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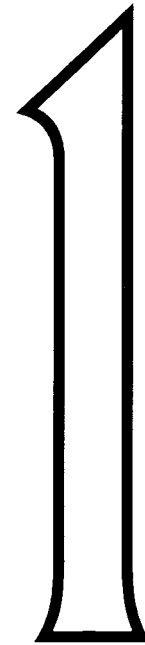
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ABSTRACT

This guide for parents and service providers contains information on autistic spectrum disorder (ASD) in young children and is the product of a review of research-based programs and models and requirements of the Individuals with Disabilities Education Act. The document begins with discussion of the definition of ASD, possible causes of ASD, and screening for and diagnosis of ASD. The main section explains 10 principles of intervention for young children with ASD. These include: (1) the earliest possible start to intervention is essential; (2) services must be individualized for children and families; (3) children with ASD require intensive engagement; and (4) family involvement and participation is critical. The following section examines approaches to providing services including terminology of behavioral approaches, behavioral approaches, developmental approaches, and approaches used by the Birth to Three System. Next, alternative or complementary treatments are considered with suggested principles for evaluating the treatment of autism and questions to ask regarding specific treatments. Concluding sections note the importance of family support, offer a note for parents by parents, and list questions and answers commonly asked the Birth to Three System by parents of children with ASD. Among 10 appendices are lists of early indicators for screening, checklists, screening and assessment tools, relevant organizations, and resources. (Contains approximately 100 references.) (DB)

ED 469 458

Service Guideline



Autistic Spectrum Disorder

*Intervention guidance for
service providers and families
of young children with
autistic spectrum disorder*

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Autism Task Force Members:

Tom Coakley, Co-chair, Birth to Three Regional Manager, Southwest Region
Deborah Richards, Co-chair, Birth to Three Regional Manager, North Central Region, 1996-2001
Martha Bellevue, Hartford Public Schools
Adrienne Benjamen, Parent
Rita Esposito, Director, Reachout, Inc., Provider
Roger Frant, State Department of Education, Bureau of Special Education and Pupil Services
Linda Goodman, Director of the Birth to Three System
Darcey Lowell, MD, Pediatrician
Elizabeth MacKenzie, Director, CES Beginnings Program, Provider
Martha McDonald, Co-Director, Project Interact, Provider
Joe McLaughlin, Director, McLaughlin & Associates, Provider
Ann Milanese, MD, Birth to Three System Medical Advisor
Deb Resnick, Birth to Three System CSPD Coordinator
Michelle Rivelli, MD, Pediatrician
Beth Slosberg, Parent
Maria Synodi, State Department of Education, Bureau of Early Childhood and Social Services
Dianne Willard, Supervisor, Early Connections Program, North Central Region, Provider

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Requests for copies of this guideline or any other guideline may be made by:

Contacting

or

Downloading from our website:

Connecticut Birth to Three System
460 Capitol Avenue
Hartford, CT 06106
(860) 418-6147

www.birth23.org

Connecticut's lead agency for the Birth to Three System is:



Department of Mental Retardation
Peter H. O'Meara, Commissioner
Kathryn duPree, Deputy Commissioner

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Introduction for Parents by Parents

It is our hope that parents reading this guideline will realize that they are not alone. Guidance and support is available. There are people who care and want to help. There is a great deal of information contained in this guideline. There are answers to many of your questions. The key is to get involved and ask for help.

Every parent reading this guideline is facing their own unique experience. For some this may be your first child, for others this might be your third. Some will have a child with severe symptoms while other will have milder symptoms. Whatever the situation, we are all facing many common issues and have similar feelings. Expect to go through many intense and sometimes overwhelming emotions: grief, anger, numbing, apathy, fear and more grief. All these feelings are natural. They might last for a long time. One of the most challenging aspects of this is that at the very time you are feeling sad and overwhelmed, you need to start actively working towards solutions. It's important to realize things will get better, and the key is to begin getting the help your child needs. You need to become your child's advocate.

The research on treatment of Autistic Spectrum Disorder (ASD) is more encouraging than ever before. We know that early, intensive intervention makes a difference. We encourage you to work with your Birth to Three provider to get a program up and running as soon as possible.

Yes, your family life will be transformed. Yes, it is difficult having therapists in your home many hours a week. But, this will help your child. When your child turns three, your living room will be your own again, as the public school community will be meeting these needs. For now, the balance at home shifts towards your child with special needs, and the rewards of this "sacrifice" can be far greater than you imagine.

PREFACE

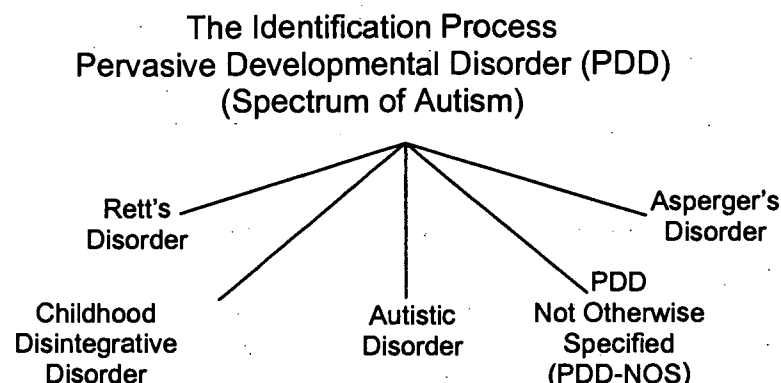
The purpose of this guideline is to help families and service providers develop intervention plans for families of children who have characteristics of disorders on the Autistic Spectrum, including Pervasive Developmental Disorder (PDD). This guideline was prepared by the Connecticut Birth to Three System Autism Task Force and is an updated version of the June, 1997 document. For the purposes of this document, the term Autistic Spectrum Disorder or ASD will be used throughout.

The information in this document is compiled from a review of research-based programs and models as well as discussions with state and national program directors, service providers, experts in the field of autism, and family members who have children with ASD. It is the Connecticut Birth to Three System's interpretation of its responsibility under the Infants and Toddlers with Disabilities section of the Individuals with Disabilities Education Act (IDEA) and in accordance with the mission of the CT Birth to Three System (See Appendix One.) The IDEA and its regulations provide the following broad definition of Autism: 20 CFR 300.5(b)(1) "Autism means a developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three, that adversely affects educational performance. Characteristics of autism include – irregularities and impairments in communication, engagement in repetitive activities, stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences." ⁽¹⁾

WHAT IS AN AUTISTIC SPECTRUM DISORDER OR ASD?

"Autism spectrum disorders are present from birth or very early in development and affect essential human behaviors such as social interaction, the ability to communicate ideas and feelings, imagination, and the development of relationships with others. Although precise neurobiological mechanisms have not yet been established, it is clear that autism spectrum disorders reflect the operation of factors in the developing brain." ⁽²⁾ There are many estimates as to how often ASD occurs, with some sources reporting as many as 1 in 500 children. Autism is 4 times more common in boys than in girls. Family income, lifestyle and education do not affect the chances of a child having ASD.

ASD is referred to as a spectrum disorder because there are a range of symptoms and characteristics that present themselves in different ways. Within the autism spectrum, there are different subgroups. These sub-groups or types are noted in the following diagram: ⁽³⁾



All of the terms used in diagnosing an autistic spectrum disorder come from a manual printed by the American Psychiatric Association called the "Diagnostic and Statistical Manual of Mental Disorders Revised" or DSM-IV.⁽⁴⁾ The DSM-IV lists the criteria for the different categories on the autistic spectrum. Children are identified as having a disorder on the autistic spectrum because they have a severe and pervasive problem in all three of the following areas of development: *social interaction, communication and a restricted range of interests and activities.*

Some of the sub-group labels are used to better describe a child's unique characteristics in these areas of development. For example, Asperger's Syndrome is sometimes referred to as "high functioning autism." Children with Asperger's Syndrome typically have difficulty in the social and behavioral area, but their communication skills are strong and they test in the average to above average range of intelligence. Children with high functioning autism may not have as many motor difficulties as children with Asperger's Syndrome and may not have the same precocious language development. Children with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) have severe problems in the major areas of development, but do not meet the criteria for a diagnosis of autism in all three areas. "Although experienced clinicians and educators can reliably identify the constellation of behaviors that define ASD, even in very young children, distinctions among 'classical autism' and atypical autism, PDD-NOS, and Asperger's Disorder are not nearly as reliable."⁽²⁾ Childhood Disintegrative Disorder and Rett's Syndrome are far less common and will not be the focus of this guideline.

WHAT CAUSES AN AUTISTIC SPECTRUM DISORDER OR ASD?

"Researchers from all over the world are devoting considerable time and energy into finding the answer to this critical question. Medical researchers are exploring different explanations for the various forms of autism. Although a single specific cause of autism is not known, current research links autism to biological or neurological differences in the brain. Several outdated theories about the cause of autism have been proven to be false. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Autism is not caused by bad parenting."⁽⁵⁾ There is considerable current research about the genetic causes of autism.

SCREENING FOR AND DIAGNOSIS OF AUTISTIC SPECTRUM DISORDERS

The most difficult conversation an early intervention provider may have with a family is one that suggests that a child may have autism. This conversation is awkward for many reasons. No one wants to be the bearer of bad news. In fact, it is not uncommon for family members or health care professionals to minimize parents' concerns for their child. Many people have limited experience and a restricted image of a child with ASD. Some feel if the child makes eye contact, then he can not be autistic. Unfortunately this simply is not true.

Most, if not all, children with ASD are referred to the Birth to Three System because of a concern about their speech development. However, unlike children who only have a speech delay, children with ASD demonstrate other problems. It is difficult to play with children with ASD. They don't use a pointing gesture or call your attention to things

that interest them. Usually, they don't respond when you call their name. It is critical to talk to parents and the child's primary health care provider about the aspects of the child's development that are atypical or different and do not represent just a delay in development. Avoiding this discussion is not justified. Parents may ask, "do you think my child is autistic?" Birth to Three providers have a responsibility to answer this question honestly. Although very few Birth to Three professionals are qualified to make a formal diagnosis of ASD, they should describe the concerns that they have and offer a screening for ASD.

Primary health care providers and early intervention professionals need to be familiar with the early signs of ASD. These warning signs include:

1. No babbling, pointing or gesturing by 12 months
2. No single words by 16 months
3. No 2 word spontaneous phrases by 24 months
4. ANY loss of language or social skills at any age.

Additional information on early indicators of ASD is found in Early Indicators for Screening (See Appendix Two). Screening should be completed if a child is exhibiting any of the warning signs or early indicators of ASD. One of the most recently developed screening tools is the Modified Checklist for Autism in Toddlers or the M-CHAT (See Appendix Three). This is an easy-to-administer tool that is based on parental report and helps to identify the aspects of the child's development that are atypical. Another recent screening tool is the BRIEF-Infant Toddler Social and Emotional Assessment (BITSEA) (See Appendix Three). The BITSEA consists of 60 items drawn from the Infant Toddler Social and Emotional Assessment (ITSEA.) It can be completed in 10 minutes by an adult who knows the child well. ⁽⁶⁾ Whatever the instrument selected, screening should be completed with all parents of children who display warning signs or early indicators. It is also recommended for children with communication or social/emotional delays as well as for any child who has a sibling with ASD. Additional screening and assessment tools for ASD are listed in Appendix Four.

The extent to which young children exhibit behaviors considered at risk for ASD and the severity of these behaviors should be discussed with the child's primary care physician. Although pursuing a diagnosis is a difficult decision for most parents to make, in hindsight, many families found the evaluation helpful because it confirmed something they already suspected or directed them to specific information about intervention and support. The process of diagnosis should also be helpful in formulating the intervention plan.

When families wish to pursue a diagnosis, collaboration between the family's primary health care provider, the diagnostic specialist, and the child's Birth to Three program is important. As part of the development of the IFSP, the team will determine how the diagnosis will take place. The Birth to Three program is responsible to ensure that this diagnostic evaluation occurs and how it will occur should be reflected in the IFSP service grid. Alternatively, the family may choose to pursue a diagnosis with a practitioner of their choice outside of the Birth to Three System. That choice, along with the payment source, should be reflected on the IFSP in the "Other Child Related Services" section. The Birth to Three System recommends that a developmental pediatrician, neurologist, or a licensed clinical psychologist complete the diagnostic evaluation. Regardless of their

area of specialty, an accurate diagnosis requires that the professional have training and experience in the area of ASD.

Components of a Diagnostic Assessment

An evaluation for ASD should confirm the diagnosis as well as provide information about the strengths and learning challenges of the child. It should be helpful in planning for intervention. The components of an evaluation for ASD should include:

1. Developmental, Medical (See Appendix Five), and Family History
2. Assessment of problems with social interaction
3. Assessment of development of verbal and nonverbal communication
4. Assessment of repertoire of activities and interests and play behavior
5. An audiological evaluation
6. An assessment of family functioning including strengths, resources, stressors and support needs, both emotional and financial.

A specific autism assessment tool is highly recommended but not required to make the diagnosis. Examples of some assessment tools are included in Appendix Four. For young children identified with ASD, timelines for a re-evaluation should be determined. A child who is assessed at 18-24 months should be reassessed by age three or four.

Recommendations for additional medical evaluations or referrals for medical follow-up must be done through the child's primary health care provider. Medical follow-up is not a service covered by the Birth to Three System. Appendix Five lists the types of medical follow-up that may be suggested.

Regardless of whether or not a child has a diagnostic label or what the label is, research strongly supports the need for early identification and treatment of the behaviors that are characteristic of ASD. The following principles should be used when developing an intervention program for children diagnosed or suspected of having ASD.

PRINCIPLES OF INTERVENTION FOR YOUNG CHILDREN WITH AUTISTIC SPECTRUM DISORDER

Because there is such variation in this disorder, it is unlikely that one intervention approach will benefit all children equally. Two children with ASD can perform very differently from one another. Likewise, two families who have children with ASD have very different needs. The following information is organized according to a list of basic principles of intervention that will apply to all young children with characteristics of autistic spectrum disorders.⁽⁷⁾

- Principle 1: The earliest possible start to intervention is essential.
- Principle 2: Services must be individualized for children and families.
- Principle 3: Children with ASD require intensive engagement.
- Principle 4: Family involvement and participation is critical.
- Principle 5: Intervention is based on a developmental curriculum designed to address the specialized needs of a child with ASD.
- Principle 6: Intervention is playful and systematic.
- Principle 7: Challenging behaviors are addressed using positive behavioral Support.
- Principle 8: Intervention should focus on developing communication skills.
- Principle 9: The development of social relationships is based on a child's ability to play and interact with others.
- Principle 10: The transition from the Birth to Three System to preschool special education and related services should be well planned.

Principle 1 The earliest possible start to intervention is essential.

Children who receive appropriate services earlier achieve better results. One of the most exciting accomplishments in the field of ASD is the ability to recognize and treat the disorder at a very early age. "The diagnosis of autism can be made reliably in 2-year-olds by professionals experienced in the diagnostic assessment of young children with ASD and children are beginning to be referred even before age two years."⁽²⁾ The earlier children receive intervention, the more positive the outlook for their future. Research on treatment for ASD is encouraging. Although characteristics of ASD may be life-long, having ASD is no longer considered a barrier to a full and happy life. Today people with ASD, including those with complex challenges, can be found living in communities, attending neighborhood schools, and working as adults.

Principle 2 Services must be individualized for children and families.

"Individualization" means that each child and family's services are based on that child's needs, strengths and interests and the family's concerns, priorities and resources. This is different for each child and family because each child and family is different. The development of the intervention plan known as the Individualized Family Service Plan (IFSP) and ongoing changes in the plan will be done with the family. Families have a decision-making role as members of the intervention team. The team will determine who will be involved in the program, when services will take place and what will be the focus.

of the services. This guideline introduces families to the framework for intervention to guide them in this discussion. Families will determine how they will be involved in implementing their child's IFSP. Even though the intervention may have a specific curriculum, the daily activities and routines are individualized step by step and customized for each family.

Principle 3 *Children with ASD require intensive engagement.*

By the very nature of the disorder, we know that children with ASD spend little of their own time engaged in purposeful, appropriate, goal directed behavior. Their tendency is to be either disconnected from their surroundings or fixated on specific aspects of objects or people. This restricts children with ASD from discovering and learning. Most children learn from interacting with their environment through observation and imitation. These opportunities may be lost to children with ASD.

Engagement refers to the amount of time a child is attending to and actively interacting with others. This may happen during the time that the early intervention staff is working with a child, and also during interactions with family members and other caretakers. The early intervention staff works with the family to develop ways to keep a child with ASD engaged. The goal of intervention for the child with ASD is to increase the amount of time he or she is engaged throughout the day in order to achieve the outcomes identified on the IFSP. The most intensive intervention program is of limited benefit if it does not result in active engagement in the times when the child is not receiving services.

For children with ASD, 15-20 clock hours per week of Birth to Three services are recommended. The precise number of hours, specified in the IFSP, will vary depending on the child and family, the age of the child, the significance of the symptoms of ASD, the child's rate of progress, the child's health, the child's tolerance for intervention, and the family's participation. Often the younger or more recently identified child will begin with a program of

5 -10 hours per week, and gradually build to a more intensive program of 15-20 hours. Team meetings are an important adjunct to intensive Birth to Three services. Time spent in team meetings, including team meetings with families, is outside of the recommended number of direct service hours. An hour of service that involves more than one interventionist is still regarded as one hour of service. In addition, families need to continue to use the same strategies throughout the child's day to increase the amount of time the child is engaged with others. Intervention should occur on a predictable and routine schedule with attention to the number of hours per day and week, number of weeks per year and the number of environments where intervention occurs. Services should take place 12 months a year. Vacations, holidays, inclement weather, staff illness, or other variations in the service calendar should be discussed with a family well in advance and there should be written documentation that the family understands and agrees with any scheduling changes that are made. Service intensity should be based on the needs of the child and the family and is not dependent on a diagnosis.

Intensive intervention takes place across many different natural learning environments. This includes the home as well as community settings where the child spends his or her time. Families work with the team to identify ways to expand learning opportunities in a variety of settings and activities.

Principle 4 *Family involvement and participation is critical.*

The mission of the Connecticut Birth to Three System is to help families meet the developmental needs of their infants and toddlers (See Appendix One). In order to do this, families play a primary role in their child's development. Families are the most important teachers for their child. They are the constant in a child's life. Service systems and personnel will change over time, but families maintain the continuity from day to day and year to year. Families become lifelong advocates for their child. The Birth to Three System assists families with identifying how they want to be involved now and in the future. The Birth to Three System will provide families with education, support, and guidance to help them develop the skills necessary to help their child with ASD reach his or her potential.

Families choose to be involved in the services for their child with ASD in a variety of ways. This is a great opportunity for families to learn about ASD and how to help their child develop. Early intervention services are delivered in the settings where the family and child spend time. This creates an opportunity to work together and develop strategies that are useful on a day to day basis. Families need to take advantage of this opportunity to develop ways for engaging and interacting with their child. Families need to be an active part of every early intervention visit (See Appendix Six). Families need to be actively involved in their child's program in the following ways:

1. planning and deciding what services their child will receive.
2. evaluating child progress.
3. training and assisting with activities of daily living and developing strategies for addressing the IFSP during daily routines.

Family may choose to also be involved in:

1. identifying services that may affect family resources such as obtaining housing, medical insurance, counseling or medical referrals.
2. networking with other parents such as parent-to-parent support or support groups.
3. taking part in program evaluation or advisory and policy committees for the Birth to Three System.

Principle 5 *Intervention is based on a developmental curriculum designed to address the specialized needs of the child with ASD.*

Curriculum for children with ASD is based on widely accepted principles of child development. The instructional program builds on these principles and the child's individual strengths while also addressing their weaknesses. The curriculum for a child with ASD needs concentrated or specialized instruction to address the areas of language, social interaction, play skills and interests. The essential areas for a specialized curriculum for a child with ASD include:

1. attending to and staying engaged in the environment, especially to other people and learning opportunities;
2. imitating others, including both verbal and motor imitation. Imitation is seen as a fundamental tool for learning;
3. using verbal and non-verbal communication such as gestures, vocalizations and words;
4. understanding and using language to communicate;
5. playing appropriately with toys;
6. playful interaction with others;
7. reciprocal interactions;
8. spontaneous interactions;
9. making choices; and;
10. following daily routines and variations in routines. ⁽⁸⁾

Principle 6 <i>Intervention is playful and systematic.</i>
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Systematic intervention or instruction is carefully planned and consistent. It involves assessing, planning, teaching and measuring progress with each intervention step. Each step is coordinated toward a meaningful set of outcomes or goals. The only reliable way to determine if our teaching is effective is to be systematic and to measure progress on a regular basis.

Systematic instruction relies on intervention decisions that are driven by data collection. Data is used to measure the change in a behavior over time. Data may be taken on the frequency (how often) a behavior does or does not occur, the duration (how long) a behavior does or does not occur, and the range of a behavior (how much support or prompting a child needs). In order to use data in reviewing the effectiveness of intervention the following must happen:

1. an assessment is completed prior to intervention;
2. outcomes and objectives are written in measurable terms. There must be a specific description of the desired behavior;
3. data on outcomes and objectives are taken prior to intervention and used as a baseline for intervention;
4. steps or tasks towards outcomes are analyzed and defined;
5. instructional strategies and supports are identified (e.g. where, when, with whom, level of support);
6. methods for motivating or reinforcing the desired behaviors are identified;
7. methods and timelines for measuring progress are determined;
8. data is taken and analyzed on a routine basis; and
9. adjustments in intervention plans are made based on analyzing progress on the IFSP.

Ongoing collaboration between the family and service providers in the analysis of data and flexibility in adjusting strategies is a key to successful teaching and learning. Continuation of ineffective strategies or relying on techniques merely because they have been shown to be effective with other children may be harmful. Many intervention teams find that a regularly scheduled meeting of all team members (including the family) is important to review data, maintain consistency in intervention, and make timely changes in the intervention.

Principle 7	Challenging behaviors are addressed using positive behavioral support.
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Positive behavioral support is a set of principles that frame the way we think about and respond to children and their behavior. The principles are grounded in the appreciation of each child's strengths and challenges. To practice positive behavioral support means getting to know the whole child and assuming his or her behavior has meaning and that the behavior is a form of communication. It requires recognizing that children develop and respond best when they are respected and supported to enjoy relationships and make choices. The Individualized Support Project or ISP model developed by Glenn Dunlap and Lise Fox provides a framework for working with families who have children with challenging behaviors.⁽⁹⁾ Challenging behaviors displayed by children with ASD are complex and may create frustration and confusion for those who interact with the child. Behavior may range from aggression, tantrums, or self-injury to withdrawal or repetitive, stereotypical actions. Some of these behaviors occur in children who are typically developing. For children with ASD we see behaviors that are extreme, occur more frequently, or are more disruptive to development. Although some behaviors occur for medical or other reasons the majority of challenging behaviors occur because of:

1. social misunderstanding;
2. communication frustration;
3. discomfort with the physical environment;
4. anxiety;
5. intense preoccupations or interests.

Before developing a plan to address problem behavior, a thorough assessment of the behavior must take place. This assessment is completed by the intervention team and helps them to understand what happens before the behavior occurs. The assessment is designed to answer questions such as "Why is the behavior happening?" "When does the behavior occur?" "What function does the behavior serve?" Is the behavior preceded by any biological, environmental, sensory, and/or emotional conditions?" The assessment will also look at what happens after the behavior occurs. "How do people respond to the behavior?" The assessment helps the family understand how their response to the child's behavior may increase or decrease the behavior.

Once the assessment is completed, a positive behavioral support plan is developed. The plan includes strategies to keep the behavior from occurring, provide the child with new skills to replace the undesirable behavior, and assist caretakers to respond to the behavior in new ways. The ultimate goal of the plan is to help the child and family gain access to new environments, have positive social interactions, develop friendships, and learn new communication skills. The result of the support should be that the child has fewer problem behaviors and more ways of interacting with others.

The plan will often include strategies to address communication. A child whose communication skills are limited will have difficulty expressing frustration due to the inability to convey needs and wants. This is a cause for socially unacceptable or challenging behaviors. Therefore, the intervention plan will include development of an effective communication system for the child (See Principle 8.)

The plan may also include strategies to address sensory problems. Many individuals with ASD display different or atypical reactions to common sensory experiences. There may be an over-reaction or under-reaction to sights, sounds, touch, movement, body position/awareness and the pull of gravity. Due to this, the individual may become over-aroused, display discomfort, complain, withdraw or engage in some sensory related behavior. This results in problem behavior.

Intervention to address sensory related behaviors is called Sensory Integration (SI) Therapy. Individuals who have difficulty processing and regulating sensory information are challenged by difficulties with attention, learning, and social interaction. There is no research that indicates that sensory integration therapy has any direct impact on ASD. However, sensory issues may be particularly overwhelming to children with ASD, so treatment that addresses them may prove to be helpful. Sensory Integration therapy strives to reduce the child's preoccupation with his/her sensory needs by satisfying the sensory craving, reducing the stimuli in the environment and increasing the tolerance for sensory stimulation. Once able to regulate the sensory input, the child is more available for engagement and learning opportunities. ⁽¹⁰⁾

<i>Principle 8</i> <i>Intervention should focus on developing communication skills.</i>

The importance of having an effective communication system cannot be underestimated. Communication is much broader than simply talking to one another. A good communicator uses verbal as well as non-verbal behavior to engage a listener. Children communicate to let their needs known long before they can talk. As children develop, their non-verbal communication (i.e. pointing to desired object, lifting their hands to be picked up) becomes natural and is understood by others. Children with ASD, whether verbal or non-verbal, must develop some type of communication system in order to be successful socially. They must be able to communicate in a manner that others will understand.

Alternative or augmentative communication systems are one way to assist children who have limited verbal language. The type of communication system used will vary depending on the child and the activities and environments in which he or she spends time. The system may include simple gestures, sign language, objects, pictures, or an electronic communication device. The use of an alternative system does not mean that the child does not develop verbal language skills or speech. The communication system is used as an aid to improve communication and speech, increase social interactions, and provide structure to daily activities or routines. Children with ASD are often successful with picture communication systems because they tend to have strong visual skills. If a child has difficulty understanding spoken communication, pictures are often used to give more information. For example, a child may be offered a choice of what he wants to play with by showing him two pictures. The child will choose what he or she wants by pointing to the picture or handing it to the adult. The purpose of an alternative system is to expand the ways in which the child can interact with and be understood by a variety of people.

One of the more common alternative communication systems used with children with ASD is the Picture Exchange Communication System (PECS).⁽¹¹⁾ PECS was developed to allow children and adults with ASD and other communication deficits to initiate communication. PECS begins by with teaching a child to exchange a picture of a desired item with an adult to request something. The system goes on to teach discrimination of symbols and then puts them all together in simple "sentences." Many young children using PECS also begin developing speech. The same is true for children who learn sign language. There are some who conclude that signs are even more likely to promote speech, since each word has its own motor movement, whereas the motor movement with every picture is the same, a point.⁽¹²⁾

Whether a child is using an alternative communication system or not, the following skills should be included in a communication curriculum for children with ASD:

1. look at person when name is called;
2. look at objects when they are labeled;
3. attend to a speaker;
4. use eye contact to maintain interaction;
5. imitate simple actions, sounds words, songs or finger plays;
6. gain someone's attention;
7. manipulate a person or object to ask for something;
8. point;
9. combine pointing with looking at a person to ask for something;
10. request more;
11. tell someone you are "all done";
12. say no or refuse;
13. greet others;
14. say yes or agree;
15. name things;
16. name people;
17. describe what others are doing.

Principle 9 The development of social relationships is based on a child's ability to play and interact with others.

In addition to difficulties with communication, young children with ASD often lack interaction and play skills. Intervention for a child with ASD needs to specifically address these skills.

Before focusing on social interaction in play, the child needs to have some skills for using toys in a playful way. Usually children begin interacting with toys by playing by themselves. To increase a child's success while playing, the environment needs to be organized. The physical space should be defined in a way that is clear for the child, for example, sitting at a table or on a rug. The choices of toys and activities need to be planned. The length of the play period and how to end the play session should be determined. Initial sessions for learning how to use toys may include simple actions on toys such as dumping, pulling, and building. Once the child becomes more sophisticated

in his or her use of toys, he or she will move on to symbolic use of toys. This will include simple imitation such as giving a baby doll a drink or talking on a play telephone.

Social play begins when a child plays with a parent or alongside another child or sibling using the same materials. This is referred to as parallel play. As the children interact with materials, they learn to share materials and themes in a play routine. Moving into play that is more cooperative or social requires skills such as turn-taking and sharing. For children with ASD, these skills may have to be taught. Children develop from simple cooperative play to participation in small group activities. Again, for a child with ASD this often requires planning and support to be successful. Just placing a child with ASD in a group setting with children is not sufficient. Often it is helpful to begin with a short, planned "play date." The number of children should also be limited to one or two familiar children and the environment should also be familiar. The toys should be identified that will be most motivating for the child with ASD and there should be sufficient number of toys for both children to have their own set.

A child's social behavior with adults and peers needs to be a focus of intervention. This focus usually begins with child-adult interactions which, over time, become child – child interactions.

The basic structure for planning for social interactions should include the following:

1. define the space;
2. organize the choices, toys or materials;
3. organize which materials are to be shared;
4. organize the expectations of the activity;
5. define the social expectations for the children;
6. determine how long the activity will continue;
7. determine how the activity will end.

These same guidelines can be used when introducing a child with ASD to a larger group setting such as a play group or nursery school class.

It may also be helpful to use the same structure in planning community experiences for the young child with ASD. Community settings may be difficult for the child with ASD because they are unpredictable. Although all aspects of a community outing cannot be organized, establishing some of the above parameters will help the child stay calm and focused throughout the experience. Community outings should begin in the presence of a trusted adult. The goal is for the child to become familiar enough with the peers to be comfortable in the community or group setting with less adult support over time.

Principle 10 The transition from the Birth to Three System to preschool special education and related services should be well planned.

Children with ASD often have difficulty with change, including change experienced when starting something new and different. During the transition to a school based program there will be changes in adults, children, settings, and routines. The child with ASD may

be so sensitive to change that they may notice differences that we do not. There are significant differences between the service delivery model used in the Birth to Three System and an educationally based program developed by a local school district. Planning and flexibility on the part of Birth to Three providers and preschool programs are necessary to assist families and children with adjusting to this change.

When planning the transition from a Birth to Three program to a school program, the following is helpful:

1. the earliest possible notification to the school system that the child is receiving Birth to Three services. This should occur even before discussions regarding transition take place. Early notification allows the school district to plan for the child with ASD. This may include identification of the appropriate staff and resources needed as well as completion of any training staff may need;
2. the earliest possible communication with the school district about the child and family's strengths;
3. details of the program that is in place and strategies that have been successful;
4. a focus on the family as well as on the child throughout the transition process.

Cooperation between a Birth to Three program and the school district is essential for effective transitions. Prior to the transition meeting that is held at least 90 days before the child's third birthday, it may be helpful to identify skills that can be introduced at home but that will be helpful in a school based program. In addition, community resources for necessary family supports that may not be available from the school should be identified.

Flexibility and creativity on the part of the school district and the Birth to Three program is needed for transitions to meet the needs of the child and family. For example, for children who turn three in the late spring or summer, the school may want to investigate whether it is possible to have the services in the IFSP continue until September using the school as a payment source. If the child is turning three early in the school year, it may make sense for the school district to consider asking the Birth to Three program to deliver services in the school setting.

Unfortunately, many children with ASD do not present their complex needs until very shortly before their third birthday. If that is the case, Birth to Three providers must work diligently to help parents understand the need to share information with the school district as soon as possible. Transition and transition activities should be a major focus of IFSPs for all children with ASD but especially for those nearing the age of three. School districts may wish to participate in joint evaluations or observations of the child. It is important for Birth to Three programs to participate in early information-sharing with school districts for all children with complex or challenging behaviors whether or not they have an ASD diagnosis.

APPROACHES TO PROVIDING SERVICES TO YOUNG CHILDREN WITH AUTISTIC SPECTRUM DISORDERS

There has been a great deal of publicity and controversy about what is the “best” way to address the needs of children with ASD. Several approaches have been widely publicized. When parents learn that their child may have an ASD, they may come to believe that a certain “brand name” program is guaranteed to resolve all of the issues associated with the condition. Extensive research has been conducted about many approaches. “Children’s outcomes are variable, with some children making substantial progress and others showing very slow gains. Although there is evidence that interventions lead to improvements, there does not appear to be a clear, direct relationship between any particular intervention and children’s progress. Thus, while substantial evidence exists that treatments can reach short-term goals in many areas, gaps remain in addressing larger questions of the relationships between particular techniques and specific changes.”⁽²⁾

Further, while research has shown that early treatment is very beneficial, “early” is usually defined as three years of age or older. “It remains to be seen whether very young children (i.e. 2 years or younger) will tolerate and benefit from teaching sessions that are as lengthy and structured as those commonly used with children 3 years and older.”⁽¹³⁾

In reality, the intervention strategies that work best for the young child with ASD are those that fit a given child’s needs. A good plan will consider the developmental strengths and needs and unique learning style of each child. One child may require a high level of direct instruction, whereas another may be over stimulated by it. Children with ASD learn in complex ways. Their learning needs, like their autism, transform as they develop. In many cases, focusing exclusively on one approach or method of instruction, which might temporarily produce a desired result could ultimately restrict a child’s growth. Sometimes, however, there may be a rationale for temporarily putting a significant effort into the development of a specific skill.

It is useful to characterize the active ingredients of treatment approaches along a continuum – from traditional behavioral approaches such as discrete trial to more contemporary behavioral approaches that use naturalistic language teaching techniques to developmentally oriented approaches. —

Terminology of Behavioral Approaches

To understand behavioral approaches to ASD, a clarification of terms is necessary.⁽¹³⁾ In brief, behavior analysis is the study of behavior, behavior change, and the agents of change. Applied Behavioral Analysis (ABA) is the science of applying what is learned from the analysis of behavior to understand the relationship between behavior and conditions. The behavior analyst uses data review to develop theories as to why a particular behavior occurs in a particular context and then creates interventions to alter the behavior(s). Information obtained from behavior analysis, therefore, is used to purposefully and systematically modify behavior.

Applied Behavioral Analysis generally emphasizes four elements:

1. antecedents (what comes before the targeted behavior such as instructions, demands, or corrections);
2. behavior (which is observable and measurable);
3. consequences (such as reinforcement); and the
4. context (the setting conditions such as people, places, materials, activities, or time of day.)

Since the 1970s, the science of ABA has been used to create programs for individuals with autism that teach specific skills in a specialized sequence with the goal of increasing or improving socialization, communication, and general adaptive functioning. Such treatment, applied intensively in the toddler and preschool years, has been referred to as Early Intensive Behavioral Intervention (EIBI). Although they are not synonymous, ABA is often used interchangeably with EIBI, particularly in the popular press. ABA also is erroneously perceived as a specific intervention technique rather than as an overall science and service delivery mechanism used to establish, guide, and evaluate ongoing intervention.

Behavioral Approaches

Among the ABA-based approaches for young children with autism developed to date, most are based on the research of Lovaas and others at the University of California, Los Angeles. This has led many to conclude inaccurately that the term “Lovaas therapy” can be used interchangeably with ABA or other intensive behavioral treatments for autism. Within both broadly defined ABA-based interventions and more specific EIBI programs, numbers of techniques are used to accomplish treatment goals. These often include traditional behavioral techniques such as functional assessment, prompting, shaping, and reinforcement, as well as techniques specifically designed for the treatment of autism (e.g. Discrete Trial Instruction).

Discrete Trial Instruction (DTI) is a method of teaching children that was first adapted for children with autism by Dr. Ivar Lovaas and his colleagues at UCLA. This method of instruction includes multiple opportunities of intensive practice or “trials” where the child is taught to respond to a command or “stimulus.” Each practice session includes a series of short, concise instructional prompts. The model emphasizes precision and organization during instruction. This includes adult control over the learning environment, the use of prompting and shaping techniques, and reinforcement when the child produces the correct response. The rationale for using DTI is the belief that children with autism are unable to learn in natural contexts due to their specific learning and behavioral characteristics. ⁽¹⁴⁾

However, there are even variations in the uses of DTI. The more recent work of Vincent Carbone and his colleagues advocate uses of discrete trials in which the curricular content is very specific to functional verbal behavior, the trials are usually mixed rather than massed, and the response time is very short. ⁽¹²⁾

The difficulties cited with using a traditional behavioral model to enhance social and communication skills include the artificial nature of the instructional setting and the lack of a clear link between instruction and the social use of a skill. ⁽¹⁵⁾

There is now a large body of empirical support for behavioral approaches using naturalistic teaching methods. These behavioral programs, also described as EIBI programs, are often carried out in community and home settings and are structured to take advantage of natural learning opportunities. Incidental teaching⁽¹⁶⁾ which often takes place in a preschool classroom setting is an example of a behavioral model of this type. The Individualized Support Program (ISP) is a behavioral approach that focuses on communication-based skill development and family support.⁽¹⁷⁾ Structured teaching (e.g. TEACCH) is a cognitively-based behavioral approach to teaching self care skills and managing disruptive behavior.⁽¹⁸⁾ Other behavioral approaches include pivotal response training, which targets behaviors that will have widespread effects on development.⁽¹⁹⁾

Developmental Approaches

There are numerous intervention approaches based on a developmental framework^(20, 21, 22, 23) Although the empirical support for developmental approaches is more limited than for behavioral approaches, there are several treatment studies that provide empirical support for language outcomes using specific strategies built on a developmental^(24, 25, 26, 27) and many case studies, with Greenspan and Wieder⁽²⁸⁾ providing the largest case review. Developmental approaches share many common active ingredients with contemporary naturalistic behavioral approaches and are compatible along most dimensions.⁽²³⁾ A common feature of developmental approaches is that they are child-directed. Intervention emphasizes the development of skills through active exploration and positive social interactions, based on the belief that children acquire skills through social interactions. These approaches emphasize naturally occurring situations as the context for instruction. Intentionality and meaning are assigned to all of the child's behaviors. The rationale for using a developmental approach to enhance development in children with autism is based on the belief that the fundamental process of learning is the same for all children, so children with autism are able to learn in natural contexts.⁽²⁹⁾ One of the developmental approaches most commonly used is the relationship-based model, also called "Floor Time" which was developed by Dr. Stanley Greenspan.

One of the drawbacks of the relationship-based approach for children with autism is the open ended quality of the instructional environment. Children who lack core skills such as joint attention and imitation or who have severe challenging behaviors may be harder to engage in this model.

Another developmental model is the *socio-communicative approach* designed by Dr. Barry Prizant and Dr. Amy Wetherby. This approach builds on a child's current communication skills, even if the child uses unconventional means to communicate. It uses more natural activities and events as contexts to support the development of the child's socialization and communication abilities. Interactions in this approach are characterized by shared control, turn taking, and reciprocity whenever possible.⁽²³⁾

The limitations to the socio-communicative approach include the inconsistency in the number of learning opportunities that occur depending on the skills of the interventionist and the difficulty some children have in a distractible learning environment. Documentation of progress may also be less specific than in a behavioral approach.

"The conceptual differences between developmental and behavioral approaches to intervention are real, yet the gaps in practice appear to be narrowing. Developmental

researchers may criticize behavioral approaches for failure to target the specific deficits associated with autistic spectrum disorders, ⁽³⁰⁾ and it has been argued that this failure to select target skills within a meaningful developmental framework results in isolated skills that are difficult to transfer to other situations and skills. ⁽³¹⁾ Behaviorists counter that the irregularity of skill development in children with ASD decreases the relevance of careful adherence to normal developmental sequencing. ⁽³²⁾ However, “developmental approaches to ASD treatment have incorporated methods that recognize the needs of children with ASD for high levels of structure, adult attention and consistency. At the same time, behavioral interventions are increasingly being used to address complex social and communication goals in normal environmental settings.” (National Research Council, 2001.)

Approaches used in the Birth to Three System

One or more of the previous approaches may be helpful in developing an individualized program for a child with ASD in the Connecticut Birth to Three System. These approaches, in conjunction with the principles of intervention, should be considered when developing an IFSP, depending on the individual needs of the child and family.

All of the intervention techniques used in the Connecticut Birth to Three System are carried out by licensed and certified staff as well as early intervention associates and assistants who meet the requirements of the Birth to Three Personnel Standards for Connecticut. Intervention for children with ASD requires that staff with expertise in the implementation of the approach be a member of the intervention team. These individuals may come from a variety of professional backgrounds such as speech pathology, occupational therapy, early childhood education, special education or psychology. These staff members have the responsibility of working with the team in the design, training, and implementation of the program.

ALTERNATIVE OR COMPLEMENTARY TREATMENTS

There is a great deal of information available today on treatment options for young children with ASD. In addition to the standard forms of treatment previously noted in this Guideline, there are others that fall into a category of physiological and/or physical interventions. These are often referred to as alternative treatments or complementary treatments. These interventions are viewed as an addition to the existing services provided and supported by the Birth to Three System. Although the Birth to Three System neither provides these services, nor covers their cost, a service coordinator can assist a family in gathering necessary information on these treatment options.

Some of the concerns service providers, as well as families, have expressed regarding these treatments include:

1. the family may have unrealistic and false expectations about the outcome of the intervention.
2. there are tendencies for some interventions to be either too narrow in focus or to claim that the intervention will affect all areas of development.
3. the financial impact on families who pursue treatments, is significant. most treatments are not reimbursable by health insurance or, if they are, very little is covered.

4. there is a lack of scientific research and documentation on the effectiveness or potential side effects (physical or emotional) that may result from the treatment.
5. there is a difficulty in finding qualified specialists to help implement and oversee treatment.

Families need to acquire as much information as possible before deciding to use these treatments. It is essential that these treatments be done under the guidance of qualified medical specialists or therapists with experience in ASD. These specialists may also be helpful in providing information on the effectiveness of the treatment based on other people whom they treat. Families need to keep in mind that participating in alternative treatments is very challenging and they will often require ongoing support to implement the treatment as well as data collection to measure effectiveness. In many cases, alternative treatments involve a change in a family's lifestyle. There are no "quick fixes" and therefore treatments require ongoing supervision and adjustments as well as family commitment. Most importantly, in order to determine if a treatment is effective, it is essential to participate in one at a time. Intervention with multiple treatments will not allow assessment of which treatment was actually successful.

To assist parents or caregivers as they evaluate different treatments, below is a list of guidelines created by Dr. B.J. Freeman in her paper "Diagnosis of the Syndrome of Autism: Questions Parents Ask."

Principles of Evaluating the Treatment of Autism

1. approach any new treatment with hopeful skepticism. remember that the goal of any treatment should be to help the person become a fully functioning member of society.
2. beware of any program or technique that is touted as effective or desirable for every person with autism.
3. beware of any program that thwarts individualization and potentially results in harmful program decisions.
4. be aware that any treatment represents one of several options for a person with autism.
5. be aware that treatment should always depend on individual assessment information that points to it as an appropriate choice for a particular child.
6. be aware that no new treatment should be implemented until its proponents can specify assessment procedures necessary to determine whether it will be appropriate for an individual with autism.
7. be aware that debate over use of various techniques are often reduced to superficial arguments over who is right, moral and ethical and who is a true advocate for the child. this can lead to results that are directly opposite to those intended.
8. be aware that new treatments have often not been validated scientifically.

Questions to Ask Regarding Specific Treatments:

1. Will the treatment result in harm to the child?
2. How will failure of the treatment affect the child and family?
3. Has the treatment been validated scientifically?
4. Are there assessment procedures specified?
5. How will the treatment be integrated into the child's current program? Do not become so infatuated with a given treatment that functional curriculum, play and social skills are ignored.

An overview of some of the alternative or complimentary treatment options and resources are included in Appendix Seven.

FAMILY SUPPORT

Children with ASD present unique challenges to their families. No two families of children with ASD will require the same support and often the need for support changes over time. Family support goals on the IFSP are often as important as child developmental goals. Similarly, these goals should be evaluated over time and changed to reflect the needs of the child and family. Parents have shared that their need for support is quite significant during the time their child was first identified with an ASD.

The IFSP should reflect a wide range of family support outcomes. These might include:

1. The need for information on ASD and intervention philosophies;
2. Opportunities to speak with other parents of children with ASD;
3. Support groups for parents of children with ASD;
4. Training on how to teach the child new skills or strategies to integrate child's intervention into daily routines;
5. Identifying appropriate childcare or respite support options;
6. Professional counseling support;
7. Support and information for siblings of children with ASD;
8. Support and information for extended family members;
9. Support for families to develop advocacy skills for their child with ASD.
10. Support at the time of transition out of the Birth to Three System or other transitions the family may experience.

Appendix Eight contains a list of resource organizations for families.

A FINAL NOTE FOR PARENTS BY PARENTS

As parents trying to guide other parents dealing with this enormous challenge, it is important to realize and accept that you and your family will need support in many different areas ranging from emotional issues to understanding the vast array of information. Your family as you know it will be dramatically altered. Emotions will be running high. Trying to learn to cope and understand exactly what this diagnosis of ASD means to you and your family will take time. Some days, weeks, and months are better than others. There will be continuous decisions that need to be made. It is important to realize that support is available in different forms depending on you and your family's needs are. Don't hesitate to ask for help. At first it will seem overwhelming...so start with the resources that you feel comfortable with and that are easily available to you.

The good news...there are books, videos, support groups, internet connections, and counseling. Talking to Moms and Dads in similar circumstances will help. It helps to realize that you are not alone and to have someone to talk with that speaks the same language and has similar experiences. You will be better prepared to help your child if you have good solid support for yourself. Even if you are not the type to go outside your family for help or if the idea of going to a group frightens you, just talking to another parent on the phone can be helpful. Your Birth to Three provider can offer a wealth of information. Use the resources identified in this document to get you started. Know that if you need the help - it is available.

QUESTIONS COMMONLY ASKED THE BIRTH TO THREE SYSTEM BY PARENTS OF CHILDREN WITH ASD

1. **Q.** *My child has not had an evaluation for ASD. Will the Birth to Three System pay for an evaluation?*
 - A.** Yes, if the evaluation is not covered by your medical insurance or any other payment source and the IFSP team determines that pursuing a diagnosis is appropriate, the evaluation may be included in section VI of the IFSP. This means that it is the responsibility of the Birth to Three program to pay for the diagnostic service. Your Birth to Three program has professionals identified for this purpose. (A member of the IFSP team typically does not perform the evaluation.) It is essential that this diagnostic evaluation be done in collaboration with the child's primary care physician.

2. **Q.** *My child's teacher has shared her concern regarding my son's development and behaviors. We recognize that he has delays and is different than other two-year-old children. We think he is too young to be brought to a specialist for a diagnosis. We would prefer to wait another year to see how he develops. Is there any harm in waiting?*
 - A.** It is important that families make the decision that they are most comfortable with for their child. You may want to review the questions on one of the screening tool (M-CHAT) in Appendix Three of this document. This will indicate if your child is at risk for ASD. You may choose to pursue a diagnosis after completing the screening. Any of the recommendations in this document can be implemented with or without a diagnosis. What is most important is that you and your team are discussing your child's individual needs and developing a plan to address his challenges. The research is very clear that intervention should begin as early as possible to be most successful and that a diagnosis is more accurate after the age of two years.

3. **Q.** *My child was diagnosed by an expert in the field who does not live in Connecticut. During the evaluation, he recommended we hire a consultant outside of the Birth to Three System to consult with us on his program. Will the Birth to Three System pay for this?*
 - A.** No, the Birth to Three programs in Connecticut are not obligated to hire an outside consultant if the program has the available expertise to implement the IFSP. Parents are welcome to invite anyone they choose to participate in the IFSP meeting. As part of the development of the IFSP, appropriate staff and supports are discussed and identified. It is the program's decision as to whether they need a consultant and, if so, who that consultant will be.

4. **Q.** *Can early intervention cure ASD?*
 - A.** No, there is no nationally accepted treatment that claims to cure ASD. Research does indicate that with early and intensive intervention, many children make substantial gains and enter kindergarten in a regular education classroom with varying levels of support.

5. **Q.** *Who is qualified to work with a young child with ASD?*

A. There is no specific credential or discipline that qualifies an individual to work with a child with ASD. We find that the complexity of behaviors and needs for children with ASD often require a team of individuals who work with the family. Team members could include any or all of the following: a special educator or early childhood educator, an early intervention assistant or associate, a speech/language pathologist, an occupational therapist, a psychologist or a social worker. It is important that the members of the team have adequate training and experience in working with children with ASD. Frequently, our providers will have experienced staff as part of their program to deal with all the components of the IFSP. If they do not have staff experienced in a specific strategy or technique, then they may hire a consultant of their choice to provide technical assistance and training to the staff and family.

6. **Q.** *Will the Birth to Three System provide a discrete trial instruction program for my child?*

A. Yes, discrete trial instruction is a technique used within a framework of applied behavioral analysis. Your Birth to Three provider will assist you with implementing discrete trial instruction if it is determined to be an effective technique based on your child's needs and is identified on the IFSP. This will typically be one component of the IFSP that also includes opportunities for generalization of skills to other settings and social interaction with others.

7. **Q.** *Will the Birth to Three System pay for an alternative therapy such as auditory training, vision therapy or cranial sacral therapy for my child?*

A. No, the Birth to Three System will assist families with finding information and resources on alternative or complimentary treatments. Often these treatments are considered medical intervention, which are not covered by our System. The System will not provide any treatment that has not been proven effective based in research studies. The Birth to Three Medical Advisory Committee in collaboration with the Birth to Three Regional Managers will advise providers and families of techniques or approaches that fall into this category.

8. **Q.** *What should I do if I am not satisfied with my child's progress or program?*

A. If you have discussed your concerns with the staff working with your child and are not satisfied, you should contact the Director of the program who provides your services. In addition, you may contact your Birth to Three Regional Manager or INFOLINE to express your concerns. They will inform you of ways to file a formal complaint if you choose. The Birth to Three System also provides formal mediation of differences between families and providers or the option of a hearing by an impartial hearing officer. Your rights to this process are explained in the Family Handbook: Guide II Orientation to Services as well as a brochure entitled "Staying in Charge." You may ask your Service Coordinator for a copy of either of these at any time.

9. **Q.** *What if I want services delivered by a program or particular provider that is not affiliated with the Connecticut Birth to Three System?*
- A.** Your Birth to Three program is obligated to provide your child and family with appropriate, individually-designed services that address your child's needs and will offer developmental benefit. The program may choose to use its own staff or may choose to use subcontractors to deliver those services. Who they use and how much they pay their subcontractors is their decision. If you have located a subcontractor that you would like them to use, you may suggest it. However, it is ultimately the program's decision.
10. **Q.** *What will happen to my child when he turns three years old and no longer receives services from the Birth to Three System?*
- A.** All school districts in Connecticut are required to provide children with disabilities, an educational program to meet each child's needs at the age of three. In order to ensure that children have services and supports in place on their third birthday, planning and communication begins at least 6 months before the child turns three. The child will be referred to the local school district and a meeting will be scheduled to review the child's progress and any additional evaluations necessary to determine if the child is eligible for services from the school district. The Birth to Three System has a handbook and a video to assist families with planning for the transition process. You can obtain these from your service coordinator.

APPENDICES – INDEX

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Appendix One



MISSION

The Mission of the Connecticut Birth to Three System is to strengthen the capacity of Connecticut's families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities. The system will ensure that all families have equal access to a coordinated program of comprehensive services and supports that:

- foster collaborative partnerships
- are family centered
- occur in natural environments
- recognize current best practices in early intervention
- are built upon mutual respect and choice

Partnerships: Effective supports for families depend on providers and families working closely with a variety of community, state and federal programs.

Family Centered: Evaluation, planning and services are designed around the family's needs, concerns, and priorities and keep the whole family in mind.

Natural Environments: Providing services within activities that occur in the child and family's home and community offers opportunities for the child to learn and practice new skills and participate more fully in his regular daily routine.

Best Practices: Research and laws continually require new approaches to services. Providers use up-to-date, effective service strategies.

Respect and Choice: Families choose their Birth to Three program. Decisions about services and supports reflect the family's knowledge, beliefs, hopes, family characteristics and culture. Achievements are made by families and providers working together on the same level and recognizing that each has important information to share.



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Appendix Two

Early Indicators for Screening of Autistic Spectrum Disorders

Age (months)	Sensory-Motor (restricted repertoire of activities)	Speech-Language (cognitive development)	Social (relating to people and objects)
Birth (0-6)	Persistent rocking Inconsistent response to stimuli	No vocalizing Crying not related to needs Does not react differentially to adult voices	No anticipatory social responses (when sees or hears mother) Does not quiet when held Poor or absent eye-to-eye contact Fails to respond to mother's attention and crib toys
6-12	Uneven motor development Difficulty with responses to textures (e.g., problems transitioning to table foods) Failure to hold objects or attachment to unusual objects (or both) Appears to be deaf Preoccupation with fingers Over or under-reaction to sensory stimuli (or both)	Babbling may stop Does not imitate sounds, gestures, or expressions Does not relate needs Does not give objects when requested to do so	Unaffectionate, difficult to engage in baby games Does not initiate baby games Does not wave "bye-bye" Not interest in toys Flicks toys away Does not show distress when mother leaves room Absent or delayed social smile Does not repeat activities that he/she enjoys Does not extend toys to other people Does not differentiate strangers from family
12-24	Loss of previously acquired skills Hyper-or-Hyposensitivity to stimuli Seeks repetitive stimulation Repetitive motor mannerisms appear (e.g., hand flapping, whirling)	No speech or occasional words Stops talking Gestures do not develop Repeats sounds non-communicatively Words used inconsistently and may not be related to needs	Withdrawn Does not seek comfort when distressed May be over distressed by separation No pretend play or unusual use of toys (e.g., spins, flicks, lines up objects) Imitation does not develop No interest in peers

Age (months)	Sensory-Motor (restricted repertoire of activities)	Speech-Language (cognitive development)	Social (relating to people and objects)
24-36	Unusual sensitivity to stimuli and repetitive motor mannerisms continue Hyperactivity or hypoactivity (or both)	Mute or intermittent talking Echolalia (e.g., repeats television commercials) Specific cognitive abilities (e.g., good rote memory, superior puzzle skills) appears to be able to do things but refuses Leads adult by hand to communicate needs Does not use speech communication	Does not play with others Prefers to be alone Does not initiate Does not show desire to please parents
36-60	Repetitive behaviors may decrease or occur only intermittently	No speech Echolalia Pronoun reversal Abnormal tone and rhythm in speech Does not volunteer information or initiate conversation May ask repetitive questions	Foregoing characteristics continue but may become interested in social activities Does not know how to initiate with peers Upset by changes in environment Delay or absence in thematic play

Source:
 B. J. Freeman, Ph.D.
 Professor of Medical Psychology
 Department of Psychiatry and Biobehavioral Sciences
 UCLA School of Medicine
 Los Angeles, CA 90024-1459

Appendix Three

M-CHAT Modified Checklist for Autism in Toddlers

Please fill out the following about how your child *usually* is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2. Does your child take an interest in other children?	Yes	No
3. Does your child like climbing on things, such as up stairs?	Yes	No
4. Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5. Does your child ever pretend, for example to talk on the phone or take care of dolls, or pretend other things?	Yes	No
6. Does your child ever use his/her index finger to point, to ask for something?	Yes	No
7. Does your child ever use his/her index finger to point, to indicate interest in something?	Yes	No
8. Can your child play properly with small toys (e.g., cars or bricks) without just mouthing, fiddling, or dropping them?	Yes	No
9. Does your child ever bring objects over to you (parent) to show you something?	Yes	No
10. Does your child look you in the eye for more than a second or two?	Yes	No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Yes	No
12. Does your child smile in response to your face or your smile?	Yes	No
13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)	Yes	No
14. Does your child respond to his/her name when you call?	Yes	No
15. If you point at a toy across the room, does your child look at it?	Yes	No
16. Does your child walk?	Yes	No
17. Does your child look at things you are looking at?	Yes	No
18. Does your child make unusual finger movements near his/her face?	Yes	No
19. Does your child try to attract your attention to his/her own activity?	Yes	No
20. Have you ever wondered if your child is deaf?	Yes	No
21. Does your child understand what people say?	Yes	No
22. Does your child sometimes stare at nothing or wander with no purpose?	Yes	No
23. Does your child look at your face to check your reaction when faced with something unfamiliar?	Yes	No

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The authors of the M-CHAT recommend conservative scoring rules in order to miss as few children on the autism spectrum as possible. Any child who fails three or more items on the entire M-CHAT, or two or more of the critical items should receive a comprehensive evaluation. The critical items are 2, 7, 9, 13, 14, and 15.

The Brief Infant-Toddler Social & Emotional Assessment (BITSEA)
(Briggs-Gowan & Carter, 2002) ©

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Child's birth date: _____
month / day / year

Today's date: _____
month / day / year

Sex of child: 1: Boy 2: Girl

Your relationship to child: 1: Mother 2: Father 3: Other

Child's ethnicity: 1: White/Caucasian
2: Black/African American

3: Hispanic/Latino 5: Native American/Eskimo
4: Asian/Pacific Islander 6:

Other: _____

Instructions: This questionnaire contains statements about 1- to 3-year-old children. Many statements describe normal feelings and behaviors, but some describe things that can be problems. **Some may seem too young or too old for your child. Please do your best to answer every question.**

For each statement, please circle the answer that best describes your child in the LAST MONTH. Circle 0 to indicate "Not True or Rarely." Circle 1 to indicate "Somewhat True or Sometimes." Circle 2 to indicate "Very True or Often."

Please choose the answer that best describes your child in the LAST MONTH:

0 = not true/rarely

1 = somewhat true/sometimes

2 = very true/often

- | | | | |
|--|---------|---|---------|
| Shows pleasure when s/he succeeds
(For example, claps for self). | 0 1 2 | 25. Imitates playful sounds when you ask him/her to. | 0 1 2 |
| Gets hurt so often that you can't take
your eyes off him/her. | 0 1 2 | 26. Refuses to eat. | 0 1 2 |
| Seems nervous, tense or fearful. | 0 1 2 | 27. Hits, shoves, kicks, or bites children (not including
brother/sister). (N = No contact with other children) | 0 1 2 N |
| Is restless and can't sit still. | 0 1 2 | 28. Is destructive. Breaks or ruins things on purpose. | 0 1 2 |
| Follows rules. | 0 1 2 | 29. Points to show you something far away. | 0 1 2 |
| Wakes up at night and needs help to
fall asleep again. | 0 1 2 | 30. Hits, bites or kicks you (or other parent). | 0 1 2 |
| Cries or tantrums until s/he is exhausted. | 0 1 2 | 31. Hugs or feeds dolls or stuffed animals. | 0 1 2 |
| Is afraid of certain places, animals or things.
What is s/he afraid of? _____ | 0 1 2 | 32. Seems very unhappy, sad, depressed or withdrawn. | 0 1 2 |
| Has less fun than other children. | 0 1 2 | 33. Purposely tries to hurt you (or other parent). | 0 1 2 |
| Looks for you (or other parent) when upset. | 0 1 2 | 34. When upset, gets very still, freezes or doesn't move. | 0 1 2 |
| Cries or hangs onto you when you try to leave. | 0 1 2 | The following questions are about feelings and behaviors that can be
problems for young children. Some of the questions may be a bit
hard to understand, especially if you have not seen them in a child.
Please do your best to answer them anyway. | |
| Worries a lot or is very serious. | 0 1 2 | 35. Puts things in a special order, over and over. | 0 1 2 |
| Looks right at you when you say his/her name. | 0 1 2 | 36. Repeats the same action or phrase, over and over.
Describe: _____ | 0 1 2 |
| Does not react when hurt. | 0 1 2 | 37. Repeats a particular movement, over and over
(like rocking, spinning, etc.).
Describe: _____ | 0 1 2 |
| Is affectionate with loved ones. | 0 1 2 | 38. "Spaces out." Is totally unaware of what's
happening around him/her. | 0 1 2 |
| Won't touch some objects because of how they feel. | 0 1 2 | 39. Does not make eye contact. | 0 1 2 |
| Has trouble falling asleep or staying asleep. | 0 1 2 | 40. Avoids physical contact. | 0 1 2 |
| Runs away in public places. | 0 1 2 | 41. Eats or drinks things that are not edible,
like paper or paint.
Describe: _____ | 0 1 2 |
| Plays well with other children (not including
brother/sister). (N = No contact with other children) | 0 1 2 N | 42. Hurts him/herself on purpose.
For example, bangs his or her head.
Describe: _____ | 0 1 2 |
| Can pay attention for a long time. (Not including TV) | 0 1 2 | | |
| Has trouble adjusting to changes. | 0 1 2 | | |
| Tries to help when someone is hurt.
For example, gives a toy. | 0 1 2 | | |
| Often gets very upset. | 0 1 2 | | |
| Gags or chokes on food. | 0 1 2 | | |

The Brief Infant-Toddler Social & Emotional Assessment (BITSEA)
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Scoring Instructions:

- 1) Convert all "N" (no opportunity) responses to 0

N responses are possible for the following two items:

"Plays well with other children"

"Hits, shoves, kicks or bites other children."

- 2) Problem domain:

Sum the responses to the following questions: 2, 3, 4, 6, 7, 8, 9, 11, 12, 14, 16, 17, 18, 21, 23, 24, 26, 27, 28, 30, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42

If 6 or more problem questions are unanswered, we recommend that you do not use the problem sum.

- 3) Competence domain:

Sum the responses to the following questions: 1, 5, 10, 13, 15, 19, 20, 22, 25, 29, 31

If 2 or more competence questions are unanswered, we recommend that you do not use the competence sum.

Cutpoints:

Problem scores that fall at or above the values listed below are considered high problems.

Competence scores that fall at or below the values listed below are considered to indicate low competence.

BITSEA Scale:	Girls Cutpoint	Boys Cutpoint
Problems		
12-17 months	13	15
18-23 months	15	15
24-29 months	13	14
30-35 months	14	14
Competence		
12-17 months	11	11
18-23 months	15	13
24-29 months	15	14
30-35 months	15	14

Combining a child's status on the Problem and Competence cutpoints provides most sensitive detection of problems and delays in competence. By combining cutpoints we mean that if a child has a high problem score and/or a low competence score s/he would be considered to screen positive on the BITSEA.

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Appendix Four

Screening and Assessment Tools for Autistic Spectrum Disorders

Adaptive Behavior Inventory for Children (1978) Mercer, J.R., & Lewis, J.F. San Antonio, TX: The Psychological Corp.
Autism Diagnostic Interview – Revised ADI-R (1994) Lord, C., Ritter, M., & LeCourteur, A. <i>Journal of Autism and Developmental Disorders</i> , 24, 659-685.
Autism Diagnostic Observation Schedule ADOS (1999) Lord, C., Ritter, M., Di Lavourre, P., & Risi, S. Los Angeles, CA: Western Psychological Services.
Autism Screening Instrument for Educational Planning (ASIEP.) (1980) Krug, D., Arick, J. & Almond, P., Portland, OR
The Brief Infant-Toddler Social & Emotional Assessment (BITSEA) © Birggs-Gowan, M. & Carter, A., 2002
Childhood Autism Rating Scale (CARS) (1988) Schopler, E., Reichler, R., & Renner, B. Los Angeles, CA: Western Psychological Services.
Communication and Symbolic Behavior Scales (CSBS) – (1993) Wetherby, A.M., & Prizant, B. Paul H Brookes Publishing, CO.
Filipek, P., Accardo, Baranek, G., Look, E., Dawson, G. Gordon, B., Gravel, J., Johnson, C., Kallen, R., Levy S., Minshew, N., Prizant, B., Rapin, I., Rogers, S., Stone, W., Teplin, S., Touchman, R., & Volkmar, F., (1999) The Screening and Diagnosis of Autism Spectrum Disorders. <i>Journal of Autism and Developmental Disorders</i> , 29, 439-484.
First Signs – Public Awareness program for early identification for children with ASD. Phone 978-346-4380 1-800-80-SIGNS Email: nwiseman@firstsigns.org
Pre-Linguistic Autism Diagnosis Observation Schedule PL-ADOS (1995) DiLavore, P., Lord, C., & Rutter, M. <i>Journal of Autism and Development Disorders</i> , 25, 355-379
Psycho-educational Profile – Revised (PEP-R) (1990) Schopler, E., Reichler, R., Bashford, A., Lansing, M. & Marcus, L. Austin, TX: Pro-Ed.
The Checklist for Autism in Toddlers (CHAT) (1992) Baron-Cohen, S., Allen, J., & Gillberg, C. Can autism be detected at 18 months? The needle, the haystack and the CHAT. <i>British Journal of Psychology</i> , 161, 839-842.
The Modified Checklist the Autism in Toddlers (M-CHAT) (1999) Robins, D., Fein, D., & Barton, M. University of Connecticut, Psychology Department, 860-486-3515
Vineland Adaptive Behavior Scales (1984) Sparrow, S., Balla, D., & Cicchetti, D. Circle Pines, MN: American Guidance Service

Appendix Five

Medical follow-up for children identified with ASD

This information is included to help parents and providers know what to expect in the course of a diagnostic assessment and medical follow-up for children with ASD. It may provide guidance about what kinds of questions to ask in order to understand and enhance the medical follow-up.

It is important to include the following in any developmental or family history:

- the level of developmental skills obtained
- whether there were any regressions in skill development, especially in language or social skill area
- a description of the quality of the child's relationships and play
- unusual eating or feeding behavior
- unusual behaviors including motor stereotypes
- unusual sensory sensitivities or reactions
- history of medical events such as head trauma, infection, birth difficulty
- history of staring episodes or seizure disorder
- history of ear infections, gastrointestinal disturbances, or allergies
- family history of ASD, mental retardation, Attention Deficit Hyperactive Disorder (ADHD), learning disabilities, Fragile X Syndrome, Tuberous Sclerosis, anxiety or depressive disorders or hearing impairment.

All referrals to medical specialists should be done through the child's primary health care provider. Medical follow-up is very specific to the unique profile and needs of the child and family.

- Audiological assessment including Brainstem Evoked Response (BSER) if child is not otherwise testable
- Complete Blood Count (CBC)
- Lead level screening
- Dermatological/Skin exam to rule out Tuberous Sclerosis
- Fragile X testing in presence of significantly delayed development and if maternal family has history of learning disabilities, mental retardation or attentional disorder
- Genetic testing (chromosomal evaluation) in presence of significant delayed development, unusual facial or body features, or family history of ASD
- Referral for neurologic assessment in presence of staring, seizures, developmental regression. This should include evaluation of head circumference, muscle tone and motor asymmetries. The neurologist may order a 24 hour EEG if sleep deprived or a MRI if EEG is abnormal
- Referral to gastroenterologist in presence of history of gastrointestinal distress including chronic diarrhea, vomiting, constipation or abdominal pain.

- Referral to allergist if significant history of food allergies or eczema in child or very strong history of family history of allergic disorders
- Referral to nutritionist to oversee “elimination” diet if food allergy is diagnosed.

Although no medications have been demonstrated to “treat” autism, there is evidence that for some older children and adults medications improve symptoms associated with autism including anxiety, depression, and overstimulation. The most common medications used are psychoactive medications. Psychoactive medications are those that primarily affect the person’s behavior, mood, or thought processes. Many of the psychoactive medications that have been used to treat other neurological or psychiatric conditions have also been tried for individuals with autism.

Diet therapies most commonly involve the elimination of milk or wheat products from the diet. It is suggested that some young children with autism are allergic to milk and/or wheat and that eliminating these foods from the diet can result in an improvement in manifestations of autism. Most of the literature focuses on eliminating cow’s milk or casein and/or wheat products or gluten. If food allergies are documented, the child should be treated with standard allergy testing methods, including elimination diets. Since children with ASD often only eat a very small number of foods, it is important to consult with a nutritionist before beginning any diet therapy, since one could be eliminating a child’s only source of important nutrients. A source of more information can be found in Lisa Lewis’s 1998 book: *Special Diets for Special Kids* (1998), Arlington, TX: Future Horizons. 800-489-0727.

Appendix Six

How parents can get the most out of their early intervention visit

(This information is also found in "A Family Handbook: Guide II Orientation to Services", p. 22, Connecticut Birth to Three System)

Parents: You know your child best. You have valuable information about your child; Birth to Three staff need your input just as much as you need theirs. Remember, you are and will be your child's best, most important, and most constant teacher and advocate.

Before Your Visit:

- **Be prepared.** Make sure you schedule your visit when you can be there and not have a lot of distractions. Decide how brothers and sisters will be involved or plan an activity for them.
- **Plan the agenda.** Let the Birth to Three staff know what you want to discuss at your visit. Remember or write down any questions that you may have since your last visit.
- **Be ready to share what has happened since your last visit.** Think about or make a list of anything you think is important to share such as a trip to the doctor or changes in routine. Think about what suggestions have worked well and those that have not worked so well.

During Your Visit:

- **Ask questions.** Make sure you understand what is being said. If you are not sure why something is being done, just ask. If it helps, ask for things in writing.
- **Ask for a demonstration.** Ask to be shown anything you don't understand. Practice strategies together during the visit. Hands-on instruction is the best way to learn.
- **Discuss ideas for carry over between visits.** Time between visits is just as important as the visit itself. Be sure to talk about ways to use the strategies and activities during everyday family activities.

After Your Visit:

- **Try things out.** Try out the suggested activities. What is working? What isn't?
- **Make a note of it.** Remember to make a mental note or keep a notebook for questions that may come up between visits.
- **Have fun.** The best teaching and learning occurs when you and your child are having fun.
- **Celebrate successes** – even the tiny ones!!

Appendix Seven

Types of Alternative or Complementary Treatments for ASD

This is not an exhaustive list but it is intended to provide a brief overview of treatment options available. These are not approaches that are recommended by the Birth to Three System. Some of these treatments are controversial and may not be generally accepted by the scientific and medical community. They are provided as a resource for families who would like to acquire more information on treatment. Involvement in any of these treatments should be discussed with the family's primary health care provider.

1. ***Hormone Therapies:*** Several health problems in children and adults are associated with deficiencies of particular hormones. Some hormone replacement therapies have been proposed as possible treatments for autism. In particular, adrenocorticotropin hormone (ACTH) and secretin (a hormone that helps regulate digestion) have been suggested. These have not been found to be effective in scientific studies for young children and the potential side effects from treatment with secretin are unknown.
2. ***Immune Therapies:*** Immune therapies include treatment with intravenous immune globulin has been suggested as a possible treatment for children with autism. Proponents of these therapies suggest that a subset of children with ASD have abnormalities in their immune systems. The only treatment described in the scientific literature is intravenous immune globulin (IVIG) therapy.
3. ***Anti Yeast Therapies:*** Anti yeast therapies have been proposed for children with autism. These treatments involve administrations of oral anti-fungal medications or special diets that include foods purported to have anti-fungal properties (such as garlic and grapefruit seed extract). The use of anti-fungal therapies is based on the theory that for some children the symptoms of ASD are caused by aggravated or an overgrowth of yeast in the intestinal tract. This theory also suggests that yeast overgrowth occurs after children are treated with antibiotics.
4. ***Vitamin Therapies:*** Administration of high doses of vitamins has been suggested as a treatment for young children with autism. High doses of Vitamin B6 (pyridoxine), magnesium or trace minerals are most common. If a child has a documented vitamin or trace mineral deficiency it should be treated. However, there is insufficient evidence to recommend it as a treatment for autism. Short-term side effects are reported to be mild, but side effects are not known for young children treated with high doses or over long periods.

5. ***Auditory Integration Therapy (AIT):*** This technique presumes that the child has a sensory dysfunction, most likely hypersensitivity to certain sounds, making a number of common sounds painful to hear. The treatment involves a prescribed treatment program of listening to sounds and music over a period of time with certain frequencies filtered out. The intent is to reduce the sound sensitivity and thereby improve behavior, social skills and cognitive functioning.
6. ***Craniosacral Therapy:*** This technique involves physical manipulation of the body to free restrictions of motion in the craniosacral system. The theory assumes that the restricted movement of cerebrospinal fluid is adversely affecting the development and function of the brain. Dr. John Upledger believes that children who have ASD show symptoms of restricted fluid movement through head banging, wrist biting, teeth grinding and hyperactivity.
7. ***Vision Therapy:*** This technique is based on the assumption that some of the unusual behaviors associated with ASD may be related to visual perception problems. Some of the difficulty experienced by young children with ASD include poor eye contacts, difficulty attending visually, staring or hyper or hypo sensitivity to light and/or color. Treatment may include use of specialized color or prism glasses or vision exercised. It is considered an experimental method for young children with ASD.
8. ***Music Therapy:*** Music therapy involves using some aspect of music that may lead to improvement in social interaction and language development in young children with ASD. The procedures for music therapy are highly variable.

Resources on Alternative or Complementary Treatments

Labels in parentheses () indicate whether this is a resource for multiple treatments or a specific treatment.

Allergy-Induced Autism
8 Hollie Lucas Road
King's Heath, Birmingham
B130QL United Kingdom
www.kessick.demon.co.uk/aia.htm (Allergies)

American Music Therapy Association
8455 Colesville Road, Suite 1000
Silver Spring, MD 20910
301-589-3300
www.musictherapy.org (Music Therapy)

Autism Network for Dietary Intervention (ANDI)
PO Box 17711
Rochester, NY 14617-0711
www.autismNDI.com (Diet)

Autism Research Institute (ARI)
4182 Adams Ave
San Diego, Ca 92116
619-281-7165
<http://www.autism.com/ari> (Multiple)

Autism Treatment Checklist (ATEC)
Developed by the Autism Research Institute as an on line evaluation tool to help in evaluating the different approaches to treatment.
<http://www.autism.com/atec/> (Multiple)

Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
800-3Autism
www.autism-society.org (Multiple)

Center for Visual Management
150 White Plains Road
Tarrytown, NY 10591
914-631-1070
www.autisticvision.com/index.htm (Vision)

Dalldorf, Joanna S. M.D. "A Pediatric View of the Treatment Options for the Autistic Syndrome" July 1999. Division TEACCH Home Page:
www.unc.edu/depts/teacch/treatment.htm#hold (Multiple)

Gerlach, E. *Autism Treatment Guide*, Second Edition, (2000) Arlington, TX, Future Horizons, Inc.
800-489-0727 (Multiple)

Heflin, L., Juane and Simpson, R.L. "Interventions for Children and Youths with Autism: Prudent Choices in a World of Exaggerated Claims and Empty Promises." *Part I: Intervention and Treatment Option Review, Focus on Autism and Other Developmental Disabilities*, Volume 13, Number 4, Winter, 1998, 194-211. (Multiple)

Hymen. S.L., & Levy, S.E. (2000). *Autistic spectrum disorders: When traditional medicine is not enough* – *Contemporary Pediatrics*, 17 (10): 101-116. (Medication)

Lewis, Lisa. *Special Diets for Special Kids* (1998). Arlington, TX: Future Horizons. 800-489-0727. (Diet)

New York State Department of Health (1999). *Clinical Practice Guideline: The Guideline Technical Report. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3)*. 518 439-7286.
www.healthstatenyus/nysdoh/eip/indexhtm (Multiple)

Nickel R, E. (1996). *Controversial therapies for young children with developmental disabilities*. *Infants and Young Children*, 8 (4): 29 – 40. (Multiple)

Rimland, G & Edelson, S. (1994) The effects of auditory integration training in autism. *American Journal of Speech-Language Pathology*. 3, 16-24. (Auditory Integration)

Society for Auditory Intervention Techniques (SAIT)
PO Box 4538
Salem, OR 97302
<http://www.sait.org> (Auditory Integration)

The Upledger Institute
11211 Prosperity Farm Road, Suite 325
Palm Gardens, FL 33410
800-233-5880
<http://upleder.com/> (Cranial Sacral Intervention)

Zimmerman, A.W., Bonfardin, B., & Myers, S. (2000).
Neuropharmacological therapy in autism. In P. Accardo, C. Magnusen & A. Capute (Eds.), *Autism Clinical and Research Issues*. Baltimore, York Press. (Medication)

Decision Makers Tool Kit
South Eastern Regional Education Service Center, Inc. (SERESC)
11 Peabody Road, Derry, N.H. 03038
603-432-9442
Cwoodman@seresc.net (Multiple)

Appendix Eight

Organizations

Atypical PDD/Asperger Syndrome Support Group
34 Bullfrog Lane
Trumbull, CT 06610
203-261-7872

The Autism Research Institute (ARI)
4182 Adams Avenue
San Diego, CA 92116
Voice 619-281-7165
Fax 679-563-6840
www.autism.com/ari

Autism Society of America
7910 Woodmont Avenue, Suite 650
Bethesda, MD 20184-30315
1-800-3-autism
www.autism-society.org

Autism Society of Connecticut (ASCONN)
125 Harrington Street
Meriden, CT 06456
203-235-7629 (evenings)

Autism Society of Connecticut (ASCONN)
South Central Connecticut ASA
20 Washington Avenue, Suite 108
North Haven, CT 06479-2343
Voice 203-239-5269
Fax 203-239-4384

Autism Society of North Carolina
Bookstore Catalogue
3300 Women's Club Drive
Raleigh, NC 07612-4811
919-743-0204
www.autismsociety-nc.org

Autism Spectrum Resource Center (ASRC)
21 Sharon Court
Shelton, CT 06484
203-924-0452

Connecticut Autism Resource Center
203-272-7529

CT FEAT – CT Families for Effective Autism Treatment
PO Box 388
Ellington, CT 06029-0388
www.ctfeat.org

Connecticut Center for Child Development (CCCD)
925 Bridgeport Avenue
Milford, CT 06460
203-882-8810
www.cccdinc.org

Connecticut Parent Advocacy Center (CPAC)
5 Church Lane
PO Box 579
East Lyme, CT 06033
800-445-CPAC

CREC – River Street School
601 River Street
Windsor, CT 06106
860-298-9079

The Farmington Valley Autistic Spectrum Disorders Support Group
Kid Works/The Sacred Mountain
1280 Hopmeadow Street
Farmington, CT 06032
860-408-9147 / 860-651-4493

Future Horizons
721 W. Abram St.
Arlington, TX 76013
800-489-0727
www.futurehorizons-autism.com

Greater Hartford Chapter Autism Society of America
25 Lakeside Drive
Bristol, CT 06010-7370
Voice 860-582-7665

The Greater Hartford New Haven PDD/Asperger Support Network
27 Broadview Road
Cheshire, CT 06410
203-272-7529

Groton Autism Support Group
c/o Cheryl Gurzynski
6 Cottonwood Road
Groton, CT 06340
860-445-0263

Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
2853 East 10th Street
Bloomington, IN 47408
812-855-9630 www.ISDDINDIANA.edu

More Able Autistic People (MAAP)
c/o Susan Moreno
PO Box 524
Crown Point, IN 46307

Natchaug Region Chapter Autism Spectrum America
95 Bolton Branch Road
Coventry, CT 06238
860-742-7529

Northeastern Region Chapter Autism Society of America
PO Box 466
Wauregan, CT 06387
860-774-7529

PDD Asperger Syndrome Support Group
60 Lealand Street
Bridgeport, CT 06606
203-374-5111

PATH/Parent-to-Parent
800-399-7284

Special Education Resource Center (SERC)
25 Industrial Park Road
Middletown, CT 06457-1520
800-842-8678
www.serc.rh.edu

State Department of Education
Bureau of Early Childhood Education and Social Services
Bureau of Special Education and Pupil Services
25 Industrial Park Road
Middletown, CT 06457
860-807-2054 (preschool special education)
860-807-2027 (special education)

Appendix Nine

References

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Single Sheet Designed for Kids
www.autism-society.org

Brochure: Autism Information Written for Kids Only
Available from: Autism Society of America
7910 Woodmart Avenue, Suite 650
Bethesda, MD 20814-3015
1-800-3-AUTISM
www.autism-society.org

Videos

Doctor, My Child Doesn't Talk
The Importance of Early Autism Diagnoses (1997)
FEAT
PO Box 255722
Sacramento, CA 95865

Discrete Trial Teaching (1999)

Family Education Series NY Families for Autistic Children, Inc.
718-641-6711

An Introduction to PECS:

The Picture Exchange System (1998)

Pyramid Ed Consultants, Inc.
226 W. Park Place, Suite 226
Newark, DE, 1974

Autism: Being Friends (a video for children)

Indiana Resource Center for Autism

3853 East 10th Street

Bloomington, IN 47408

812-855-6508

www.iidc.indiana.edu (publications catalog screen)



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