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ABSTRACT

This guide is designed to assist families and service providers with developing individualized family service plans (IFSPs) for families of children (birth to 3) in Connecticut who exhibit characteristics of pervasive developmental disorder (PDD), autism, or related disorders. Sections address the following topics: terminology, early identification and diagnosis, characteristics of children with PDD/autism, intervention, principles of child development, curriculum, intensity of intervention, supportive teaching environments, measuring progress, intervention in natural environments, functional approach to problem behaviors, family support, controversial or alternative treatments, transition to preschool, strategies and intervention techniques, embedding teaching strategies into natural routines, focus on communicative intent, sensory integration, augmentative/alternative communication, applied behavior analysis, discrete trial instruction, and incidental teaching. Also included are answers to questions parents ask and 10 appendices including the mission statement of the Connecticut Birth to Three System, the Checklist for Autism in Toddlers, a list of early indicators for screening, and suggested questions for parents to ask regarding treatments. (Contains approximately 50 references.) (DB)

Service Guideline 1

PDD/Autism

Intervention guidance for service providers and families of young children with characteristics of PDD or autism

June, 1997

Connecticut
Birth to Three
System

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PREFACE

This document was prepared by The Connecticut Birth to Three System's Autism Task Force. The guidelines were designed to assist families and service providers with developing individualized family service plans (IFSPs) for families of children who exhibit characteristics of PDD (Pervasive Developmental Disorder), autism, or related disorders. The information in this document is a compilation of a review of research-based programs and models, personal discussions with program directors and experts in the field, and an interpretation of the responsibilities of the Connecticut Birth to Three System under the Infants and Toddlers sections of the Individuals with Disabilities Education Act (IDEA).

The Mission of the Connecticut Birth To Three System - 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 settings
- Recognize current best practices in early intervention, and
- Are built upon mutual respect and choice

(See Appendix 1)

All IFSPs for children with PDD/autism and related disabilities will be developed in accordance with the Birth to Three Mission.

The Connecticut Birth to Three System supports 38 programs, 34 of which provide comprehensive services to children with a wide range of disabilities and delays and their families (see Appendix 2.) Each of these comprehensive programs is prepared to assist families with the process of developing an IFSP for a child with characteristics of PDD or autism. Families are offered the option of choosing the comprehensive program they feel is most compatible with the outcomes defined for their child and themselves. The Birth to Three System is committed to providing support and technical assistance to the programs in implementing all services on the IFSP that have been recommended. The most critical component of this process is the collaboration and ongoing communication between the family and their chosen program in the design and implementation of an individualized family service plan.

Terminology - Autism is often referred to as a spectrum disorder, meaning the symptoms and characteristics of autism can present themselves in a wide variety of combinations from mild to severe. Young children can exhibit any combination of the behaviors described in the next section and two children, both with a diagnosis of autism, can act very differently from one another. In addition, two families who each have a child with autism may identify very different needs for their child and family. The individualized family service plan will guide the intervention process for all children and families in the Birth to Three System.

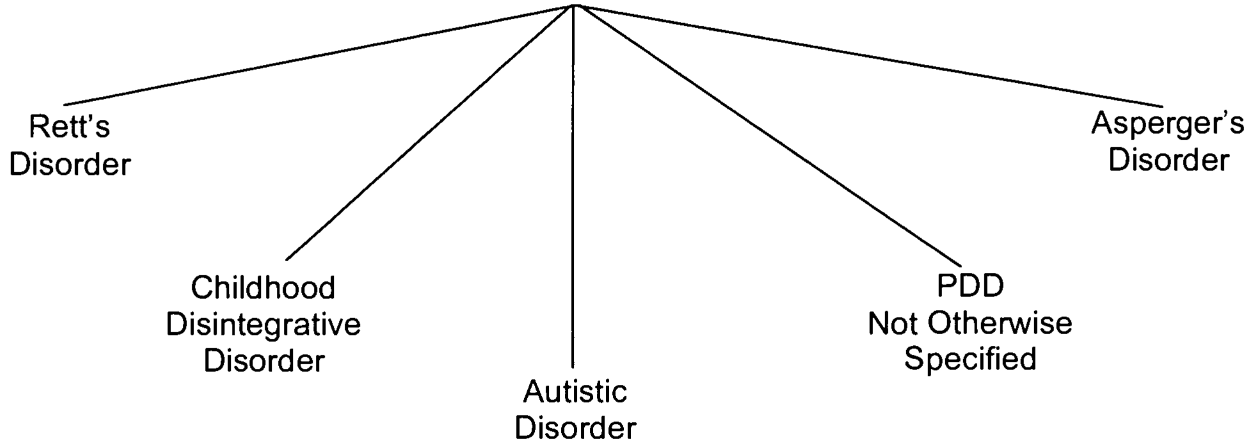
For the purpose of this document, the terminology PDD/autism will be used throughout.

Early Identification and Diagnosis

For children with PDD/autism, the identification process is based on a diagnostic manual printed by the American Psychiatric Association called the "Diagnostic and Statistical Manual of Mental Disorders or DSM-IV (1994)". According to the DSM-IV, the term PDD is not a specific diagnosis, but an umbrella term under which the following specific diagnoses are defined: Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), Rett's Disorder, Childhood Disintegrative Disorder, Autistic Disorder, and Asperger's Disorder.

The Identification Process
Pervasive Developmental Disorders (PDD)

(The Spectrum of Autism)



Often for young children, other diagnostic labels such as severe language delay or disorder, social emotional disability or multisystem developmental delay have been suggested.

Regardless of where a family and child are in the diagnostic process, or what the diagnostic label is, research strongly supports the need for early identification and treatment of the behaviors that contribute to or represent a developmental delay.

Children with a formal or suspected diagnosis frequently exhibit characteristics in the following areas at a very young age. A diagnosis of autism is based on children demonstrating characteristics identified in all three areas.

1. <u>Impairment in social interactions as seen by:</u>
   - A) Marked lack of awareness of the existence or feelings of others (e.g., does not recognize the difference between primary caregivers and strangers);
   - B) No or abnormal seeking of comfort at times of distress (e.g., does not respond to comfort when hurt or tired);
   - C) No or impaired imitation of others (e.g., does not wave bye bye);
   - D) No or abnormal social play (e.g., does not interact in simple games such as peek-a-boo or prefers repetitive play such as opening and closing a cupboard without exploring items inside);
   - E) At a later age, gross impairment in interest and ability to play with peers.

2. Impairment in development of verbal and nonverbal communication:
   - A) Lack of development in verbal communication such as babbling, facial expression, or beginning sounds or words;
   - B) Markedly abnormal nonverbal communication such as eye gaze, facial expression or gestures (e.g., does not point to ask for an item on a shelf, does not look at person or smile when they are approached);
   - C) Marked abnormalities in producing speech (e.g., sing song melody, unusual pitch, monotonous tone);
   - D) Marked abnormalities in the content of speech (e.g., repeats jingle from a TV commercial but does not use beginning words such as "mama" or "dada".)

3. Markedly restricted repertoire of activities and interests and atypical play behavior as manifested by the following:
   - A) Stereotyped body movements (e.g., spinning, head banging, rocking);
   - B) Persistent preoccupation with parts of objects (e.g., spinning the wheels on a toy car, feeling texture of an object);
   - C) Attachment to unusual objects (e.g., insists on carrying piece of string);
   - D) Marked distress over small changes in environment (e.g., tantrums when a vase is moved from usual position);
   - E) Unreasonable insistence on following a routine in detail (e.g., insisting on eating the same food in the same order for each meal);
   - F) Markedly restricted range of interests and preoccupation's (e.g., will only watch the same cartoon video, starting at the same point or only interested in lining up objects rather than playing with them.)

   Other symptoms may occur such as:
   - A) Sensory disturbances as seen by unusual response to stimuli (e.g., overreaction, indifference or withdrawal to touch, sound, light, movement, smell and taste);
   - B) An uneven acquisition of skills (e.g., a child who at a very young age identifies letters but does not communicate his/her needs verbally.)

(Minnesota, 1996)

Additional information for identifying young children with characteristics of PDD/autism is attached in Appendices 3 and 4 and in the resource list at the end of this document.

A child with the characteristics associated with PDD/autism may be found eligible for Birth to Three services without a formal diagnosis of autism. Whether or not a child has been diagnosed with PDD/autism, the Birth to Three team and the family will develop an IFSP that addresses the child's and family's needs.

The extent to which young children exhibit these behaviors and the severity of the behaviors often prompts a family to seek a formal diagnosis. This is a process that often occurs between a child's second and third birthday. Families have reported that providers often want to protect the family or themselves by minimizing or dismissing discussions of a diagnosis. Many parents have found the diagnostic process to be helpful because it confirmed something they already suspected or directed them to a wealth of information about intervention and support options. Providers are encouraged to initiate the discussion of diagnosis with a family to determine if they are interested in proceeding with this process.

When families wish to pursue a diagnosis, collaboration between medical services and Birth to Three is an important part of this process. In a situation where the IFSP team determines pursuing a diagnosis is appropriate, then the evaluation may be included as a Birth to Three service in Section V of the IFSP. Programs are responsible to provide this diagnostic service as part of their comprehensive services. The diagnosis may be made either by a physician or a licensed, clinical psychologist. Regardless of the area of specialty, an accurate diagnosis requires that the person have training and experience in the area of PDD/autism.

Whether a child has a formal diagnosis or not, these behaviors are early indicators that cause concern and should be addressed in the intervention process.

I waited seven years before the birth of our daughter Melissa. I think that more than anything I ever wanted, I wanted to be a parent. The day that Melissa was born was for me like it is for most parents, a unique, tender moment in time. I knew that life would be forever changed for me the moment I looked at that beautiful, shining, new face of hers. She was perfect, and I was lucky enough to be her mom.

The first year of Melissa's life was spent admiring her growth and development. She was considered by all friends and relatives to be such a beautiful, happy, easy baby. However, I did on occasion express concern about her not sitting, only doing an army type crawl and rarely using her voice. Her pediatrician said that all kids develop at different rates, so we could just relax and wait.

As Melissa approached age two, the uneasy sense I had that something was wrong continued to deepen. She wasn't playing like the other toddlers. There were new different behaviors that I couldn't explain, like her toe walking and staring off into space. Was I doing something wrong? Finally, we came to a place within ourselves when we had to insist upon obtaining another professional opinion.

INTERVENTION FOR CHILDREN WITH PDD/AUTISM

Every individualized program for children with PDD/autism should be consistent with the principles of normal child development, reflect research supporting intensive interventions, systematically measure progress towards outcomes, occur in natural environments, provide support to families, and prepare children/families for transitions to new programs. When planning a program, the following characteristics are considered the foundation to effective individualized programs for children with PDD/autism with a wide range of abilities and challenges:

Consistent With Principles of Normal Child Development - Regardless of the behavior(s) a child exhibits or the diagnosis, early intervention is based on widely accepted principles of normal development. The program for a young child with PDD/autism builds on the individual strengths and competencies of that child and family, acknowledging the child's similarities to all other children of his/her age and respecting his/her individuality. All children develop best in a setting that respects a developmentally appropriate framework. The National Association for the Education of Young Children has articulated these principles of child development. They are listed in Appendix 5 at the end of this document. Consistent with these principles, children learn best in an environment where they feel psychologically safe. For any child to optimally develop, he or she must establish and maintain positive relationships with all care givers. For this reason, the Birth To Three System prohibits any intervention for young children that uses punishment or aversive techniques as part of an IFSP without prior approval. In specific cases when an aversive technique is proposed, all other positive procedures must have been exhausted. Aversive techniques such as time out or physically restraining a child's hands must be approved in advance in accordance with stringent review procedures established by the Birth to Three System. Positive and proactive strategies are considered the most appropriate intervention, even for the most challenging behaviors. Families and providers must collaborate to develop an IFSP that is developmentally sensitive to the unique qualities of the child and family.

Curriculum Content

There are a wide variety of curriculum strategies that are used in early childhood programs. For young children with PDD/autism, the curricula should emphasize development in the following areas. The ability to:

1. attend to elements in the environment, especially to other people and learning opportunities;
2. imitate others including both verbal and motor imitation. Imitation is seen as a fundamental mechanism for learning;
3. comprehend and use language (functional communication skills);
4. play with toys appropriately to promote functional use of toys and symbolic play;
5. socially interact with others, especially peers;
6. make choices; and
7. follow daily schedules and routines

Intensity of Intervention - A review of multiple research studies shows: "Children with PDD/autism appear most able to benefit when intervention is begun very early, between the ages of 2 and 4, making far more progress then do older children receiving the same interventions, and when intervention is intensive, including 15 or more hours per week of focused treatment with very low child to adult ratios." (Rogers, 1996)

The Connecticut Birth to Three System recognizes that every child and family is different. The choice of program, the types of interventions, the professional disciplines of the interventionists, and the frequency and intensity of interventions are determined by the unique needs of each family and child, not by diagnostic labels. Any guidance which quantifies the amount of service a child and family should receive is potentially harmful if it causes the IFSP team to look to the guidance rather than to the individual child and family circumstances. But, it is also irresponsible to avoid the question of giving guidance which may help structure the thinking of the planning team. The Connecticut Birth to Three System believes active and supported engagement with activities and materials and adults or other children for as much as 15-20 hours per week, on a consistent schedule throughout the week, may significantly enhance the progress of a young child with PDD/autism. A program of this intensity is often designed with a strong component of family participation and training. This is determined based on the individual needs of the child and family and adjusted on a regular basis through the IFSP review. In addition, services are available on a twelve month basis in the Birth to Three System. Predictability and consistency of the intervention routine and personnel are essential.

Highly Supportive Teaching Environments and Generalization Strategies

This intensive intervention must occur across many different environments where skills will be used. This will include home as well as community settings as identified by the family. Regardless of the setting, these principles are essential:

1. Skills are taught in a structured context and on a predictable and routine schedule with attention to number of hours per day/week, number of weeks per year, and number of environments where intervention occurs;

2. There is a high adult to child ratio - often 1:1 or 1:2;

3. Adults are well trained and supervised by professionals with expertise in the field of PDD/autism;

4. Supervision and training of individuals implementing a program for a child with autism may take many forms. Frequently this includes a mixture of on-site or in-home consultations, team meetings and team trainings for staff and family. Staffing will often include the use of a supervised paraprofessional, volunteers or extended family members. The goal of supervision and training is to ensure consistency in instructional techniques and analysis of progress towards outcomes.

5. Strategies are designed to minimize distress and confusion;

6. Gradual fading of high level of support or prompts and systematic generalization of new behavior to more complex environments is planned;

7. Adults are used as facilitators or supports through daily routines. They identify naturally occurring opportunities to strengthen new behaviors.

There is a tremendous amount of information on intervention approaches. To make informed decisions about effective teaching for each child, we must constantly evaluate our methods.

Progress Towards Outcomes - Ongoing assessment of progress towards outcomes, as defined on the IFSP and measured by individualized data collection systems, should guide the intervention process. Systematic and intensive evaluation of progress and effectiveness of the specific intervention(s) is essential. Continuation of ineffective strategies or relying on techniques merely because they have been shown to be effective with other children may be harmful to a particular child and reduce opportunities for successful interventions. Collaboration between the family and the service providers in this evaluation and flexibility to adjust strategies in a timely manner, is one of the keys to success.

Data Driven Decision Making

1. Outcomes and objectives are written in measurable terms;
2. Data is taken prior to intervention;
3. Steps or tasks are analyzed and lead to progress towards outcomes;
4. Methods for motivating or reinforcing behavior are identified;
5. Methods and timelines for measuring progress are determined;
6. Data is taken and analyzed on a routine basis;
7. Adjustments in intervention plans are made in response to analysis of progress.

Intervention in Natural Environments - The mission of the Birth to Three System is to provide services in natural environments. In cases where there is some justification for not using natural environments, it is important to understand the rational. We must ensure that the use of an environment where typically developing children do not participate is directed towards the goal of helping the child to participate in life's activities in natural environments to the greatest possible extent. Young children with PDD/autism often benefit from some intensive one to one intervention which may increase a child's attention to instruction and promote skill acquisition in a structured context for the first time. These learning opportunities are often controlled to allow minimal distraction and maximum opportunities to practice a particular skill. Although children benefit from these intensive individual services, a program developed solely on this method may be an obstacle to skill generalization and social adaptation in the future. Therefore the Birth to Three System strongly believes that opportunities for children with PDD/autism to interact with typical peers in natural settings is a priority, even if the plan may include some one-to-one or other highly structured interventions.

One of the primary goals of the program is to foster the development of peer relationships for all children. For very young children, this often begins with the modeling of peer play behaviors. Supporting peer relationships for young children who have social deficits may require peers with excellent social interactive skills. Including competent two, three or four year old players as models may require some coaching or facilitation to be most effective. A child's program should be developed with a focus on the need for these interactive and social learning opportunities as well as a need for individualized services. Often young children with PDD/autism will exhibit behaviors that limit their opportunities to interact with peers. This may need to be addressed through analysis and intervention in the social situation. Placing a child with PDD/autism in a community setting without this support and analysis is often not sufficient.

Opportunities for peer interaction should be developed based on characteristics of the family's community, and the use of the natural system of supports that the family already identifies with from that community. Options should include participation in activities and places where families choose to spend their time. Some families may find that intensive individualized structure in social community based activities is inconsistent with their belief about the purpose of providing intervention in this setting. The team should work with the family and community staff to develop strategies which provide structure and learning opportunities that match their beliefs and values.

Functional Approach to Problem Behaviors

1. Decrease inappropriate behavior by increasing interest and engagement in activities and people.

2. Analyze communicative or sensory function of behavior in natural routines.

3. Assess behavior through:
   A. Detailed record of behavior:
      - Situations
      - Time of day
      - Events that preceded behavior
      - How others responded

   B. Generate hypotheses of the function of the behavior in order to identify intervention strategies. These may be communicative or sensory in nature.

4. Change environment to support appropriate behaviors or teach appropriate behavior to cope with situation.

5. Intervene with strategies to improve communication skills or address sensory deficits and increase the amount of time the child is engaged with people or activities.

6. Use typically developing peers as models of appropriate behavior.

Family Support - Children with PDD/autism present unique challenges to their families. No two families of children with PDD/autism will require the same support and often the need for support will change over time. Family support goals on IFSPs 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 was most significant during the time their child was first identified with PDD/autism.

IFSPs should reflect a wide range of family support outcomes which may include:

- the need for information on PDD/autism and intervention philosophies;
- opportunities to speak with other parents of children with PDD/autism;
- opportunities to speak with other professionals regarding parenting a child with PDD/autism;
- training on how to teach their child new skills, or strategies to integrate a child's intervention plan into their family routine;
- counseling and family support;
- marital and family counseling;
- identifying resources for respite or specially trained babysitters;
- identifying appropriate child care options;
- support for brother and sisters;
- inclusion of extended family members in support;
- opportunities for families to develop advocacy skills;
- support at the time of transition.

Appendix 6 contains a list of resource organizations for families. One area in which families frequently request support is in determining the appropriateness for controversial or alternative treatments.

Controversial or Alternative Treatments

There is a great deal of information on treatment options or philosophies of intervention for children with PDD/autism. Included in these options are a number of therapies in current practice that do not have credible scientific research documenting their effectiveness. These "controversial treatments" are described by Nikel (1996) as having the following characteristics:

⇒ Treatments that are based on overly simplified scientific theories

⇒ Therapies purported to be effective for a variety of conditions

⇒ Treatments that claim that most children will respond dramatically and that some may be cured

⇒ Treatments supported by a series of case reports or anecdotal data and not by carefully designed research studies

⇒ Treatments initiated with little or no attention to identifying specific treatment objectives or target behaviors

⇒ Therapies that are said to have no or unremarkable side effects, thus, there is no reason to do controlled studies

The use of controversial treatments raises significant concerns. Among these are:

1. False expectations or hopes by the family in the outcomes of an intervention;
2. The tendency for all intervention efforts to be focused on an approach that addresses a narrow aspect or behavior of the child;
3. The financial impact on the family for treatments they choose to pursue outside of the Birth to Three System;
4. The lack of documentation of potential side effects or physical or emotional harm resulting from treatments.

Although the Birth to Three System will not provide a controversial treatment as a service, service coordinators will assist families with gathering information and making decisions regarding any treatment for their child. The Birth To Three Medical Advisory Committee in collaboration with the Birth To Three Regional Managers will advise providers of techniques or approaches that have a sound scientific basis. The checklist in Appendix 7 is included to assist families in researching specific treatment options.

Transitions - Children with PDD/autism often have difficulty with change, including change experienced when introduced to something new or different such as unfamiliar adults, children, settings, routines and other differences that we may not even notice.

Children with PDD/autism do learn new skills but their skills may not automatically be used or generalized to new settings or new people. These children also present a wide variety of educational challenges and educational needs when learning and utilizing their skills. The challenges of change, not only confront children with PDD/autism, but also confront their families. Families' need for continuity, support, and/or resources can make the transition from the Birth To Three System to a new setting, a challenging and sometimes difficult experience.

The transition from the Birth To Three System to preschool special education provided by school districts is most successful when planning is done far enough in advance of a child's third birthday and when coordinated with school district personnel. For children with PDD/autism, the diagnosis of PDD/autism often occurs at the same time as the development of a child's early intervention program. This often also coincides with the beginning of the transition process addressing the movement from the Birth To Three System to a school district preschool special education program. It is essential that "transition" and transition-related activities be discussed by the family and their service coordinator throughout the development and implementation of the IFSP.

Steps to Preschool Transition

This process should include:

1. Early notification to local educational agency (LEA/school district) that a child and family are receiving services through the Birth To Three System;
2. A formal referral to the school district, referring a child for special education at least six months before the child turns three years-of-age;
3. With parental consent, sharing of all relevant records and information, such as recent evaluations and IFSPs;
4. Determination of eligibility for preschool special education through the school district PPT process (i.e., information gathering, evaluation, joint LEA and Birth to Three assessments);
5. Convening a transition conference by the Birth To Three System to:
   a) Identify the steps involved in easing transition;
   b) Identify the skills necessary to adjust to and function more independently in the next setting; and
   c) Train and discuss with parents future placements and other matters relating to a child's transition;
6. Development of the individualized education program; and
7. Identification of an appropriate educational program and implementation of the child's individualized education program.

The Birth to Three System has a Family Handbook, Transitions Guide III, which is designed to assist families with planning the transition process.

STRATEGIES AND INTERVENTION TECHNIQUES

One or more of the following strategies may be helpful in developing an individualized program for a child with PDD/autism. This is not an exclusive list, but intended to demonstrate the wide variety of methodologies that may be considered depending on the individual needs of the child and family. These strategies are techniques that the Birth to Three System recognizes as means to accomplish child outcomes.

All intervention techniques used in the Birth to Three System are carried out by professional and para-professional staff who meet the requirements of the System's Personnel Standards. They also require staff trained in the implementation of the approach (e.g. augmentative communication -- speech pathologist; discrete trial teaching -- psychologist or special educator.) These staff members have the responsibility of working with all of the team in the design, training, and implementation of the strategy.

Embedding Teaching Strategies or Therapies into Natural Routines - This technique includes identifying specific skills that a child needs to use in the context of a daily home or school routine, and integrating that instruction into the daily activity. Some characteristics of this teaching strategy include:

- Taking advantage of the child's natural interests
- Using naturally occurring activities
- Allowing the child to experience natural or relevant prompts or reinforcers
- Developing and implementing strategies by all intervention staff and care givers

Grant's speech pathologist has been helping his family develop strategies to use more words. Grant has been saying "dada" and "doggie" for a few months. His father said he would love for him to tell him he is "all done" at the end of a meal rather than throw his cup or bowl.
At dinner, Grant throws his cup on the floor. Rather than taking him out of his chair, his father picks up the cup and puts it on his tray. He says "Grant, you're all done" and uses the manual sign for "done." Grant puts his hands together and says "da." His father says: "You are all done" as he picks him up out of his high chair. He remembers to mention this to Grant's day care provider in the morning.

(See Izeman, Noonan & McCormick: Resources List Pages 32 and 33)

Focus on Communication and Development of Communicative Intent - This strategy is based on the work of Barry Prizant. He recommends an assessment of the preverbal behaviors displayed by children and used prior to their development of verbal communication such as pointing or vocalizing to express themselves. The focus is to build on what a child is currently doing rather than on behaviors or skills that are absent. Intervention involves moving from a less sophisticated and conventional means of communication (for example grabbing your hand and pulling you to an item) to a more sophisticated and conventional means of communication (pointing to a shelf and saying a sound related to the label of the item.) The immediate focus of the intervention may not be on speech but on using any socially acceptable means of communicating. Priorities are determined by what is most functional for the child and family. Outcomes are identified that assist families with providing opportunities that encourage meaningful communication from the child.

Grant is sitting in his high chair waiting for breakfast. His meal has not started and he is hungry. He bangs on his tray. His Dad does not respond. Grant bangs again, looks at his Dad, and says: "Da, Da, Da." His Dad comes over with the bowl of oatmeal and says: "You're ready to eat!"

(See Prizant, Schuler, and Wetherby: Resources List Page 33)

Sensory Integration(SI) - This method is based on the work of Dr. Jean Ayers, occupational therapist, who suggested that many individuals with PDD/autism demonstrate problems in the sensory area. A functional analysis of problem behaviors often identifies problems in dealing with sensory stimulation. This interpretation is based on the observation that individuals with PDD/autism display atypical reactions to common sensory experiences. They may be overly sensitive or not sensitive enough to sounds, sights, touch, movement, body position, or deep pressure.

Sensory integration is not used as a treatment for autism. It is used as a technique to respond to the child's sensory need or deficits. The goal is to increase tolerance to offensive stimuli as well as satisfy sensory cravings. This play-based treatment technique is popular due to its attractiveness to children, permitting numerous opportunities for interaction with other adults and peers. It is usually provided as one of multiple teaching strategies in a child's program.

When Grant is not chewing on a pacifier, he bites or mouths all objects he picks up. His family is eager to wean him from the pacifier so that he is free to utter sounds and imitate vocalizations. Grant's occupational therapist has identified his need for an above average level of sensory information, especially to his mouth. She suggests:

- *having Grant or his mother brush the biting surfaces of his teeth several times a day;*
- *offering Grant foods that are dense or crunchy rather than smooth and non-textured;*
- *making available opportunities to jump atop a mattress or trampoline to give deep pressure to the entire body;*
- *firm hugs on a regular basis;*

(See Ayers: Resources List Page 32)

Augmentative/Alternative Communication (AAC) - AAC refers to "the wide variety of techniques used to supplement a person's ability to speak" (Burkhardt, 1993.) This may include facial expressions, gestures, and sign language or the use of picture/symbol communication aids. AAC is often used to develop functional communication skills for children with limited verbal language. It is also used as a strategy to improve verbal communication or speech, increase social interactions, and structure daily activities and routines.

For children with PDD/autism, AAC is often used as a tool to intervene with challenging behaviors. Often, the behavior a young child is exhibiting is an attempt to communicate frustration or distress. Developing other methods of communication when speech is not yet developed, becomes a part of the intervention strategy. Children with PDD/autism are often successful with picture/symbol communication systems because of their strong visual skills. Many programs are designed to structure a child's day via a picture/symbol schedule and to encourage a child to communicate preferences by making choices with pictures or symbols. Pictures and symbols may be used as a means to provide information to a child as well as receive information from a child.

Grant keeps banging his cup on the tray of his highchair. His mother knows that he is thirsty but does not know what he wants to drink. She shows him a picture of chocolate milk, plain milk, and apple juice. He immediately grabs the picture of the apple juice and hands it to her.

(See Burkhardt and Frost/Bondy: Resources List Page 32)

Applied Behavioral Analysis (ABA) - This is a process of applying and evaluating the effects of behavioral teaching. An attempt is made to determine the functional relationship between behavior and the teaching environment. A functional relationship exists when behavior change is demonstrated to occur as a result of the teaching procedure, a change in the environment or some other stimulus. There are many ways ABA can be used to teach.

In its simplest form, ABA means that the parent, teacher, or interventionist analyzes a child's behavior. Behaviors or skills are broken down into small steps, and these steps are taught systematically. The analysis is used to understand which things are antecedents (happen before the behavior,) which are reinforcers (make the behavior occur again,) and which are punishers (make the behavior less likely to occur.)

The ongoing process of ABA includes the following steps:

- Identify the outcome or behavior to be taught
- Take baseline data prior to intervention
- Identify the specific learning objective
- Develop a plan for intervention including how change or progress will be measured
- Monitor the progress and evaluate the effectiveness of the intervention technique

Outcome - Grant will tell the adult when he is finished at a meal.
Baseline - Grant throws a cup or bowl on the floor at the end of each meal each day.
Objective - Grant will hand his cup or bowl to the adult who is feeding him.
Plan - Prior to the end of a meal - When Grant starts squirming in his chair or does not appear interested in food, the adult will model "all done" and extend a hand to accept the bowl or cup. Once Grant places the cup or bowl in the hand, he will be taken out of the high chair.

Two methods of ABA include:

1. Discrete Trial Instruction - Discrete Trial is a method of teaching children with PDD/autism, initially developed by a psychologist named Ivar Lovaas. Discrete trial is based on the same instructional methodology as Applied Behavior Analysis. This method of instruction includes multiple opportunities of intensive "mass practice" instruction or trials where the child is taught to respond to a command or "stimulus." Each instructional practice session would include a series of short, concise instructional prompts with a definite beginning and end. Once simple skills such as imitation and attending are learned in this manner, they can be combined into more complex skills for language or play skills. The teaching sequence looks like this:

   - Instruction - Get child's attention and state the desired behavior
   - Child Response - Child responds either correctly, incorrectly, or not at all.
   - Consequence - If child is correct, child is praised and given a reinforcer. If child is incorrect or does not respond, the child is given verbal feedback or physical guidance to respond correctly.
   - Between Trial Intervals - For 3-5 seconds between each teaching trial there is a period of no instruction. This defines, for the child, that one request is finished and a new one will begin.

Instruction: Adult sits across from Grant at the table and says: "Give me the cup."
Child Response: Grant hands the cup to the adult.
Consequence: Adult praises Grant and gives him a small piece of Cheerios, his favorite food.
Between Trial Intervals: Adult and Grant wait 5 seconds to practice the task again.

(See Lovaas or Maurice: Resources List Page 32)

2. Incidental Teaching - Incidental teaching is another technique that uses the principles of applied behavior analysis (ABA.) This technique focuses on the interaction between an adult and a single child which: 1)naturally occurs in an instructional situation such as free play, and 2) is used by the adult to give the child information or practice in developing a skill. Although incidental teaching takes place in a natural setting, learning opportunities are planned as opposed to being totally spontaneous. Unlike the discrete trial method, the principles of incidental teaching rely on using multiple teaching opportunities spread throughout the day rather than multiple teaching opportunities condensed into a short teaching session. The teaching sequence would look like this:

   - The teacher identifies the specific behavior the child should learn
   - The child initiates an interaction
   - The teacher decides whether to use the situation as a teaching opportunity
   - The teacher focuses the child on the specific behavior
   - The teacher reinforces the child for the behavior

This technique requires some one-on-one teaching opportunities and analysis of data to determine if progress is being made.

Grant picks up his cup and plays with it at the end of lunch.
The teacher knows Grant has dropped his cup on the floor every day for four days.
The teacher puts out his hand and says "you are all done with lunch."
Grant hands the teacher the cup and the teacher helps him out of his chair.

There are many nationally recognized model programs that effectively use incidental teaching. such as: The Walden Preschool, TEACCH, and LEAP. All of these programs have published research on the effectiveness of their models.

(See Harris and Handelman and Guralnick: Resources List Page 32)

CONCLUSION

Connecticut's Birth to Three System is committed to working with families to develop IFSPs that meet the unique needs of each child and family. This process is designed to include a reflection of the child's and family's current strengths and challenges as well as assist them in developing a vision for the future. It is through this partnership of families and service providers that the Birth to Three System will work to identify and promote best practices in the fields of early intervention and PDD/autism.

In the words of Dr. Susan Izeman: "There is no magic cure for PDD/autism, and parents must be cautious to avoid being misled by extravagant claims made by people promoting their brand of therapy." (Izeman, 1995.) Treatments that are effective should work with reasonable amounts of effort. A treatment program that works for one child may be useless for another. A parent should follow his or her own good instincts. Selected techniques deserve a reasonable period of application during which the child's responses are monitored by caregivers and interventionists. Ineffective methods should be eliminated or replaced with alternative strategies. Combining several different approaches is often effective. The hardest challenges we face are choosing which methods of intervention to try. Connecticut's Birth to Three System of comprehensive programs is committed to working with families through this process.

Questions commonly asked the Birth to Three System by parents of children with PDD/autism:

1. Q. *Who is qualified to work with a young child with PDD/autism?*

   A. There is no specific credential or discipline that qualifies an individual to work with a child with PDD/autism. We find that the complexity of behaviors and needs for children with PDD/autism often requires a team of individuals who work with the family. These could include any or all of the following: a special educator, an early intervention associate, a speech/language pathologist, an occupational therapist, a psychologist, or a social worker. It is important that members of the team have adequate training and experience in working with children with PDD/autism. Frequently our programs will have experienced staff as part of their comprehensive program to deal with all the components of a family's plan. If the program does not have staff experienced in a specific strategy or technique, the Birth to Three System will assist with identifying individuals who may provide technical assistance or training to the program and family.

2. 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 treatments. Often these are considered medical interventions which are not covered by our services. The System will not provide any treatment, that has not been proven effective based on empirical 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.

3. Q. *Will the Birth to Three System pay for a discrete trial program for my child?*

   A. Yes, discrete trial is one example of using applied behavioral analysis as a teaching methodology. A comprehensive provider will assist families with implementing a discrete trial program if it is considered to be the most effective treatment option and it is included in the child's IFSP. This will typically be only one component of a child's plan that also includes both opportunities for the child to generalize skills to other natural environments and interaction with typically developing peers.

4. Q. *Can early intervention cure PDD/autism?*

   A: No, there is no nationally recognized program that has researched the effectiveness of intervention on young children with PDD/autism that claims to cure PDD/autism prior to the age of five. 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. *What do I do if I don't feel my child is making progress? How do I know if my child is making progress?*

   A. The IFSP is designed to state what changes you expect to see in a child, how the change will be measured, and what the timelines are for this change. Minimally, each outcome on the IFSP must be reviewed every 6 months and be re-written annually. For children with PDD/autism, we find this may need to be done more frequently, such as every three months. In addition, each outcome on the IFSP should be broken into measurable steps so progress towards outcomes can be measured during each intervention opportunity.

6. Q. *My child was diagnosed by an expert in the field who does not live in Connecticut. During this evaluation process, the evaluator recommended we hire a consultant outside the Birth to Three System to consult with us on his program. Will the Birth to Three System pay for this?*

   A. The comprehensive programs in Connecticut's Birth to Three System are not obligated to hire outside consultants if the program has available the expertise to implement the requirements of the IFSP. Parents are welcome to invite anyone to participate in the IFSP meeting. As part of the development of the IFSP, appropriate staff and supports are discussed and identified.

7. Q. *How do I know which treatment approach is best for my child?*

   A. This is the most difficult question for families to answer, and one that may change over time. Often the best approach is a combination of approaches. What works for one child, may not work for another. What works one month may not work the next for the same child. Parents are advised to be good consumers of the intervention their child receives. This includes ongoing discussion of treatment options and approaches and the progress of the current intervention. The list of questions in Appendix 9 is included as a guide to determining effective treatment options.

8. Q. *My child has not had an evaluation for PDD/autism. Will the Birth to Three System pay for an evaluation?*

   A. When the team determines that pursuing a diagnosis is appropriate, then the evaluation may be included as a Birth To Three Service in Section V of the IFSP. This means that the program is responsible to provide payment for this diagnostic service. The program may have as part of their team, staff identified to provide this evaluation. It is essential that any diagnostic evaluations be done in collaboration with the child's primary physician.

9. Q. *What will happen to my child when he turns three-years-of-age and will no longer be receiving services through the state's Birth To Three System?*

   A. All school districts in Connecticut are required to provide children with disabilities, ages three through five and older, a free appropriate public education to meet their individual needs. In order to ensure that children with disabilities are provided services and supports through their school district by the age of three, planning and communication between the child's Birth To Three program and school district personnel must take place as early as possible. Early activities that are essential to the transition process include referral of a child to his or her school district and the sharing of relevant and recent child information such as current evaluations, assessments and IFSPs. The school district will work with a child and their family to:

   - determine a child's initial eligibility for special education,
   - conduct planning and placement team meetings,
   - write the individualized educational program; and
   - identify the educational program and services that the child will receive through the school district.

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

   A. If for any reason a family is not satisfied with services and cannot reach an agreement with their current program, they are encouraged to choose a different program. Often this is not the solution, since most of our providers operate with similar philosophies and guidelines. There is a Birth to Three Regional Manager assigned to each region of the state who is available to speak with families regarding any concerns they have about the services their child receives. Infoline may also be contacted to initiate this process or to discuss a complaint. The system provides for formal mediation of differences between families and providers (should the parties choose to dialogue in this manner.) The system also offers hearings by an impartial hearing officer if required. This process is initiated by contacting the Regional Manager.

11. Q. *My child's service provider has shared her concern regarding my son's development and behaviors. We recognize that he has delays and is different from other two year olds. We think he is too young to be brought to a specialist for a label or diagnosis. We would prefer to wait another year or so to see how he develops. Is there any harm in waiting?*

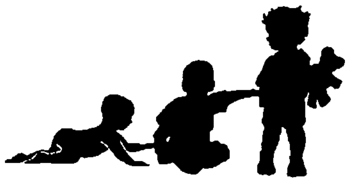
   A. It is important that families make the decisions that they are most comfortable with for their child. Any of the recommendations in this document can be implemented with or without a formal diagnosis. There is also a wide range of techniques and strategies identified. Some of these are more directive than others. What is most important is that the specific outcomes identified by the family are addressed. The research is very clear that intervention should begin as early as possible to be most successful.

APPENDICES - INDEX

Appendix - One

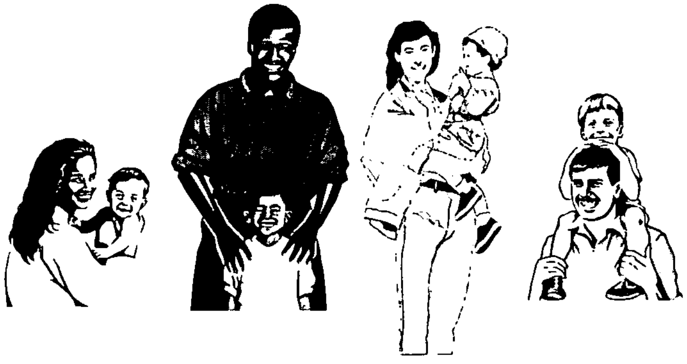
Mission

of the Connecticut Birth to Three System



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 settings*
- ➢ *recognize current best practices in early intervention*
- ➢ *are built upon mutual respect and choice*



- collaboration - partnerships - family centered - opportunity - equal access - inclusion - choice -
- natural environments - best practice - comprehensive programs - mutual respect - teamwork -

Partnerships: *Supporting families requires a collaborative approach which encourages partnerships between the family, their community, service and health-care providers, schools and child care programs. Close coordination between and integration of health care and developmental services is critical. Partnerships should attempt to enhance the competence of families to develop and strengthen lasting networks of natural support.*

Family Centered: *A family centered approach places the whole family as the focal point for supports. Evaluation, planning and services are based upon the uniqueness of the family and its culture. Strategies for promoting a child's development are integrated into the family's daily activities and routines and strengthen the role of family members.*

Natural Environments: *Services and supports should occur in settings most natural and comfortable for the child and the family. They should foster opportunities for the development of peer relationships with children without disabilities. Home-based intervention and inclusive community group settings are preferred. The unique characteristics of the family's community - and the development of a natural system of supports within that community - should be promoted at all times.*

Best Practice: *Services and supports should reflect the current values for best practice accepted in the field of early intervention in order to yield the most positive outcomes. Interventionists and families should work in teams, sharing their knowledge and skills, communicating, planning and collaborating with each other. Plans should be outcome oriented and understandable by families. They should be based on developmentally appropriate practices geared to the individual needs of the child. Transitions should be well planned and collaborative in nature. The knowledge about best practice is always increasing. Therefore, service provision should be based on the most accurate and recent research available.*

Respect & Choice: *Recognition and inclusion of the knowledge, beliefs, aspirations, culture and preferences of families should be a cornerstone of all planning and delivery of supports and services. Professionals should openly share roles and assist one another in expanding competencies. Teamwork, wherein the family is an important participant, should guide all decisions. Families should be provided with opportunities to choose programs whenever possible. Their satisfaction with services should be an important factor in selecting and evaluating providers of support.*

Appendix - Two

Connecticut Birth to Three Comprehensive Programs

For a complete description of each program, call The Connecticut Birth to Three System at 1-800-505-7000 or visit the Birth to Three Website at: http://www. birth23.com, or look them up in the Birth to Three Central Directory at your local public library.

	Connecticut Health and Human Service Regions				
	North West	North Central	Eastern	South West	South Central
Ahlbin Centers for Rehabilitation Medicine, Inc.				X	
American School for the Deaf	X	X	X	X	X
ARC, Greenwich				X	
Board of Education & Services for the Blind	X	X	X	X	X
Cheshire Public Schools	X				
Child & Family Network				X	
Children's Therapy Services	X				
Connecticut Children's Medical Center		X			
Cooperative Educational Services/Beginnings				X	
CREC Birth To Three Program		X			
CREC Hearing Impaired Program	X	X	X	X	X
Danbury Public Schools	X				
Early Connections	X	X	X	X	X
East Hartford Public Schools		X			
EASTCONN			X		
Easter Seal Goodwill Industries & Rehabilitation					X
Easter Seal Rehabilitation of Stamford				X	
Easter Seal Rehabilitation of Waterbury	X				
Easter Seal Rehabilitation Center of Central CT					X
Education Connection / SEED	X				
HARC Steppingstones		X			
Hill Health Corporation					X
Jane Bisantz & Associates, LLC		X			
Key Service Systems		X			
LEARN			X		X
McLaughlin & Associates, LLC		X	X		
Project Interact	X	X			
REACHOUT, Inc.					X
Rehabilitation Associates of CT., Inc.	X			X	X
SARAH, Inc.					X
St. Vincent's Special Needs Services				X	X
STAR / Rubino Center				X	
The Kennedy Center, Inc.				X	
Therapy Solutions Center, Inc.	X				
Therapy Unlimited	X				X

Appendix - Three

Checklist for Autism in Toddlers (CHAT)

Child's Name ______________________________ Date __________

Date of Birth ______________________________ Age __________

Section A (Ask Parent)

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 make a cup of tea using a toy cup and teapot, 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 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

Section B (GP or Health Visitor's Observation)

1. During your appointment, has the child made eye contact with you? Yes No
2. Get child's attention, then point across the room at an interesting object and say "Oh look! There's a [name a toy]!" Watch child's face. Does the child look across to see what you are pointing at? Yes[1] No
3. Get the child's attention, then give child a miniature toy cup and teapot and say "Can you make a cup of tea?" Does the child pretend to pour out tea, drink it, etc.? Yes[2] No
4. Say to the child "Where's the light?", or "Show me the Light". Does the child point with his/her index finger at the light? Yes[3] No
5. Can the child build a tower of bricks? (If so, how many?) (Number of bricks) Yes No

[1] To record yes on this item, ensure the child has not simply looked at your hand, but has actually looked at the object you are pointing at.

[2] If you can elicit an example of pretending in some other game, score a yes on this item.

[3] Repeat this with "Where's the teddy?" or some other unreachable object, if child does not understand the word "light". To record yes on this item, the child must have looked up at your face around the time of pointing.

Note: The "red flag" items from Section A are numbers 2, 4, 5, 7, and 9

Source:
Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). "Can autism be detected at 18 months? The needle, the haystack, and the CHAT" British Journal of Psychiatry, 161, 839-843.

Appendix - Four

Early Indicators for Screening

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 response 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" No 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 overdistressed 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

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 more 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 - Five

National Association for the Education of Young Children

Principles of child development and learning that inform developmentally appropriate practice

1. Domains of children's development - physical, social, emotional, and cognitive - are closely related. Development in one domain influences and is influenced by development in other domains.

2. Development occurs in a relatively orderly sequence, with later abilities, skills, and knowledge building on those already acquired.

3. Development proceeds at varying rates form child to child as well as unevenly within different areas of each child's functioning.

4. Early experiences have both cumulative and delayed effects on individual children's development; optimal periods exist for certain types of development and learning.

5. Development proceeds in predictable directions toward greater complexity, organization, and internalization.

6. Development and learning occur in and are influenced by multiple social and cultural contexts.

7. Children are active learners, drawing on direct physical and social experience as well as culturally transmitted knowledge to construct their own understandings of the world around them.

8. Development and learning result from interaction of biological maturation and the environment, which includes both the physical and social worlds that children live in.

9. Play is an important vehicle for children's social, emotional, and cognitive development, as well as a reflection of their development.

10. Development advances when children have opportunities to practice newly acquired skills as well as when they experience a challenge just beyond the level of their present mastery.

11. Children demonstrate different modes of knowing and learning and different ways of representing what they know.

12. Children develop and learn best in the context of a community where they are safe and valued, their physical needs are met, and they feel psychologically secure.

Source:
National Association for the Education of Young Children (1997)
Developmentally Appropriate Practice In Early Childhood Programs (revised ed.).
Washington, DC: Brederkemp & Lopple (Ed.).

Appendix - Six

Family Information and Support Resources

The Autism Research Institute 4182 Adams Avenue San Diego, CA 92116	Parent-to-Parent Network, The Family Center Connecticut Children's Medical Center 282 Washington Street Hartford, CT 06106 1-(860)-545-9024
Autism Society of America 7910 Woodmont Avenue, Suite 650 Bethesda, MD 20814 1-(800)-3-Autism	More Able Autistic People (MAAP) c/o Susan Moreno P. O. Box 524 Crown Point, IN 46307
Autism Society of Connecticut (ASCONN) 125 Harrington Street Meriden, CT 06456 1-(203)-235-7629 (evenings)	Greater New Haven PDD Support Network 1-(203)-272-7529 1-(203)-261-7980
Connecticut Parent Advocacy Center (CPAC) 5 Church Lane P. O. Box 579 East Lyme, CT 06333 1-(800)-445-CPAC	Connecticut Center for Child Development, Inc. (CCCD) Formerly Parents for Education of Children with Autism (PECA) P. O. Box 793 Newtown, CT 06470 1-(203)-426-0449
Connecticut Task Force on Issues for the Education of Children with Autism Special Education Resource Center 25 Industrial Park Road Middletown, CT 06457 1-(800)-842-8678	Sibling Information Network The A.J. Pappanikou Ctr. on Special Education and Rehabilitation 249 Glenbrook Rd. U-64 Storrs, CT 06269 1-(860) 486-5035
The Indiana Resource Center for Autism Institute for the Study of Developmental Disabilities 2853 East 10th Street Bloomington, IN 47408 1-(812)-855-9630	

Resources:

1. State Department of Education
   Bureau of Early Childhood Education and Social Services
   Preschool Special Education Consultant
   25 Industrial Park Road
   Middletown, CT 06457
   (860) 807-2054

2. **Document**, "***Transition, Guide III: A Family Handbook,***" can be obtained from any of the Birth to Three Programs listed in Appendix 2

3. **Document**, "***Connecticut Task Force on Issues for the Education of Children with Special Needs,***" can be obtained from:
   State Department of Education
   Bureau of Special Education and Pupil Services
   25 Industrial Park Road
   Middletown, CT 06457
   (860) 807-2027

4. **Document**, "***Keys To Success: A Resource Package for Parents of Children with Special Needs,***" can be obtained from:
   Special Education Resource Center
   25 Industrial Park Road
   Middletown, CT 06457
   (860) 632-1485

Appendix - Seven

Parents: Questions To Ask Yourself Regarding Specific Treatments

⇒ What characteristic behaviors of autism am I trying to target? Does the treatment that I am considering target these characteristic behaviors?

⇒ Are there any harmful side effects associated with this treatment?

⇒ What positive effects of treatment would I hope to see?

⇒ What short-term and long-term effects might I see with this treatment?

⇒ Can this treatment be integrated into my child's current program?

⇒ What is the cost of treatment?

⇒ Will my insurance company pay for the treatment?

⇒ How much time does the treatment take? Can I realistically devote the time required to the treatment?

⇒ Has this treatment been validated scientifically?

⇒ Have I researched the treatment?

⇒ Was I able to interview other parents and professionals about the treatment? If so, list stated pros, cons, and other areas of interest.

⇒ Do proponents of the treatment claim that this procedure can help nearly everyone. If so, this should be seen as a "red flag" . . . slow down and be more careful than ever in your consideration of this technique.

⇒ What do my pediatrician and other professionals involved with my child think about the treatment's appropriateness?

Source: Fields V. Autism Advocacy in Lane County; Oregon: A Handbook for Parents and Professionals. Eugene, Ore: University of Oregon: 1993. Thesis

Appendix - Eight

Points to Ponder When Considering Participation in a New Intervention

⇒ What are the anticipated outcomes of this intervention? What positive changes can I expect to see in my child's behavior, communication, eating, sleeping, learning, etc.? Do these outcomes address what I see as an area of need for my child? Do these outcomes match my expectations or goals for my child? Are there any potentially negative outcomes of the intervention?

⇒ How will this be evaluated? How will I know if my child is making progress toward desired outcomes? What method will be used to evaluate child progress? How often will we evaluate child progress? Who will conduct the evaluation? How long will we continue until a change can be made in the intervention?

⇒ What are the potential risks? Will my child face any immediate risk? Are there any risks for other family members? Are there any activities, foods, etc. that will be restricted?

⇒ What is the back-up plan if we choose to discontinue this intervention? Is there any risk of discontinuing the intervention? What kind of early intervention services will my child receive if we decide to stop the intervention?

⇒ Is there a good fit between the intervention and our family life? Can we do what will be asked of us?

⇒ Have I gotten information about this from a variety of sources?

⇒ Is this intervention published in peer-reviewed journals?

⇒ Are there alternatives that are: less restrictive? better researched?

⇒ How will this new intervention be combined with strategies and therapies that we are already using with my child?

Source: Izeman, S. (1995). "Points to ponder when considering a new intervention" Early Intervention vol. 6, number 2, page 3.

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Available from:
Autism Society of America
7910 Woodmart Avenue, Suite 650
Bethesda, MD 20814-3015
1-800-3-AUTISM

Most resources available from:
Autism Society of North Carolina
Bookstore Catalogue
3300 Women's Club Drive
Raleigh, NC 07612-4811

Indiana Resource Center for Autism
3853 East 10th Street
Bloomington, IN 47405

Some Internet Resources

Autism@sjuvm.stjohns.edu - To subscribe, send an e-mail message (with nothing in the subject line) to Listserv@sjuvm.stjohns.edu that says "Subscribe Autism <email address>". This is a large international parent support group, with some professionals. It sends about 100-150 messages a day. A list of listserv commands is available by sending a message to Listserv that says "Send Refcard".

Web Pages

http://web.syr.edu/~jmwobus/autism - "Autism Resources" - has many links to other sites; well organized and informative
http://info.med.ya.e.edu/chldstdy/autism - "Yale Child Study Center"
http://ww.autism.org - Autism Center in Portland, Orevon - variety of information on autism and related topics.
http://www.autism.org/contents.html#issues - has lists of topics
http://www.EngPrevHealCtrAtl.com - web page of Dr. Steven Edelman, source of information about biological/medical issues
http://www.udel.edu/bkirby/asperger - Asperger's Syndrome Information
http://pages.prodigy.com/dpocari/recovery_zone.html - "Recovery Zone" - information about Lovaas approach, including testimonials
http://www.autism-society.org - Autism Society of America
http://web.syr.edu/~thefci - The Facilitated Communication Institute at Syracuse University

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