o Symbolic representation in symbolic and constructive play,
  o Imitation strategies,
  o Anticipation of routines and event knowledge.

Evaluation of the child’s social emotional development includes achievement of key milestones, peer interactions, and behavioral functioning. Typical social emotional development involves:

• Emotional Development
  o Development of feeling of security – sense of trust, development of intimacy,
  o Ability to express and interpret emotions,
  o Development of empathy/perspective taking,
  o Self-esteem,
  o Frustration tolerance/ability to delay gratification,
  o Regulation of mood and affect (adaptability, reactivity),
  o Regulation of attention,
  o Self-control of behavior,
  o Individuation/independence – understanding of separateness and interest in maintaining boundaries; reconciling one’s personal characteristics with the requirements of interpersonal relations and roles (assertion vs. cooperation)

• Socialization
  o Learning to follow codes and standards,
  o Learning to get along with others,
  o Establishing and maintaining relationships with others,
  o Interacting appropriately with adults,
  o Interacting appropriately with peers - play and social communication.

Children with autism often have significant behavioral difficulties which can be a major source of stress for the family, particularly when these behavioral difficulties limit community participation and interactions with the extended family, affect a parent’s ability to work, or increase marital stress due to disagreements regarding etiology and an appropriate discipline approach. Families may not be able to find babysitters and/or child care providers willing to serve their child due to these behaviors. The family stress may also affect siblings. Behavioral challenges in a child with autism may be related to communication difficulties, environmental stressors, or need for routine and structure. Careful assessment of the possible functional nature of the challenging behavior, including identification of precursors and consequences of the behavior, is necessary for appropriate intervention planning.

Assessment of the family’s functioning and coping resources also is key to developing an effective intervention plan, and may identify the psychosocial emotional factors that influence the child’s coping skills. Family interactions are transactional in nature, with each person in the family being influenced by and influencing the other members. Assessment of the stressors that affect the family’s ability to support the child include the structure of the family, supports, financial resources, personality patterns and coping
strategies, status of marriage, extended family issues, and/or mental health, substance abuse, and medical problems.

Although delays in fine and gross motor skills are not necessarily associated with the diagnosis of autism, the evaluation should include an assessment of motor development. Because of the integrated nature of development in young children, delays in other areas may impact the child’s motor development or ability to demonstrate his or her skills, and intervention should address any delays that are shown. Unusual responses to sensory information are common in children with autism and can contribute to behavioral difficulties as well as impact the child’s adaptive functioning. For example, many children with autism show a combination of hypo-responsiveness (e.g., not responding to social bids), and hyper-responsiveness (e.g., overly responsive to sensory information such as textures and sounds). Appropriate intervention planning will depend on careful assessment of the child’s sensory processing.

**Autism Specific Measures**

When a child demonstrates characteristics of autism and/or has failed an autism screening, specific measures may be utilized to assist in the diagnostic process. The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured, standardized tool that provides opportunities for observation of social, communication, and play behaviors, and presses for key diagnostic indicators for the age range of toddlers through adulthood. For young children, the ADOS allows for observation of social communication skills, joint attention, integration of eye gaze with other forms of communication, and play skills. It includes a standard series of tasks designed to elicit information in the areas of communication, reciprocal social behavior, and restricted and repetitive behavior. Specific indicators included in the ADOS include:

- Frequency of vocalization directed to others,
- Stereotyped/idiosyncratic use of words or phrases,
- Use of other’s body to communicate,
- Pointing,
- Gestures,
- Unusual eye contact,
- Facial expressions directed to others,
- Shared enjoyment in interaction,
- Showing,
- Spontaneous initiation of joint attention,
- Response to joint attention,
- Amount and quality of social overtures,
- Social responses,
- Play,
- Stereotyped behaviors and restricted interests.
The Autism Diagnostic Interview-Revised (ADI-R) is often paired with the ADOS when evaluating a child for autism and provides critical information about current and early development. The ADI-R is a standardized, semi-structured interview conducted with parents or caregivers of individuals suspected of having an ASD. The interview has questions specifically related to early development, language and communication, social development and play, and interests and behaviors. Both current and past behaviors are discussed, with emphasis on potential regression and, for older individuals, focus is on the developmental period between ages 4 - 5 years. The interview takes approximately 1 ½ hours for preschoolers and slightly longer for school-age children. This measure is considered appropriate for children with a mental age of 24 months and older. The ADI-R has a diagnostic algorithm that produces an estimation as to whether the person appears to meet the formal criteria for an ADI-R diagnosis of autism and provides an overall estimation of how severely the person may be affected.

Providing Information to Families. Receiving information about their child’s diagnosis and evaluation results can result in varying emotions for parents. Some parents are distressed whereas others are relieved to have answers, and many parents and other family members experience multiple and conflicting emotions as they search for answers and supports for their child. Families who have good information can use it to understand the child’s difficulties and needs in order to obtain services and get support from other parents. Establishing an effective partnership with parents includes respecting the parents’ right to have information about their child and their ability to cope with difficult information. Prior assessment of the family’s social support network, as well as the parents’ strengths, resources, coping styles and strategies, and conflict resolution style, will enable the professional to provide the family with the information they need in a manner that ensures it will be accessible to them. Professionals may need to attend to their own stress in talking with parents about difficult topics in order to best help the families they serve.

Parent satisfaction with information sharing from professional staff is typically associated with receiving clear information and direct answers, feeling that professionals are sympathetic and understanding of their reactions and feelings, getting information sooner rather than later, getting as much information as possible, having opportunities to ask questions and hear information repeated and re-explained, and receiving information that is both realistic and encouraging for the future.

In talking with families about the information gained in evaluation processes, points to consider are as follows:

- Give feedback as soon as possible to reduce families’ anxiety and stress,
- Provide information consistent with parents’ educational and cultural background, and avoid jargon,
- Explain the reasoning that led to the conclusions and recommendations,
- Allow time for the family to process the information,
- Encourage the family to ask questions,
- Discuss questions; parents may not voice but often have fears and ideas about what may have caused the child’s symptoms (e.g., genetics, perinatal course, environmental exposure, family events such as the birth of another sibling),
- Provide an opportunity for parents to process their feelings about the information by reflecting on their verbal and nonverbal feedback and acknowledging their feelings,
- Avoid arguing with parents; parents’ and other family members’ perspectives are critically important to identifying and understanding the best supports and services for the child,
- Keep prognostic information to a realistic period, stressing the need to refine expectations/conclusions as time continues,
- Be available for questions or additional feedback as needed.
Intervention Recommendations for Children with Autism

The importance and effectiveness of early intervention for young children with autism has been well documented. In fact, a review of programs by the National Research Council in 2000 concluded that “intensive early intervention for children with autistic spectrum disorders makes a clinically significant difference for many children”. Evidence suggests that early intervention may often improve developmental functioning and decrease maladaptive behaviors and symptom severity. However, intensive intervention is not the same as multiple hours of direct therapy. Whereas direct therapy is critical to infants and toddlers with autism, dependent upon the concerns, priorities, and resources of the family and the developmental needs of the infant or toddler, it also is well documented that infants and toddlers learn best within their daily routine activities and that their parents and other caregivers are key to these learning processes. Opportunities for natural learning occur for all very young children within natural settings. Parents, and indeed, all the adults around the child, can learn how to identify and use strategies with very young children who have or are suspected of having autism. These strategies, when used within the family’s daily routines, will make the most difference for the child, as natural learning opportunities are multiple, varied, and allow for repetition and success for the child.

The key in intervention is to use strategies that have an evidence base in order to assure that both direct therapy and support to parents and other caregivers in identifying and using natural learning opportunities will be as effective as possible. Evidence based practice is the required standard for Part C Early Intervention services and outcomes for children as shown on the child’s Individualized Family Service Plan and through summary outcomes for the period of intervention must reflect these evidence based practices.
Further, whereas there is a wealth of literature regarding early learning and early childhood special education directly related to the provision of Part C early intervention, specific research on infants and toddlers with autism is not as rich. This is due in part simply to the age of the children; as noted previously, many children with autism are not diagnosed within the infant and toddler years. Nevertheless, information gained not only from early learning and early childhood special education and those studies which have focused specifically on autism can be used together to provide a sound evidence base for Part C early intervention for children having, or suspected of having, autism.

Most early childhood research studies have focused on preschool aged children (3 – 5 years) with autism or may span the age range from two years through the preschool period. For example, the National Professional Development Center on Autism Spectrum Disorders has identified 24 evidence-based practices, many of which are effective for preschoolers and older children/adults; fewer of these have documented effects for children as young as two years old.

Not only are studies focusing specifically on infants and toddlers less prevalent, those that do exist often have methodological limitations, isolate a discrete skill or treatment, or are single-subject or small sample size studies. Similarly, the National Standards Project conducted a large scale review of effective practices for individuals with autism spectrum disorders under age 22 and concluded that only a limited number had enough evidence to be included for children birth to two years of age: Behavioral, Comprehensive Behavioral Treatments for Young Children, Joint Attention, and Naturalistic Teaching Strategies. Clearly, those strategies which identify and support natural learning opportunities for very young children within their usual, everyday settings and routines are best practices or emerging practices, but detail is still lacking. Most studies have not shown clear evidence on which specific interventions are useful for which children and which symptoms children display. Several current and promising research efforts are focused on identifying effective (evidence-based) treatments in this young age range to help answer these questions. As much of the current research evidence is focused on children who are preschool age, it is very important to understand that for infants and toddlers, less intensive and fewer hours of direct therapy can be appropriate, whereas increased naturalistic learning and social engagement opportunities are critical. Infants and toddlers differ from older children in their social relationships, their cognitive and communicative processes, learning characteristics and daily routines. Interventions should be tailored to meet these unique developmental needs; for example, young children will need experiential learning opportunities within their natural environments and interactions rooted in social play (e.g., in group interactions with other children and/or in natural settings with their families). Infants and toddlers should receive Part C Early Intervention services that support natural learning and routines based intervention.

Results were recently released from the first controlled study of an intensive early intervention appropriate for children with ASD who are less than 2½ years of age; the youngest subjects were 18 months. The intervention, called the Early Start Denver Model (ESDM), integrates applied behavioral analysis (ABA) teaching methods with developmental relationship-based approaches, thereby allowing a more natural delivery method, often in the home, by trained therapists and parents. Each child receives individualized, comprehensive treatment; ESDM content areas include communication, social interactions, play skills, fine and gross motor development, cognition, and personal independence/participation in family life routines. The ESDM uses teaching strategies focused on interpersonal exchanges and positive affect, and on verbal and nonverbal communication.

Children in the study were separated into two groups. One group received up to 20 hours a week of intervention – two two-hour sessions five days a week – from University of Washington specialists. They also received five hours a week of parent-delivered therapy. Children in the second group were referred to community-based programs for therapy. At baseline, the two groups were similar in functioning. At the conclusion of the study, the IQs of the children in the intervention group had improved by an average of
close to 18 points, compared to only seven points in the comparison group. The intervention group also had an equally impressive improvement in receptive language (listening and understanding) compared to approximately 10 points in the control group. In sum, results of this study demonstrated that this novel early intervention program was effective for improving IQ, language ability, and adaptive behavior in children as young as 18 months.

While the particular type of intervention for children with autism is not well studied, specific suggestions have been made for the amount of intervention that may be most beneficial. It has been recommended that children receive intensive intervention, with active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate educational activities designed to address identified objectives. There is, as of yet, no clear blueprint for how these hours are spent. While some of the intervention time should most likely be in 1:1 sessions with therapists who specialize in early intervention and autism, other hours of engagement should be spent in structured child care settings or in focused time with parents or other caregivers.

Children with or suspected of having autism, like typically developing children, need many and varied opportunities to be included in every day settings. Families, child care teachers, and other caregivers can provide opportunities for and support of children’s learning, specific to the child’s needs, with the support of early interventionists. Active engagement of the child can occur in many settings and within many routines-based activities within the normal day of the child. As noted below, active engagement is recommended, and multiple settings and social interactive partners are needed; this active engagement should not be restricted to therapy sessions.

Treatment for autism is a very intensive, comprehensive undertaking that involves the child's entire family and a team of professionals. Some programs may take place in the child's home with professionals and trained therapists and may include Parent Training. Some programs are delivered in a specialized center, classroom or preschool.

While young children with autism share a common diagnostic label, each has individual needs. Because of the individual differences among these children, the Autism Society of North Carolina supports an individualized approach that addresses the core deficits of autism spectrum disorders (e.g., communication, social, sensory, academic difficulties) and that matches each family's preferences and needs. In designing effective programs, the Autism Society recommends that professionals and family members consider the following components:

- A curriculum that addresses deficit areas, focuses on long-term outcomes, and considers the developmental level of each child. Deficit areas include:
  - Inability to attend to relevant aspects of the environment, shift attention, and imitate the language and actions of others,
  - Difficulty in social interactions, including appropriate play with toys and others, and symbolic and imaginative play, and
  - Difficulty with language comprehension and use, and functional communication.
- Programs that capitalize on children's natural tendency to respond to visual structure, routines, schedules, and predictability,
- A focus on generalization and maintenance of skills, using techniques such as incidental teaching approaches,
- Effective and systematic instructional approaches that utilize technology associated with Applied Behavior Analysis, including chaining, shaping, discrete trial format, and others,
Coordinated transitions between service delivery agencies, including 0-2 programs, early intervention/preschool programs, and kindergarten environments,
- Use of technology associated with functional behavioral assessment and positive behavioral supports with a child who presents behavioral challenges,
- Family involvement, including coordination between home and involved professionals; an in-home training component; and family training and support.  

**Comprehensive Interventions.** Many terms are used to describe intervention programs that target symptoms or associated features of ASD. One way to categorize different intervention programs used for individuals with ASD is to consider interventions that are comprehensive (intense practices designed to have a broad impact on core features of ASD) compared to those that are focused (practices intended to change a targeted behavior). A recent study of early intervention service providers in California revealed over 40 strategies or programs that were described as important for children with autism. Comprehensive intervention programs are typically implemented for longer periods of time than focused interventions, and target a broader range of skills and behaviors than focused interventions. For example, a comprehensive program may be defined as one which addresses a core deficit area in autism, including language, social interaction, cognition, or play. Many comprehensive programs involve increases in hours of intervention as well. These interventions may incorporate a range of methods, including focused intervention practices provided by therapists and/or parents or other caregivers. Each comprehensive program has as its basis a conceptual model.

Described below are a small selection of programs which are considered to be comprehensive. The key in reviewing this information is to recognize that specific strategies within the child’s natural settings are what are required for Part C Early Intervention.

**Applied behavior analysis (ABA)** is a broad term that includes the design, implementation, and evaluation of environmental changes to produce socially significant improvement in behavior. It takes what we know about behavior and uses it to bring about changes of the behavior (e.g., how often it occurs, when it occurs, what the behavior looks like). Behaviors are analyzed using behavior assessment to determine the functional relationship of the behavior within the environment. ABA focuses on evaluating and changing antecedents (what is happening before a challenging behavior) and consequences (what happens after a behavior) to produce practical changes. Many intervention programs for children with autism use ABA principles in part or as the entirety of the program.

**Discrete trial training (DTT)** is a form of ABA often referred to as “Lovaas” or “EIBI/Early Intensive Behavioral Intervention.” A discrete trial consists of a 4-part teaching episode: 1) instruction from a therapist or parent, 2) response from the child, 3) consequence provided by the therapist or parent, and 4) a pause between intervals. The University of California Los Angeles (UCLA) Young Autism Project is one treatment program that uses DTT as a primary instructional method for toddlers who have autism. This program involves a set progression of instructional programs that begins with early receptive language and includes programs focused on self help, community and school readiness. Not all programs using DTT follow the same program sequences or curriculum as the UCLA project. Many studies of DTT have demonstrated improvements in a range of skills for young children with autism.

**Pivotal Response Training (PRT)** is a treatment approach that focuses on motivation and initiative that is derived from ABA and the Natural Language Paradigm. PRT capitalizes on naturalistic interactions rather than adult-directed mass trial procedures (as in DTT) to develop child motivation and initiative. PRT targets a range of skills including motivation, responsivity to multiple cues, self-management, and social initiations.
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*Walden/Incidental Teaching* refers to the Walden Early Childhood Programs and uses incidental teaching, a form of ABA that involves capitalizing on the child’s interest to promote communication and social initiation skills. This program at Emory University is a classroom-based, inclusive program for toddlers with autism. Research has demonstrated some positive effects, particularly in language, in children under 3. Incidental teaching itself is often a component of other comprehensive and focused interventions.

*TEACCH* is a method based on cognitive social learning theory, a theory that suggests that there are additional factors to consider when examining how children learn other than antecedents and consequences. Specifically, this theory focuses on the importance of mental states (e.g., attention, motivation) in how a child learns. Based on this model, the TEACCH program emphasizes structured teaching for children with autism. This intervention method builds on autism-specific characteristics involving visual-spatial skills, need for predictable routines, environmental structure, and strengths in visual as opposed to verbal communication. TEACCH also emphasizes parental involvement. For toddlers, this method includes a focus on use of objects to aid in communication and transitions, and teaching play skills through visually clear activities.

The *Denver Model/Early Start Denver* model (ESDM), as noted above, integrates applied behavioral analysis (ABA) teaching methods with developmental "relationship-based" approaches, thereby allowing a more natural delivery method, often in the home, by trained therapists and parents. Each child receives individualized, comprehensive treatment; ESDM content areas include communication, social interactions, play skills, fine and gross motor development, cognition, and personal independence/participation in family life routines. A recent randomized control trial of ESDM compared to community intervention found improvements in cognitive and adaptive skills as well as decreases in autism symptoms relative to the comparison intervention.

The *Developmental, Individual Difference, Relationship-based (DIR/Floortime)* model uses an approach focused on initiation and spontaneity in communication and following the child’s focus of attention and motivations (social-pragmatic approach). The DIR/Floortime program aims to increase socialization, improve language and decrease repetitive behaviors. This method is primarily a parent training program that uses play-based activities to target joint attention and contingent communication.

Responsive teaching models include *It takes two to talk- Hanen* and *Responsive Teaching*. Responsive teaching models focus on a transactional theory of development which proposes that both the child and his or her conversation partners continuously adapt to each other’s behaviors. These intervention models involve training parents to increase their responsiveness to children’s communication attempts, and following their child’s leads.

**Focused Interventions.** Focused intervention approaches target a specific skill, or set of skills, such as joint attention, imitation, symbolic play, or behaviors, such as aggression. The National Academy of Sciences identified intervention approaches that promoted communication, social, and adaptive behavior as well as interventions that addressed problem behavior, finding different levels of evidence for each area. There are many focused interventions for children with autism that practitioners and families may use.

The *Picture Exchange Communication System (PECS)* is a program that targets communication skills using pictures based on behavioral principles. Children are taught to use pictures to initiate requests, respond to questions, and to make social comments.
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Joint attention, play, and imitation interventions have been developed by several research groups to focus intervention on targeting joint attention (e.g., situations when a child and adult share their attention on a similar target), symbolic play, and imitation. Some involve direct child teaching, while others focus on training of parents. Each utilizes a variety of ABA, developmental, and/or responsive teaching approaches. For example, Kasari and colleagues have developed two joint attention programs: one for children and one for parents. In each, children have shown lasting gains in joint attention skills as well as other social-communicative behaviors. Ingersoll has developed a program to teach imitation skills to young children with autism, and has found promising results. For more detail on selecting an intervention program, see Appendices A and B.

Common Elements of Effective Intervention Programs. A report of the National Research Council, *Educating Children with Autism*, includes a review of ten well-known model approaches to early intervention for children with autism and identifies common elements of effective programs. The programs reviewed were diverse and utilized strategies from several different models, including traditional applied behavior analysis, developmental focusing on play skills, relationship-based developmental, parent-training, peer-mediated, naturalistic behavioral intervention, structured teaching, and incidental teaching. The common elements among the reviewed programs which were identified include:

- Specific curriculum content,
- Highly supportive teaching environments and generalization strategies,
- Predictable routines,
- Use of a functional approach to problem behaviors,
- Carefully planned transitions across intervention settings,
- Active family involvement,
- Highly trained staff,
- Adequate resources,
- Supervisory and review mechanisms, and
- Individualizing interventions to meet the needs of each child and family.

The report concluded that due to the fact that “children with autism spend much less time in focused and socially directed activity when in unstructured situations than do other children… it becomes crucial to specify time engaged in social and focused activity as part of a program for children with autistic spectrum disorders.” Based on their review of the research, information about the reviewed program, and information from the general education and developmental literature, the committee recommended that services should:

- Begin as soon as a child is suspected of having an autistic spectrum disorder,
- Include daily, intensive, individualized, and systematically planned developmentally appropriate educational activities aimed toward identified objectives,
- Include individualized attention on a daily basis,
- Involve assessment of progress in meeting objectives on an ongoing basis, with changes made in intensity, programming time, curricula, or training and consultation for providers if no progress is seen over a 3 month period.
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The report also recommended that interventions include a focus on:

- Functional, spontaneous communication,
- Social instruction delivered in various settings, including interactions with typically developing children as appropriate,
- Play skills, including play with peers and appropriate use of toys and other materials,
- Cognitive development, including generalization and maintenance in natural contexts,
- Problem behaviors, using strategies that incorporate information about the contexts in which the behaviors occur and use positive, proactive approaches, functional assessment, functional communication training, and reinforcement of alternative behaviors.

**Linking assessment to intervention.** A primary purpose of assessment is to determine the child’s strengths and needs in order to develop effective intervention plans. Using diagnostic tools is not only helpful in making a diagnosis, but also clearly targets intervention. Assessment information allows families and providers to see the child across settings and with other children, leading to a better understanding and renewed focus that the child is – first and foremost – still a child, whether or not he or she may have autism. All children need natural learning opportunities individualized for their current developmental levels; this is true of typically developing children just as it is true of a child who has a diagnosis or developmental delay.

Evidence based practices in early childhood and early intervention are applicable to supporting the development of all children, including those with and without disabilities. For a child diagnosed with or suspected of having autism, the specific interventions must be connected to the child’s needs and tied to functional outcomes in early intervention, but as with all children who have developmental delays, there are several key themes that underlie the provision of high quality early intervention. Children learn best when participating in natural learning opportunities that occur in everyday routines and activities of children and families and as part of family and community life; and are interested and engaged in an activity, which in turn strengthens and promotes competency and mastery of skills. Learning about children’s interests in interactions with children and in talking with their families allows professionals and families to find multiple and varied situations in which natural learning for the infant or toddler can occur, which in turn facilitates the family’s support of their child’s development. 5, 37, 42, 43, 53
These themes are not new to those who have been practicing early intervention; but early interventionists must consider how to translate them into practice. Effective early intervention occurs when early interventionists provide resources, strategies, and support for families and caregivers, who themselves are enhancing their child’s development and learning. The focus of intervention sessions is on enhancing family capacity and competence in facilitating their child’s learning and participation in family and community life. Effective interventions focus on what’s working and what’s challenging for the child and family’s participation in their every day routines and activities of community life. Therefore, effective early intervention services incorporate opportunities to reflect with the family on what is working, work on problem-solving regarding challenges, and help the family adapt interactions, actions, routines, the environment, and their schedule while they apply successful strategies. Using these key strategies during intervention sessions can significantly enhance the family’s capacity and competence in successfully implementing strategies to meet IFSP outcomes. 5, 19

Already, Sammy’s family and child care teacher can see some changes in Sammy. He seems to be able, at least sometimes, to communicate with them and with some of the other children in the child care classroom. Just this morning, Sammy’s child care teacher saw that while Sammy and another child were playing with trains, Sammy waited for the other child to move her train first, and then Sammy moved his train.

Summary

This document reflects guidelines for Part C early intervention services for infants and toddlers who have, or are suspected of having, autism. Although infants and toddlers may not be diagnosed at the time of entry into the Infant Toddler Program, there may already be concerns named by parents or other caregivers of the child, or the child may have received a screening for autism that leads the primary care physician or other professional or family member to question autism as a diagnosis for the child. The purpose of this document has been to provide information and guidance on best and/or emerging practices. The key is always to support the infant or toddler’s development, whether associated with autism or not, with strategies that occur within natural learning opportunities and settings and support the family and other caregivers in their pivotal role in caring for and teaching the child.

The fields of early intervention and autism are rapidly changing and new practices are emerging. The professional serving very young children with developmental delays, including autism, must always stay on the forefront of learning associated with new research and evidence. Many current initiatives on autism specifically speak to new and emerging practices with young children which have an evidence base, and the websites noted herein are continually updated. Please continue to use all the resources at hand with evidence to support the very young children and families you serve.
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References for Guidelines for Part C Early Intervention Services for Infants and Toddlers with Autism

1 Individuals with Disabilities Education Act, Part C (2004), Public Law 108-446.


7 http://www.cdc.gov/ncbddd/autism/facts.html


10 http://www.kennedykrieger.org/


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16 http://www.cdc.gov/nchs/slaits/nsch.htm

17 www.cdc.gov/mmwr/preview/mmwrhtml.

18 http://www.aap.org/healthtopics/autism.cfm


21 http://www.cdc.gov/vaccinesafety/Concerns/Autism/Index.html


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48 wpspublish.com.


55 www.teacch.com


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63Autism Speaks. Reprinted with permission.


71APA Policy Statement on Evidence-Based Practice in Psychology.


Appendix A

Selecting an Intervention Program

Parents of young children with autism are presented with an overwhelming array of educational and developmental intervention options, many of which have similarities despite their dissimilar presentation and titles. Some programs are controversial and have limited to no scientific or theoretical support, despite claims of efficacy, as well as significant risks. Among the options which do have some scientific and/or theoretical support, the similarities and differences between approaches, coupled with disagreements among advocates of various approaches, make it difficult for families to navigate the process of choosing an approach for their child. Parents of a child who has been newly diagnosed or parents who have been told their child is at risk of a diagnosis of autism may need guidance in evaluating the appropriateness of different intervention options for their child and family.

Selecting the appropriate type of intervention for a young child with autism is complicated by several issues, including a lack of, or limited, research evidence supporting the effectiveness of many intervention programs available, differences in approaches to evaluating the effectiveness of intervention programs, and variability in the availability of different programs in a particular location. While data is available for some programs and models, current research data provides little guidance for matching a particular approach to a particular child. As research continues into the efficacy of different intervention approaches, parents and professionals should consider several additional factors when deciding on a particular approach, including the professional judgment of those who have evaluated and/or provided intervention for the child; the values and preferences of the family, caregivers, and child; and the capacity and quality of programs available in the local area. Professionals can assist families by providing information about different treatment approaches, including the available research data, and information about local providers.71

Finally, professionals can help families evaluate risks and benefits for particular treatment approaches. These considerations include the financial, emotional, energy, and time costs to all family members, including siblings of the child with autism. Once an intervention program is selected, a review of the child’s progress and the family’s satisfaction with the program should be conducted frequently, with adjustments to the intervention plan made accordingly. Regardless of the available data for a particular intervention approach, it does not guarantee a positive outcome for an individual child and family. Evaluations should be conducted using systematic measures, whenever possible, to assist with decisions as to whether to continue, alter, or end intervention, based on how well the child and family are doing.62

Professionals can assist families in selecting an intervention by helping them review the questions in Appendix B: Questions Families Can Ask.

Evaluating the available scientific data for intervention programs for children with autism is not straightforward due to limitations of the research and differences in approaches of the studies. Conducting clinical outcomes research with young children is ethically and logistically complex, expensive, and time consuming, and many of the studies that are available have methodological weaknesses of varying degrees. For example, some studies are descriptive rather than based on controlled experimental research design. In addition, it is often difficult to determine the degree to which other interventions or therapies that the children in the study have received have contributed to the results. Data from randomized controlled trials (RCT) are considered the strongest evidence of the effectiveness of an intervention or therapy. These studies involve randomly assigning study participants to either the group receiving the intervention being studied or a control group which receives a different intervention. This eliminates the possibility that the results were impacted by a characteristic of the participants rather than the treatment itself (for example, the children in the experimental group had higher IQs than the children in the control
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group). Additionally, study participants are assigned without the participants or researchers knowing which group they are in to eliminate placebo effects and bias on the part of the researchers.

Other important considerations in evaluating a research study include the sample size and whether participants were selected to represent the population of children for whom the treatment is designed, whether clear conclusions can be derived from the data, and whether the results can be generalized to other settings or groups. Careful review of the definitions of outcomes measured in a particular study can aid in determining how applicable the results are to an individual. Goals included in the study may be measurable but not necessarily good indicators of long-term goals or consistent with the needs of the child for whom treatment is being selected. The degree of statistical significance reported, the meaningfulness or importance of the data, the size of the difference between the groups studied, and the absolute levels of performance of the groups should also be carefully reviewed when considering the possible implications of a research study.

Finally, it is important to consider the source of the research report and whether the researchers and sponsoring institutions are respected. Research funded by groups with a vested interest in the findings should be considered less trustworthy. Media reports must be evaluated with particular care because they may oversimplify the results, which is likely to lead to misinterpretation. In this case, the reader should review the original article or get additional information from other sources. Research published in peer-reviewed research journals (as indicated in the information for authors submitting articles) has had an independent assessment by other researchers knowledgeable in the topic and therefore is considered more trustworthy than unpublished work or work published without such review. All research needs to be considered in the context of the literature as a whole and what other findings in the same area have been published.68

Several projects have attempted to review the available research literature on the effectiveness of specific interventions for children with autism using a predetermined set of criteria to establish which interventions are evidence-based. While the information from these reviews can be helpful, it may be difficult to resolve differences between the reports due to differences in the literature reviewed, definitions of “evidence-based” used, and levels of specificity of the interventions reviewed. This has limited the consensus in the field of autism about what is evidence based intervention. Focusing on the mechanisms of change, or intervening processes, identified in evidence based treatments, may be helpful in resolving some of these questions.62 In addition, concerns about the applicability of research on evidence based treatments (EBT) to the clinical setting have lead to the adoption of a broader concept referred to as evidence based practice (EBP), which involves the integration of clinical knowledge about the individual client with the research data.34, 61

One such review of the literature is the 2001 report of the National Research Council, Educating Children with Autism.55 The charge to the committee that produced the report was to “integrate the scientific, theoretical, and policy literature and create a framework for evaluating the scientific evidence concerning the effects and features of educational interventions for young children with autism.” The report is extensive and describes the characteristics of effective interventions for impacting the development of communication, social, cognitive, and sensory and motor skills for children with autism, as well as adaptive functioning and problem behaviors. Using predetermined guidelines for evaluating areas of strength, limitations, and the overall quality of the outcome data reviewed, the committee concluded that nearly all children with autism spectrum disorders show some benefit from intensive early intervention and that a subset of children with ASDs make significant progress. However, the available research did not support unequivocal statements on the efficacy of a given approach, claims of recovery from ASDs as a function of early intervention, or comparative statements of the superiority of one model or approach over another.
Guidelines for Part C Early Intervention Services for Infants and Toddlers with Autism

The National Standards Project of the National Autism Center\textsuperscript{57} provides information from a review of the educational and behavioral treatment literature involving people with autism spectrum disorder under the age of 22 published between 1957 and 2007, including information about treatment effectiveness based on age, diagnostic groups, and treatment targets. The reviewers used a rating system involving five dimensions of experimental rigor to evaluate whether the methods used in a study were strong enough to determine whether or not a treatment was effective. Each study also was examined to determine if the treatment effects were beneficial, ineffective, adverse, or unknown. An attempt was made to classify treatments, or intervention strategies, into categories to make the results more clear. Finally, a system was developed to indicate how confident the project staff was about the effectiveness of a treatment, based on the quality, quantity, and consistency of research findings for each type of intervention. Treatments were identified as falling into one of four categories:

- Established: Sufficient evidence is available to confidently determine that a treatment produces beneficial treatment effects for people with ASD. Eleven treatments fell into this category.
- Emerging: Although one or more studies suggest that a treatment produces beneficial treatment effects for people with ASD, additional high quality studies must consistently show this outcome before firm conclusions can be drawn about treatment effectiveness. Twenty-two treatments fell into this category.
- Unestablished: There is little or no evidence to allow firm conclusions about treatment effectiveness to be drawn. Additional research may show the treatment to be effective, ineffective, or harmful. Five treatments fell into this category.
- Ineffective/Harmful: Sufficient evidence is available to determine that a treatment is ineffective or harmful for an individual with ASD. No treatments were found to have sufficient evidence specific to people with ASD to meet this criteria. This is likely due to the fact that researchers typically stop their focus on a treatment when preliminary results suggest it is ineffective or harmful, and researchers would not study treatments found to be ineffective or harmful with different populations just to show that it is equally harmful or ineffective with people with ASD.

The National Professional Development Center on Autism Spectrum Disorders\textsuperscript{56} is an ongoing project which seeks to promote the use of evidence-based practice for children and adolescents with ASDs by providing professional development, technical assistance, evaluation, and content development to programs. The project has identified interventions that produce specific behavioral/developmental outcomes for a child, have been demonstrated as effective in applied research literature based on specific criteria\textsuperscript{56} and can be successfully implemented in educational settings. Information about the interventions, the evidence base, and steps for implementation is provided for the interventions that meet the project’s criteria for being evidence-based practices. The Center recommends that decisions about which EBP to use for a particular child be made by considering:

- Specific goal/objective that is being targeted,
- Domain of behavior to which the goal relates,
- Which practices address that domain of behavior,
- Program’s strengths/needs,
- Judgment of professional,
- Child’s learning style, temperament, interests, and motivators,
- Supports already in place,
- History of what has and has not worked.

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North Carolina Division of Public Health
Appendix B

Questions Families Can Ask

Rationale and Purpose of Program

- What is the rationale, philosophy, or purpose underlying the treatment program?
- How is the philosophy tied to the specific treatment techniques?
- How were the philosophy and treatment methods developed (e.g., scientific research, clinical experience, application or extension from a related field such as learning disabilities)?
- Are you comfortable or do you agree with the philosophy of the program?

Program description

- Exactly what is involved for the child and the family?
- Does the treatment program focus on one particular skill or is it a general, comprehensive approach?
- What are the short-term and long-term effects?
- Do parents, care providers, teachers, others need to be trained in the treatment technique?
- Is there coordination between the treatment program and other individuals/services working with the family (e.g., teachers, therapists, doctors)?
- Are the treatment program goals individualized for each child and his or her family?
- Is there follow up and/or support after treatment termination?
- What are the possible negative effects or side effects of the treatment?
- What impact might the program have on the family's life style? Are there any risks for other family members? Are there any activities, foods, etc. that will be restricted?
- What is the length of treatment? What is the frequency of sessions? How much parent time is required? Can I realistically devote the time required to the treatment?
- What is the cost of treatment?
- Will my insurance company pay for the treatment?

Effectiveness of the Program

- Has this treatment been validated scientifically?
- Is this intervention published in peer-reviewed journals?
- Is there any independent confirmation of the effectiveness of the treatment program?
- Have I received information about this from a variety of sources?
- Was I able to interview other parents and professionals about the treatment?
- Do proponents of the treatment claim that this procedure can help nearly everyone? If so, this should be seen as a "red flag" to slow down and be more careful in consideration of this technique.
- What do my pediatrician and other professionals involved with my child think about the treatment’s appropriateness?
- Are there alternatives that are: less restrictive? better researched?
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Appendix B (Continued)

Questions Families Can Ask

Credentials of the Program Director and Staff

- What is the background of the program staff? Their training and professional credentials?
- What is the staff's training and experience in autism? What is their understanding of the nature of
  the disorder?
- How much experience have they had in providing this type of treatment?
- Is the program staff open to questions and input from the family or other professionals involved
  with the child?

Appropriateness of Program for My Child

- What characteristic behaviors of ASD am I trying to target? Does the treatment that I am
  considering target these characteristic behaviors?
- What positive effects of treatment would I hope to see?
- Can this treatment be integrated into my child’s current program? How will these new
  interventions be combined with strategies and therapies that we are already using with my child?
- Does the program/therapy and anticipated outcomes meet the unique strengths/challenges/goals
  for my child? Do these outcomes match my expectation or goals for my child? What positive
  changes can I expect to see in my child’s behavior, communication, eating, sleeping, learning,
  etc.?
- How will these goals/outcomes be evaluated? How will I know if my child is making progress
  toward desired outcomes? How often will we evaluate my child’s progress? Who will conduct the
  evaluation? How long will we continue until a change can be made in the intervention?
- What is the back-up plan if we choose to discontinue this intervention? Is there any risk of
  discontinuing the intervention? What kind of early intervention services will my child receive if
  we decide to stop the intervention?

References:

55www.teacch.com

58Ohio Developmental Disabilities Council, Autism: Reaching for a brighter future: Service guidelines for
individuals with Autism Spectrum Disorder/Pervasive Developmental Disorder (ASD/PDD).
Primary Care Physician (PCP) is notified as soon as possible about the evaluation result and service plans in order to have a follow-up with the family. Release of Information (ROI) should be completed. PCP shares results of audiological evaluation and other referrals (if any) with the CDSA as soon as results are reported.

Notes:
Autism specific evaluations and/or confirmation of an autism diagnosis are influenced by the age of the child and findings; younger children and those with less significant symptoms are more difficult to diagnose.
Referral Flow Chart Legend & Notes

• Questions of autism for a specific infant or toddler:
  The AAP recommends simultaneous referral for ASD evaluation, EI services, and audiology evaluation.
  – leads to a referral to your Children’s Developmental Services Agency (CDSA)
  – leads to a referral for an audiology evaluation
  – may lead to a referral to a Developmental and Behavioral pediatrician, geneticist, or neurologist for assistance with an etiologic workup and/or a search for coexisting conditions if indicated.

• When referring, include:
  – Diagnosis of autism if you have made it
  – Copies of child’s MCHAT
  – Additional information as appropriate
  – Copies of family’s release of information for communication from and to pediatrician/CDSA

ACTION STEPS

• As Primary Care Practices begin screening for autism per AAP recommendations:
  – PCP’s:
    • Discuss CDSA resources with CDSA staff
    • Discuss other community resources with community partners, including CDSA
    • Facilitate communication between primary practice, other diagnostic referrals, and CDSA
  – CDSAs:
    • Discuss CDSA resources with community PCP’s (e.g., possibility of audiological evaluation)
    • Assure feedback to referring PCP’s regarding eligibility of child. (Complete Release of Information if it has not been obtained at the primary care practice.)
    • Continue communication regarding additional assessment as needed
North Carolina
Infant-Toddler Program

State of North Carolina
Department of Health and Human Services
Division of Public Health
Women’s and Children’s Health Section
Early Intervention Branch
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