

### **SERVICE GUIDELINE ONE**

### **AUTISM SPECTRUM DISORDER**

INTERVENTION GUIDANCE FOR SERVICE PROVIDERS



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#### 2018 Revision

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### **PREFACE**

The purpose of this guideline is to help families and service providers develop and carry out intervention plans for families of children who are diagnosed with Autism Spectrum Disorders (ASD). The Connecticut Birth to Three System originally developed its autism guideline in June 1997 with revisions in 2002, 2008 and 2011. This latest revision takes advantage of the latest evidence-based practices and research, incorporates many of the guiding principles from the original guideline and blends Activity-Based Teaming (ABT) into the delivery of Birth to Three autism based supports and interventions. For the purposes of this document, the term Autism Spectrum Disorder (or ASD) is used throughout.

The information in this document is compiled from a review of research-based methods 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 Connecticut Birth to Three System (See Appendix One.)

### WHAT ARE AUTISM SPECTRUM DISORDERS (ASD)?

ASD is a complex developmental disorder that affects how a person behaves, interacts with others, communicates, and learns. Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. Often, there is nothing about how people with ASD look that sets them apart from other people. However, people with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need extensive help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder.

About 1 in 68 or 1.5% of children were identified with ASD based on tracking in 11 communities across the United States in 2012. Boys were 4.5 times were more likely to be identified with ASD than girls (Christensen, Baio, Van Naarden, & Braun, 2016).

#### WHAT ARE THE MOST COMMON SYMPTOMS OF ASD

Parents of children with ASD generally report concerns about their children before the child is aged eighteen to twenty-four months (CDC, 2014). Yet the mean age of diagnosis remains at 4 to 5 years (Fountain, King, & Bearman, 2011). Much current research efforts have been made to increase earlier identification of children in order to maximize opportunities for early intensive interventions. Research has shown the following symptoms have been identified in some but not all infants and toddlers later diagnosed with ASD:

- Does not respond to name
- Does not look at or show interest in socially meaningful stimuli (caregivers, siblings other children)
- Shows a preference for geometric shapes rather than images of children
- Abnormal body movement and motor delays
- Emotional dysregulation and lower sensitivity to social rewards (doesn't calm when being soothed by caregiver)
- Slowing in acquisition of new skills over the first two years of life
- Reduced social smiling, eye contact, social interest, affect and response to name at 12 months (but not at 6 months) (Zwaigenbaum, et al., 2015).

Some other common traits found in some but not all older children with ASD are:

- social interaction and relationship difficulties- for example, does not respond to name, prefers to play alone, avoids or resists physical contact, has flat or inappropriate facial expressions
- verbal and nonverbal communication difficulties- for example, uses few or no gestures, appears not to listen to others, does not point, uses words in idiosyncratic ways
- restricted, repetitive behaviors and sensory integration issues- for example, lines up
  toy or other objects, plays with toys the same way every time, flaps hands, rocks
  body or spins self in circles, picky eating preferences, apparent indifference to pain
  heat or cold or hypersensitivity to sound, light, touch. (Boyd, Odom, Humphreys &
  Sam, 2010).

What is most important to consider when looking for symptoms of ASD in infants, toddlers and children is the following: "Researchers have not found a single behavioral sign or single developmental trajectory that is predictive of all diagnoses of ASD" (Zwaigenbaum, et al, 2015). ASD remains stubbornly unique and individualized across all children- its one commonality is its heterogeneity.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM5) (American Psychiatric Association, 2013) lists the following diagnostic criteria for ASD:

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):
  - 1. Deficits in social-emotional reciprocity, ranging, for example from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  - Deficits in nonverbal communicative behaviors used for social interaction, ranging for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  - 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):
  - 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  - 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take some route or eat same food every day).
  - 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  - 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement.
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual

developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

**Note:** Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

## WHAT CAUSES AUTISM SPECTRUM DISORDERS (ASD)?

The simple answer is that we don't know. Researchers from all over the world are devoting considerable time and energy to finding the answer to this critical question. One of the things that we do know is that autism is not caused by bad parenting. Through twin studies, scientists have determined that autism is a genetically based condition. If one identical twin has autism then there is an 80-90% chance that the other twin will also be diagnosed with an autism spectrum disorder. For non-identical twins, there is a 3-10% chance that both twins will develop autism spectrum disorder. The chance that siblings will both be affect by ASD is also approximately 3-10%. Scientists are unsure what, if any, environmental triggers may be involved in autism (Sandin,et al., 2017).

The Centers for Disease Control is working on one of the largest U.S. Studies to date, called the Study to Explore Early Development (SEED). SEED is looking at many possible risk factors for ASDs and other developmental disabilities, including genetic, environmental, pregnancy and behavioral factors. The study includes 2700 children ages 2-5 from six states (Schendel, et al., 2012). Other studies are focusing on different possible risk factors including prematurity, parental risk factors, and early neurobiological processes (Zwaigenbaum et. al., 2015).

### WHAT HAS THE CONNECTICUT BIRTH TO THREE SYSTEM DONE TO ADDRESS THE ISSUE?

The Birth to Three System has both autism-designated programs and general programs(Please see Appendix Two) Ensuring that the system has the capacity to provide high quality services to children with ASD and their families throughout the state is a priority. Programs with an autism designation have assured the state that staff and supervisors have clinical expertise specific to working with children with ASD. This includes having a Licensed Behavior Analyst on staff who is able to oversee systematic instruction relying on intervention decisions that are driven by the results of data collection. These programs also have ongoing training in the use of empirically validated

autism specific curricula and practices as identified by the most recent version of the National Standards Project. General Birth to Three programs may also support families of children with ASD and have staff with expertise in this area. A family may already have a child enrolled in a general program. Or, they may be familiar with a specific general program or have made a strong positive connection with the initial evaluators from a general program. All families will be offered the choice to remain with their general Birth to Three program or transfer to an autism designated program.

### SUPPORTING FAMILIES

### **Assessment and Diagnosis**

For many families the months leading up to an autism assessment and diagnosis have been filled with anxiety and worry. Unfortunately, despite their concerns families often experience long delays between when they first had concerns and when their child receives a diagnosis of ASD (Zuckerman, Lindley, & Sinche, 2015). Often the delay can be attributed to attitudes of family members, friends and healthcare professionals. In seeking to reassure anxious parents that nothing is wrong, they may actually contribute to the delay of a diagnosis of ASD and implementation of services (Nissenbaum, Tollefson & Reese, 2002; Chawarska & Volkmer, 2005). By the time families actually receive a diagnosis they may be experiencing a mixture of emotions; anger at professionals for not listening to their concerns, guilt, sadness and fear over what the future for their child will look like. Many parents are often filled with an almost frantic effort to make up for all the lost time between when they first suspected autism and when they received the diagnosis of autism.

It is during this emotionally turbulent time that Birth to Three providers must explain the diagnostic process to families and present the results of the autism assessment. Research has been clear on this- the majority of families indicate the news of their child's disability was communicated poorly to them (Sloper &Turner, 1993; Nissenbaum, Tollesfson & Reese, 2002; Harnett, 2007).

The National Best Practice Guidelines for Informing Families of their Child's Disability (Harnett, 2007) have identified the following principles:

- 1. **Family Centered Disclosure:** Every family is different-each disclosure should fit the emotional, informational and individual needs of the family.
- 2. **Respect for Child and Family:** This should include using both child and parent names frequently, acknowledging and supporting the family's emotions, reactions and respecting their cultural and linguistic diversity.
- 3. **Sensitive and Empathetic Communication:** Being open, honest, empathetic and understanding is essential. Blunt, rushed and insensitive communication regarding the diagnosis will lead to significant and lasting dissatisfaction with the program by families.
- 4. **Appropriate, Accurate Information:** Trying to meet the family's information

needs is key and will greatly influence subsequent levels of parental stress and satisfaction. Again, every family is different and information should be given at the pace the family needs without either providing insufficient information or information overload.

- 5. **Positive, Realistic Messages and Hope:** Helping families focus on the child not the disability will tilt families away from fixating on worst- case scenarios. Help them celebrate their child while offering realistic, positive messages of hope.
- 6. **Team Approach and Planning:** Informing a family of their child's disability is a process and requires close communication among team members.
- 7. **Focused and Supported Implementation of Best Practice:** Support for these guidelines is required at all levels. Management and staff need to carefully take into account the need for time, physical environment and information needed to effectively disclose this new information.

The following are recommendations on how best to inform families of the diagnostic results of an autism assessment:

- The results of the assessment should be given verbally and in person (never over the phone).
- Allow yourself plenty of time-a rushed approach comes across as dismissive to families. Families should feel like they are a priority
- Ideally both parents should be present-if this is not possible ask if there is anyone
  else the family would like to be there.
- The results should be conducted in the family's primary language and arrangements should be made in advance to have interpreters present.
- Use names frequently-both the parent's name and the child. Avoid calling them "mom" or "dad" "kiddo" or "grandma."
- Sit close to parents to attend to emotional cues
- Allow for parents to be emotional-be prepared for tears, sadness or anger and respond to emotions with empathy
- Present information in a thoughtful, caring way, with information given in chunksnot all at once
- Allow time for questions throughout.
- Keep explanations simple and jargon free
- Do not argue with parents
- Don't criticize other providers

- Have parents tell you their understanding of what you have said
- Understand that parents may not retain much of what is being said
- Provide telephone numbers and brochures of parent support networks
- Offer positive, realistic messages and hope
- End with another opportunity for questions

Families are all different in how they process information. Taking the time to plan for and deliver the news of an autism diagnosis is critical in setting the stage for future interactions with families. Keep in mind, while this may be the 100th autism assessment you have done, it is the first this family has experienced. They will remember every detail of these moments. The acceptance, empathy and hope you offer them, however they might respond to this news, is key in beginning to build a positive relationship with families.

#### The IFSP Process

As discussed previously, many parents have been worried about and waiting for this diagnosis for a long time. They may have talked to friends, family members and their primary care providers about what kind of services will be most effective. They may have scoured the internet to find the best possible treatment for their child. Some families may have heard that early and intensive services may even "cure" their child.

It is not unusual for families to come to the first IFSP after an autism diagnosis with a preconceived idea of what kinds of services they want for their child. Their ideas may differ dramatically from what their Birth to Three team thinks will be effective. These two divergent approaches to the IFSP process can lead to conflict. Research indicates that there are certain factors that escalate and deescalate conflict between families and providers of special education services. Keeping these factors in mind can help guide families and providers to a smoother IFSP process- one that brings family and provider together instead of to opposing sides.

The following are the eight categories of factors the can contribute to escalation or deescalation of conflicts between families and providers (Lake & Billingsley, 2000):

- 1. Differing views of a child and/or a child's needs. Families often believe that providers do not know or appreciate the unique talents of their child. Providers believe families can become "single-minded" about what they want for their child and this can lead to them rejecting good alternatives.
- 2. Knowledge. Most families in Birth to Three are new to the world of early intervention. This lack of knowledge leads to a feeling of imbalance. To families, the providers have all the knowledge about how the system works. This, families believe, puts them at a distinct disadvantage when it comes to advocating successfully for their child.

- 3. Service Delivery. While program constraints are inevitable- families' thoughts and ideas should be respected, listened to and play a role in the planning of the IFSP. Responding to families with an immediate "No, we don't do that," or "That's not our model," immediately puts families on the defensive.
- **4. Constraints.** Time, staffing, money are all factors affecting conflicts. These conflicts can intensify when families perceive that other families (friends, neighbors, relatives) are receiving more services than their child is.
- 5. Valuation. Both families and providers must feel that they are equal partners in the relationship. Families can feel devalued if they believe the provider is withholding information or services from them or that they underestimate their child's ability. Providers feels conflicts become worse when families become emotional and criticize the staff coming into their home.
- 6. Reciprocal Power. When conflicts intensifies providers and families may consciously or unconsciously engage in power plays to get an advantage. For families this may include threatening to or actually following through with their due process rights. For providers it may mean, cutting back on services, changing staff or sending staff out in pairs due to an increasingly hostile environment in the home.
- 7. Communication. When communication is lacking, conflict can quickly escalate. Families and providers alike can feel misunderstood when they sense they are not being heard or listened to. Offering opportunities for both families and providers to communicate about their needs and feelings in a place that is safe and comfortable is essential. Sometimes it may take a neutral third party facilitator in a mediation or facilitated IFSP to achieve this.
- **8. Trust.** If families and providers both felt they trusted and respected one another, little glitches or minor mistakes on both sides would be much easier to tolerate. When trust is not present, communication suffers. Without trust and effective communication, often the only thing that can solve the conflicts is to transfer the family to another program.

When factors that lead to conflict are identified, it is easier to understand the conflict and work towards positive outcomes. Learning to disagree without devaluing the opposing party is essential if working relationships are to survive. Conflict in itself is not necessarily bad. Constructive conflict can exist when both families and providers are satisfied and feel that they have gained as a result of the conflict. The challenge to providers and families when conflict does arrive, is to maintain an attitude of "conciliation and cooperation," when disagreements arise (Lake & Billingsley, 2000).

The way we respond to conflict not only impacts our chances of resolving the issue, but may also affect our emotional and physical well-being. The following are five styles of

responding to conflict. Check which style best describes how you respond to conflict. Keep in mind, each style may be an effective intervention during certain conflicts.

- 1. Avoiding. By not addressing the existence of conflict or a difficult issue, you can avoid a "hot topic" or simply wait for a more appropriate time to address an issue. But, important decisions may happen without your input and your silence may send some the message that your opinion doesn't matter.
- 2. Competing. Standing up for your rights and being assertive about your beliefs, values and concerns is best used when someone needs to take charge in a challenging situation or when an issue is vital to either the family or the program. But, this sets up a "win-lose" situation that can quickly escalate into conflict.
- **3. Accommodating.** Letting go of your own ideas in a conflict to satisfy someone else's interests and giving into the wishes of others is best when they stakes are small and the issues are more important to the other person. However, this tactic can deprive you of influence later.
- **4. Compromising.** Searching for the middle ground where each side gives up some things and not others is effective when it's more important to solve the problem them to "win." However, many families and providers feel this approach leads to an atmosphere of constant negotiation. For example, this can happen when a family offers to give up four hours of a developmental therapist, in order to increase the speech therapist's hours.
- **5. Collaborating.** When people go beyond their own interests and solutions to create something new, the new solution works for everyone without compromising anyone's beliefs. This is a great intervention style, but it takes time, energy and lots of hard work by everyone involved.

During the IFSP process by far the most effective strategy for both families and providers is allowing each side the opportunity to not just have time to voice their concerns, but to feel that their concerns are really being heard. This means listening without interrupting or looking at your phone. Look for areas where you agree and focus on the positives. Ask open-ended questions like "What will the outcome of this look like?" "How will we know if this is working?" Present options in a collaborative way: "we can," instead of "you should," and "yes and" instead of "yes but."

### **GUIDING PRINCIPLES**

The crafting of this guideline has been influenced deeply by a set of principles that reflect both the science of early intervention and a core group of values. These principles are:

- Principle 1: The earliest possible start to intervention is essential.
- Principle 2: Services must be individualized for each child and family
- Principle 3: Family involvement and participation is critical.
- Principle 4: Families have a right to evidence-based practices.
- Principle 5: Intervention is based on a developmental curriculum designed to address the specialized needs of the infant or toddler with ASD.
- Principle 6: Intervention is planned and systematic.
- Principle 7: Infants and toddlers with ASD should have regular and deliberate exposure to typically developing peers
- Principle 8: Challenging behaviors are addressed using positive behavioral interventions and supports.
- Principle 9: Intervention should focus on developing communication skills.
- Principle 10: The development of social relationships is integral to successful outcomes
- Principle 11: Getting to quality outcomes is not just about hours of services but about increasing the child's learning through meaningful participation in everyday activities
- Principle 12: 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. Routine screening can identify risk for ASD in children who are 16 months and older. 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 K-12 schools and colleges, and working as productive adults.

All children referred to Birth to Three who are at least 16 months old are screened for ASD as part of the initial evaluation process. If a child has been recently screened as part of routine medical care, the screening results will be used in lieu of conducting an

additional autism screening. Preferred Birth to Three screening instruments include the Modified Checklist for Autism in Toddlers, revised with Follow-Up (M-CHAT-R/F), (Robins, Fein & Barton, 2009) and the Brief Infant Toddler Social-Emotional Assessment (BITSEA), (Briggs-Gowen & Carter, 2001). At this time there are no reliable autism screening instruments for children younger than 16 months of age. As the field advances, many experts are anxious to be able to reliably screen for autism in children younger than 16 months old.

When additional factors exist, such as older siblings or parents with ASD, Birth to Three programs are encouraged to carefully observe the child's development in the areas of social interaction, communication development and the presence of stereotypical and/or repetitive behaviors and develop an appropriate plan of services. If there are questions about the child's overall communication development or the child is very young, the program may choose to use the Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP Infant-Toddler Checklist). This instrument is appropriate for assessing potential risk for autism in children as young as six months (Wetherby & Prizant, 2002). More information on these three tools can be found in Appendix Four. General programs must screen children who are enrolled in Birth to Three at an earlier age when those children reach 16 months of age.

When the screening tool indicates that the child may have ASD, the Birth to Three Program will offer the family an autism assessment. Most often, this will be conducted by a Birth to Three program that has been designated as one that conducts autism assessments. This designation assures the following:

- The person with direct supervision of the program and staff must have at least three years of experience administering a program for children with autism spectrum disorders and families under Part C of IDEA
- The program has a history of providing services to children with autism spectrum disorders and their families for at least three years or, the requirement listed above is documented The program has staff clinically trained in the use of an autism-specific diagnostic instrument such as the Autism Diagnostic Observation Schedule (ADOS-2) for children 12 months or older or the Childhood Autism Rating Scale (CARS 2) for children 24 months and older
- The program routinely conducts all autism assessments in the child's natural environment
- The program has at least one clinical staff person (clinical licensed social worker, licensed psychologist or licensed physician) with diagnostic experience with the DSM-5

It is important to know, at the time of assessment, whether the child's hearing is adequate for speech, through either a hearing screening or an audiological exam.

This process is not one that only happens at the time a child is referred to Birth to Three. If, at any time, a parent, a Birth to Three provider, the referral source, a care provider, or someone else who knows the child observes that a child is having difficulty with developing meaningful communication or is regressing in communication skills, has issues with social reciprocity, and/or is limited in development by repetitive behaviors, it is essential that the IFSP team have a discussion with the family about the advisability of repeating the ASD screening. This may be a more difficult discussion than the one that was held initially, since it will arise as the result of concerns rather than as a routine procedure. Birth to Three staff must be prepared to have a well-thought-out, helpful, professional, and supportive conversation with a family about a challenging topic. Postponing this conversation, not allowing adequate time for the parent to reflect on it, excluding family members, or being equivocal can have serious negative consequences for the child, family, and program (Please see Talking with Families About Autism).

The purpose of this screening and assessment process is to assure that children who have a DSM-5 diagnosis of ASD have access to appropriate services provided either by autism-designated programs or, if families prefer, by a Birth to Three program without an autism designation (Please see Appendix 2) Autism assessment reports (as well as those diagnostic evaluation reports received from outside evaluators, must include information on the three core deficit areas of ASD (communication, social interaction, and a restricted range of interests and activities) as well as general developmental information to indicate what led the evaluator(s) or diagnostician to conclude that the child has an autism spectrum disorder. The assessors should also be able to make a differential diagnosis, i.e. why they think this child has ASD rather than some other primary diagnosis or classification such as ADHD, deafness, or sensory processing issues. At the same time, the assessors need to consider co-occurring diagnoses because a child with ASD can also have ADHD, deafness, or sensory processing issues. An occupational therapist on the assessment team may help the team to think about the role of sensory issues in the diagnosis/classification.

Additional information on early indicators of ASD is found in Early Indicators for Screening - Appendix Three. Additional assessment tools for ASD are listed in Appendix Four.

### Principle 2 Services must be individualized for children and families

"Individualization" means that each child and family's supports and 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 unique and has different needs and values. The development of the intervention plan, known as the Individualized Family Service Plan (IFSP), and ongoing changes in the plan are done with the family. Families have a decision-making role as members of the IFSP team.

The team determines who will be involved in the program, when services will take place, and what will be the focus of the supports and services. Even though the intervention may follow a specific curriculum, the infusion of intervention into daily activities and routines must be customized for each family. Therefore, it is essential that the IFSP be sensitive to and respectful of the enormous diversity in family life circumstances that impact family member's participation in intervention. The life circumstances include, but are not limited to: family structure, income stability, informal supports, and coordination with other relevant services. (Please see Best Practices in Early Intervention)

### Principle 3 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). Families are the first and most important teachers for their children. They are the constant in their children's lives. Infants and toddlers learn as they experience life with their families. 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 children. The partnership between Birth to Three and the family begins when the family places a call to Child Development Infoline because of concerns about their child. Throughout the eligibility determination process and the developing of outcomes for the IFSP, the family identifies how their child functions in family life and routines and what areas of need are most important to them. The IFSP process describes the roles of service providers, family members, and others in achieving the family's identified outcomes. 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.

The provision of Birth to Three supports and services is only a small part of the process of helping a child with ASD develop. Family members and early interventionists work together constantly to connect what the child is doing with family life to the content of the visits. Active dialogue between interventionists and parents, modeling and practicing during visits, tailoring carry-over strategies to changes in the family and child's life, designing and carrying out manageable record keeping systems are all parts of the Birth to Three experience. Family members and team members together can determine when it is time to consider revising the IFSP, what to work on next, and how to change activities or strategies that have not been as successful as hoped. Visits need to be scheduled at times and in ways that family members can fully participate. The content of all visits must be directed to assuring that family members and other caregivers acquire the skills and resources to help the child develop. It is almost certain that progress toward outcomes will be slower if families are not an active part of every part of the Birth to Three process including home visits.

Families need to be actively involved in their children's program, at a minimum, in the following ways:

- 1. planning and helping to decide what supports that they and their children need in order to meet their desired outcomes;
- 2. working together with the team to develop outcomes which are of importance to them;
- 3. participating in the development and selection of strategies for addressing the needs of their children and family;
- 4. implementing strategies with their child during and between visits in the context of their everyday activities
- 5. assisting in the evaluation of progress of their children.

Relationships between families and professional should reflect a respectful reciprocity where both parties learn from each other. Family members are not expected to be primarily responsible for delivering the specialized services on the IFSP; however, they are absolutely necessary partners in implementing intervention strategies within daily routines and activities.

### Principle 4 Families have a right to evidence-based practices

Part C of the IDEA mandates that states have in effect a policy that "ensures that appropriate early intervention services based on scientifically based research, to the extent practicable, are available to all infants and toddlers with disabilities and their families..." (20 U.S.C.1435(a)(2)). Families should expect that all services delivered as part of the Individualized Family Services Plan (IFSP) are based upon a contemporary understanding of efficacious intervention practices as articulated by the National Autism Center's National Standards Project report Phase 2 (2015) and the National Professional Development Center on Autism Spectrum Disorders definition of evidence based practices (EBP) for children with ASD (2014). Moreover, families should have a right to supports and services that address all the core deficits of ASD.

Intervention selection is complicated and should be made by a team of individuals who consider the unique needs and history of the infant or toddler with ASD and their family along with the environments in which he or she lives. However, in all cases, it is strongly encouraged that the IFSP team selects established evidence-based practice (Please see Evidence-Based Interventions section). For service delivery to any infant or toddler with ASD. Established interventions have sufficient evidence of effectiveness. The IFSP team must give serious consideration to these interventions because a) these methods have produced beneficial effects for children involved in the research studies published in the scientific literature and, b) access to methods that work can be expected to produce more positive long-term outcomes. However, it should not be assumed that these methods will universally produce favorable outcomes for all children with ASD.

In addition to relying on established interventions first, the judgment of professionals with expertise in working with the individual child with ASD must be taken into consideration (see Best Practice in Early Intervention). Once methods are selected, these professionals should collect data to determine if a method is effective. Professional judgment plays a particularly important role in decision-making when:

- A method has been correctly implemented in the past and was not effective or had harmful side effects.
- The method is contraindicated based on other information (e.g., the use of prompts for a child with a prompt dependency history).

Moreover, the values and preference of the parents or other primary caregivers play an important role in decision-making. An essential goal of intervention is to support the parents understanding and use of strategies in order for them the help their child learn and develop.

Finally, early intervention providers should be well positioned to correctly implement the selected intervention. Developing capacity and sustainability of an established method may take a great deal of time and effort, but all people involved in intervention to young children with ASD should have proper training, adequate resources, and ongoing feedback about fidelity. Capacity plays a particularly important role in decision-making when:

- A program has never implemented the intervention. Many evidencedbased methods are very complex and require precise use of techniques that can only be developed over time.
- A program has implemented a system for years without a process in place to ensure the intervention is being implemented correctly (with fidelity). For more about evidenced-based practice in early intervention please see Best Practices in Early Intervention.

### Principle 5 Intervention is based on a developmental curriculum

IFSPs for infants and toddlers with ASD should be based on widely accepted principles of child development. The instructional program builds on these principles and the child's individual strengths while also addressing his or her unique needs. The curriculum for a young 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 an infant or toddler with ASD include:

1. attending to and staying engaged in the environment, including people and developmentally appropriate play materials;

- 2. using verbal and non-verbal communication such as gestures, vocalizations and words;
- 3. understanding and using language to communicate;
- 4. playing appropriately with toys;
- 5. playful interactions with others;
- 6. reciprocal interactions;
- 7. spontaneous interactions;
- 8. making choices;
- 9. following daily routines and variations in routines; and
- 10. addressing atypical sensory preferences and aversions.

### Principle 6 Intervention is planned and systematic

Intervention is carefully planned, concentrated, and consistent. It involves assessing, planning, teaching, and consistent measuring of progress with each intervention step. Each step is coordinated toward a meaningful set of outcomes or goals. The only reliable way to determine if the intervention is effective is to be systematic and to measure progress on a regular basis. It is important to note that many indicators that are easiest to measure, such as vocabulary, intelligibility of words, or duration of eye contact may not be as meaningful or important to the family as the sense of the child and family's quality of life, such as reduced frequency or tantrums, increased child participation in family and community activities, ease of transition between home and other settings, or the ability of family members to spend quality time together.

Systematic instruction relies on intervention decisions that are driven by the results of data collection. Data is used to measure the change in a behavior or skill over time. For example, 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 independent nature 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. objectives are written in measurable and functional 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 outcomes.

Ongoing collaboration between the family and service providers in the analysis of data and adjustment of 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. The Birth to Three System highly recommends 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. The team meeting should be included in the IFSP service grid and if it is, programs will be reimbursed for team meeting time. It is also essential that services are carefully coordinated and involve the disciplines needed to address the unique needs of the child and family.

# Principle 7 Infants and toddlers with ASD should have regular and deliberate exposure to typically developing peers

This empirical and values based principle has, at its core, two irrefutable facts. First, children with ASD experience significant social relationship delays that represent primary diagnostic criteria (Luisell, Russo, Christian, & Wilczynski, 2008; Mahoney & Perales, 2003; Strain & Schwartz, 2009). Second, by a wide margin, the most effective intervention in this domain involves teaching typically developing children to be therapeutic resources (National Autism Center, 2009; Strain & Bovey, 2008). For children ages birth through two years, this means involvement in preschool/child care settings, "play dates", or planned interactions between siblings, where the early intervention team could facilitate peer training scenarios.

## Principle 8 Challenging behaviors are addressed using positive behavioral support (PBIS).

Positive behavioral support is a set of principles that frame how to think about and respond to children and their behavior (Carr et al., 2002). The principles are grounded in the appreciation of each child's strengths and needs. To practice positive behavioral support means getting to know the whole child and understanding that his or her behavior, a) has meaning, and b) is a form of communication. It requires recognizing that a child develops and responds best when he or she is respected and supported to enjoy relationships and make choices. Challenging behaviors displayed by a young child 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 also occur in a child who is typically developing. For an infant or toddler with ASD, behaviors can be extreme, occur more frequently, disrupt development, or contribute to high levels of stress among family members.

Before developing IFSP outcomes and strategies to address problem behavior, a thorough assessment of the behavior must take place. This assessment, which may be referred to as a "functional behavioral analysis" is completed by the appropriate members of the IFSP team and 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 also looks at what happens after the behavior occurs: "How do people respond to the behavior?" The assessment helps the team 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 as part of the IFSP. The plan includes developing strategies to keep the behavior from occurring, providing the child with new skills to replace the undesirable behavior, and assisting family members or other caregivers 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 activities and settings, 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 typical ways of interacting with others (Dunlap & Fox, 1999).

## Principle 9 Intervention should focus on developing communication skills

The importance of having an effective communication system cannot be understated. Communication is much broader than simply talking to others. A good communicator uses verbal as well as non-verbal behavior to engage a listener. Children communicate to make their needs known long before they can talk. As young 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. Young 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.

Some toddlers with ASD lack verbal communication while others with ASD may have large vocabularies or imitate spoken language well, but lack joint attention skills or functional use of language to communicate. Alternative or augmentative communication systems are one way to assist a toddler who has limited verbal language. The type of communication system used varies 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. Because a child with ASD tends to

have strong visual skills, he or she is often successful with picture communication systems such as the Picture Exchange Communication System (PECS) (Bondy & Frost, 1994). 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 chooses 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.

Whether a child is using an alternative communication system or not, communication interventions noted in the IFSP should focus on the development of functional communication, including receptive and expressive language skills such as getting someone's attention, requesting, commenting, pointing to objects, asking for help, and greeting others appropriately.

A first step in addressing communication issues with children who are suspected of having ASD is to assure that their hearing has been reliably tested. Hearing or an alternative to hearing such as sign language is a critical component of communication. An observer may not know whether 1) a hearing loss is causing autistic behavior, or 2) autism makes it seem as if a child has hearing loss, or 3) the child has both autism and hearing issues. Obtaining an accurate hearing assessment of a child with ASD can be challenging.

## Principle 10 The development of social relationships is integral to successful outcomes

In addition to difficulties with communication, infants and toddlers with ASD typically lack appropriate interaction and social skills. Intervention for a child with ASD needs to specifically address this core, defining characteristic as early as possible. Infants and toddlers develop based on experiential learning that happens in their natural environment as well as through "interactions rooted in social play that occur within the context of everyday caregiving activities" (Zwaigenbaum, et al, 2009; Zwaigenbaum, et al, 2015).

Promoting the child's development and expansion of social play while participating in the everyday activities of the family is integral for learning. For instance, bath time, dressing, mealtime, walking the dog, going grocery shopping all provide opportunities for using strategies that are aimed at increasing a child's appropriate social interactions with others. These interactions with family members during everyday activities and routines allow for frequent focus on and practice in expanding pleasurable and appropriate social interactions. This serves as a base for expanding social interactions in other situations and with other people and peers.

While promoting the social development of infants and toddlers with ASD must be one of the primary goals of early intervention services, facilitating the ability of young

children with social delays to develop appropriate friendships is also important. With early and intensive intervention, the seemingly pervasive social skill deficits of many children with ASD can be remediated (Lovaas, 1987; McGee, Daly & Jacobs, 1993; Strain, 1987). To successfully target these important skills, intervention efforts, even within early intervention must include; a) regular access to typical peers, b) thoughtful planning of meaningful social situations embedded throughout the day, c) the use of "social" toys, d) multiple-setting opportunities (home or inclusive, community-based) to practice emerging social skills, and e) intensive data collection in order to make midcourse corrections to existing intervention plans (Strain & Danko, 1995).

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 well 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. To encourage the generalization of skills and caregiver's ability to target identified outcomes it is important for providers to utilize play items and materials that are available to the child, a) in their natural environments, and b) on a daily basis and providers should refrain from bringing special (novel) toys into homes that are used only during intervention sessions.

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 be limited to one or two familiar children and the environment should also be familiar. The toys that will be most motivating for the child with ASD should be identified 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-to-adult interactions which, over time, become child- to- child interactions.

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 parent or caregiver. 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 11 Getting to quality outcomes is not just about hours of services but about increasing the child's learning though meaningful participation in everyday activities

There can be no doubt that achieving quality outcomes is first and foremost on the minds of families affected by ASD. In many situations, and for many years, families and providers have assumed that getting a certain amount of hours of service or a certain intervention practice is the essential ingredient to achieving quality outcomes. Regretfully, this simple and seductive formula is highly questionable and misleading.

Similarly, there has been a narrow focus on delivering a singular intervention approach. Some individuals advocate for only Pivotal Response Training, or Discrete Trial Instruction, or Incidental Teaching, and so on. The problem is that these established interventions vary greatly in their relative efficacy for certain target behaviors. For example, Peer-mediated Intervention has been shown to be the strongest evidence approach for target behaviors in the social domain. Incidental teaching has been used almost exclusively with verbal language behaviors. Visual schedules are particularly helpful during transition times, and so on. The point is that no one approach can hope to yield the best outcomes across all the likely goals of any child or family.

If a narrow focus on hours or a narrow focus on getting a certain intervention model is not recommended, then what are the relevant factors? These are five evidence-based factors that are suggested:

Factor 1. Intensity. While hours of service may not be a particularly valid measure of intensity, intensity is a highly relevant factor. The alternative view of intensity is based on several decades of research showing that the level of children's active and appropriate engagement in everyday routines is a powerful predictor of developmental growth (McWilliam, et al, 2009; Strain & Schwartz, 2009). That is, when young children are actively and appropriately engaged one can assume that skill acquisition is occurring. Instead of asking "How many hours of service are on the IFSP," the alternative question could be, "Are the IFSP outcomes, strategies and corresponding early intervention services sufficient to influence the child's engagement across all daily routines (dressing, eating, play, bedtime, etc). Intensity with toddlers must also be sensitive to the fact that essential interventions can be delivered across many routines by adult family members who have been coached by providers in specific teaching strategies. Moreover, keep in mind that very young children with ASD (and any similar age children) require adequate time during the day for rest and sleep. Very young children are simply not "developmentally available" for the same level of intensive intervention as are older children.

**Factor 2. Fidelity of intervention delivery.** Selecting an "Established Intervention" does not guarantee that the infant or toddler will receive the intended approach. It is essential to ask what experience providers have with the intervention approach, do they have a protocol for judging that the intervention is correctly implemented, and what are the plans if intended outcomes are not achieved.

<u>Factor 3. Social validity of goals.</u> Social Validity refers to the degree to which there is an immediate impact on the child's quality of life when a particular goal or objective has been met. For example, teaching a toddler to label colors when presented with 3x5 cards of different colors would have low social validity compared to teaching the same toddler color recognition when a peer at an art table says, "Do you want some red?" or when her mom says, "Want your red or blue pajamas?" In the latter cases, the child's new color knowledge can directly control her environment and meet immediate needs. Therefore, this teaching goal would have high social validity.

**Factor 4. Comprehensiveness of intervention.** In research for infants and toddlers with autism spectrum disorders under the age of 3, the central role of parents has been emphasized. Interventions should be planned to include a variety of learning opportunities in the context of the family's everyday activities. Through the family's use of strategies to increase their child's participation during everyday activities, teachable moments are capitalized on and opportunities for generalization are maximized. (Zwaigenbaum, et al, 2015).

**Factor 5. Data-based decision making.** As has been emphasized elsewhere in this guidance document, a key component to effective early intervention is to install a data monitoring system and related decision-making strategies to optimize the delivery of effective supports.

Data collection regarding the effectiveness of supports, information from the family on carry through in everyday activities and generalization, and discussion of the family's priorities and the amount of support they feel is necessary to assist them in attaining their outcomes for their child all influence determination of IFSP supports for the family and child. The supports and services should be the product of a carefully designed IFSP and not determined arbitrarily. As mentioned earlier related to Factor 1 (Intensity), the ultimate number of hours must address the amount of support the family feels they need to increase their confidence and competence in helping their child learn, as well as be sensitive to the developmental availability of toddlers in general to engage in structured activities. Related research by Dunst and colleagues suggests that early intervention plans that result in families having a narrow and sole focus on getting the maximum amount of intervention may have harmful effects on both family functioning and on ultimate child outcomes (Dunst, Trivette & Hamby, 2007). Implementation of these guidelines will ensure that more and more children and families affected by ASD will achieve the quality outcomes they desire and deserve.

# Principle 12 The transition from the Birth to Three System to preschool special education and related services should be well planned

Toddlers 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. Children with ASD may be so sensitive to change as to notice differences that others 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 for special education services. 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:

- The earliest possible release of referral information, with parent consent, to the local school district for a preschool special education (IDEA Part B) evaluation. This must occur before a transition conference with the local school district takes place (which can be as early as nine months prior to age three). Early referral allows the school district time to plan for the child with ASD.
- 2. The earliest possible communication (with parent consent) with the school district about the strengths and needs of the child and family;
- 3. Details of the early intervention supports and services that are in place and strategies that have been successful;
- 4. A focus on supporting the family as well as the child throughout the transition process.

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. As an example of one possible Planning and Placement Team decision, if a child turns three in the late spring or summer and the IEP includes Extended School Year Services, the school district may want to investigate whether it is possible to contract with the child's Birth to Three program so that the services in the IFSP can continue until the next school year begins. 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 its services in the school setting or to fully enroll the child in school earlier than age three. It is possible for an IFSP and an IEP to overlap for a child younger than three, as long as the intent of both plans is to make the transition smooth and not to merely add classroom services to existing home-based or child-care based services.

Unfortunately, many children with ASD are not identified 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 activities should be a major focus of IFSPs for all toddlers with ASD but especially for those nearing the age of three. Cooperation between the Birth to Three program and the school district is essential for effective transitions. School districts may wish to participate in joint evaluations or observations of the child. Prior to the transition conference it may be helpful to identify routines and 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 should be identified that may be not available from the school.

Parents and Birth to Three programs should be aware that the determination of eligibility for special education services is made by the school district's Planning and Placement Team (PPT). And there may be instances where a child is determined to be eligible for Part B services and has participated in an autism-specific Birth to Three program but the PPT prefers to report the child to the State Department of Education in the IDEA category of "developmental delay" instead of "autism." The district is still obligated to provide appropriate services to meet the needs of the child in the areas of communication, social interaction, and behaviors or any other areas of need that are identified through an evaluation, regardless of the selected IDEA primary disability category.

### BEST PRACTICES IN EARLY INTERVENTION

### Blending Activity-Based Teaming and best practices in the field of Autism

According to best practices in the field, the Connecticut Birth to Three System provides early intervention to meet the unique needs of a child with a developmental delay or disability by supporting the family's increased confidence and competence in enhancing their child's development. As endorsed in recommendations from a national panel of experts, the key principles for providing Early Intervention to all children through Part C of IDEA include:

- 1. Infants and toddlers learn best through every day experiences and interactions with familiar people in familiar contexts.
- 2. All families, with the necessary supports and resources, can enhance their children's learning and development.
- 3. The primary role of a service provider in early intervention is to work with and support family members and caregivers in children's lives.
- 4. The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child's and family members' preferences, learning styles and cultural beliefs.
- 5. IFSP outcomes must be functional and based on children's and families' needs and family-identified priorities.
- The family's priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.

7. Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations. (Workgroup on Principles and Practices in Natural Environments, 2008).

Three of these evidence-based practices are recognized to be most effective when providing supports in early intervention and are emphasized in Connecticut's Birth to Three System. We call this approach Activity-Based Teaming and it includes:

- natural learning environment practices
- the use of coaching during interactions with caregivers to support their abilities to help their child achieve developmental outcomes and family-identified priorities
- primary service provider approach to teaming

### Natural Learning Environments Practice: Activity Settings

Natural learning environments are more than places where children live, learn, and play. Natural learning environment practices start with looking at the activities children participate in with their families and other important people in their lives at home and in their community. These everyday activities provide a wide variety of learning opportunities which, in turn, lead to skill development for the child. (Connecticut Birth to Three: Natural Environments Guidelines, 2017) Best practice affirms that children learn best when they are participating with familiar people, in familiar places during these naturally occurring learning opportunities. The role of Birth to Three is to support families and other caregivers as they address outcomes for their child during every day routines and activities, in the real life of the child and family. (Division for Early Childhood, 2014).

These regular activities of the child and family serve as the starting point for using strategies that help their child be successful. The goal for the child is increased participation in everyday activities in order for skill development and behavior change to take place. These activities are happening regularly throughout the days providing many opportunities for practice. During every activity that a family has to or wants to do, there are many things that a child can learn. Attention is paid to working together to determine strategies that will allow a wide variety of learning, in many different developmental areas. This insures that a family gets the biggest bang for their buck: one activity provides a wealth of learning opportunities for their child.

### What might this look like for a family with a child with Autism?

- One goal for children with autism is to have more meaningful participation in daily life and during interactions with people in their lives. This can look very different for families with children across the autism spectrum. Parent's ideas and input are crucial for determining activities and strategies to work on with their child during their everyday routines.
- A family may share that they regularly take the dog for a walk together. This activity
  could happen as part of the Early Intervention visit. Strategies would be developed
  together and practiced by the family that address a variety of learning opportunities
  for the child when walking the dog. This recurring practice when walking the dog can

- lead to skill development and behavior change for the child. Supports may include: developing strategies for transition in and out of the house, ways to support communication when walking the dog, working on motor skills during the walk, strategies to increase social interactions with a sibling that goes on the walk ....
- Activities are happening all throughout the family and child's day that provide
  opportunities for learning. Some of the many activities might include: mealtime, bath
  time, wake-up time, playing on swings with sibling, walking to visit grandpa, doing the
  laundry, grocery shopping, playing in sandbox at childcare, hang-out time in the
  kitchen while dad cooks, playing a favorite tickle game with brother, running in
  sprinkler, water play on deck, attending church services, shoveling the snow, baking
  muffins together, music time at childcare. All of the regular activities that the family
  has to or wants to do are opportunities where strategies can be used to support
  learning.

### **Natural Learning Environments: Child Interests**

Natural Learning Environment practices also focus on tapping into a child's interests in order to increase their participation and engagement in activities and with the people in their life. "Child personal interests include, but are not limited to, their likes, preferences, favorites, strengths, etc. that encourage child engagement and interaction with people and doing things." (Raab & Dunst, 2006b) Parents are critical partners in identifying their child's interests: using those interests to encourage appropriate interactions with others as well as increase their child's ability to join in naturally occurring activities in the home and community.

Child interests are used to increase engagement in developmentally appropriate activities and/or as a bridge to increase participation in activities that may be difficult for a child. This increased participation allows for expansion of learning opportunities in their daily life.

### What might this look like for a family with a child with Autism?

- A family and additional members of the team may identify that a child is very interested small cars and lining them up. The child may be having a hard time with bath time. Lining cars up on the tub may serve as a bridge to help the child transition into the tub. Eventually, as the bath becomes more acceptable and enjoyable, the family would work on fading out the need to line up cars on the tub. (Rush & Shelden, 2011)
- A child may be interested in letters or numbers but has sensitivities for touching a variety of textures during self-care and meals. Strategies may be developed using plastic letters in the bathtub to increase interest and willingness to participate in water play and touching soap or washcloth. Another strategy may be developed for mealtime using cooked macaroni letters in order to increase the child's willingness to touch the food and independently eat. These strategies would be expanded to capture other learning opportunities within the activity such as using communication strategies during mealtime, developing fine motor control using utensils, or strategies to increase social interactions at the table.

- Using a preferred food to help a child develop more interest in participating in mealtime (staying at the table, interacting with others at mealtime, being acceptant of food on plate) or pairing a preferred food with a non-preferred food to try to expand what is acceptable to the child.
- Using a favorite toy as a transitional item to help parents manage the transition from one activity to another.
- Developing strategies for tapping into a child's interests to help the activity go smoothly and offer opportunities for learning during a visit to the grocery store, errands, or sibling activities.

### Natural Learning Environment Practices: Parent Responsiveness

A third critical aspect of natural learning environment practices as well as best practice in the field of autism affirms that a parent's responsiveness to their child is key to maximizing the child's ability to engage in learning. (Shelden, Rush, 2013) Current best practice validates that parents have an integral role and major impact on supporting their children's development and that they should have active involvement in their child's intervention. (National Autism Center, 2015; Zwaigenbaum et al. 2015). "Using responsive strategies, parents help their child learn successful ways to communicate, learn new things, interact and play with others, and participate in family activities" (Davis, 2014).

One goal of Early Intervention is to foster a parent's confidence and competence in helping their child grow and develop through use of responsive strategies that encourage their child's learning. Providers join families in their daily activities and support them in reading and responding to their child's cues. Parents are the ones who know their child best, understand his/her subtle signs, and have already tried various strategies with their child. With support from an early intervention team, parents and other caregivers can strengthen their knowledge and use of additional strategies that allow their child to be successful. Through the use of responsive strategies, a parent can maximize their child's opportunity for learning new skills and changing behaviors.

Providers also explore parent's ideas for what the family is interested in. When activities are addressed that are interesting for the child, the parent, and siblings, increased opportunities for learning and carry-over can be expected. When parents and other caregivers have an interest in a specific activity it also increases their engagement and supports additional connections with their child.

### What might it look like for a family with a child with Autism?

 A father taking the lead during playtime with his daughter while being supported, as needed, by the early interventionist in developing and trying different strategies. Responsive strategies may include learning to read his child's cues or signals, inviting his daughter's engagement by talking in a calm or playful voice, and using strategies to help her be successful during playtime with her brother. • A caregiver in childcare learning to meet the child where he/she is at, with an early interventionist supporting the caregiver during an activity to help create opportunities for growth for the child. For instance, a child might be having difficulty joining the class for circle/songs. The childcare teacher could be supported by the early interventionist to jointly develop strategies to increase the child's engagement in circle/song time (i.e. having child shake bells that he/she likes during the song, using a favorite mat to encourage child to sit in circle with friends) but yet allowing some freedom to move away from the group after a certain time.

### **IFSP Outcomes and Detailed Child Programs**

IFSP outcomes for all children are based on naturally occurring activities that the family feels will best allow them to address their priorities for their child. These outcomes are developed to increase their child's functional and developmentally appropriate participation in daily activities. This allows for frequent practice and repetition during naturally occurring daily routines which allows for the best chance for skill acquisition and behavior change. IFSP outcomes are not the only activities that will be worked on with the family but they are the ones that will be used to measure progress.

IFSP outcomes are also used to drive detailed programs for each child based on their individualized needs for support. While all children can show increased skills and behavior changes from use of strategies during their everyday activities, some may need additional support in order to fully participate in those naturally occurring activities. Detailed child programs are designed to further break down skills and support the behaviors that allow a child to increase his/her engagement and participation in the functional IFSP outcomes. If necessary, a skill would be taught for a specific purpose that relates back to the functional IFSP outcome, not for the sake of teaching isolated and unrelated skills. The goal is always to provide support during naturally occurring activities as this has been shown to allow significant potential for growth. (5)

### What might it look like for a family with a child with Autism:

The following is an example based on information from the National Professional Development Center on Autism Spectrum Disorders and Frank Porter Graham Child Development Institute: The Donovan Family Case Study (Kucharczyk, Shaw, & Tuchman-Ginsberg, 2012).

- The team does an evaluation/assessment that includes information from many sources in order to gather information on Joey's development, his strengths and challenges during his everyday activities, and the families concerns and priorities.
- As part of the initial assessment, information is also gathered on interests of the family and Joey. The family shares that Joey loves to play in and around water, turn faucets on/off, being outside, and riding on the tractor.
- Information is gathered on family activities which include farming, riding the tractor, tending to crops and the garden, walking to and playing in the creek, tending to the

- dogs, along with the more typical activities around mealtime, bath time and bedtime.
- Several functional IFSP outcomes are developed.
- One Possible Outcome: When mom or dad are working in the garden, Joey will participate by watering a plant: walking to the garden, holding the watering can and letting mom know when he needs more water.
- Additional criteria for deciding how they will know when the outcome is met would be determined.
- Joey's detailed child program information would further address development of skills and strategies that would support his participation in the activity. Skills taught may include:
  - Using a 2 step visual sequence
  - Holding the watering can while walking to the garden
  - Watering the plants
  - Looking when shown an object/following a distal point
  - Pointing to request/spontaneous request for more water
  - Following directions related to safety: come here, stop, wait
  - Imitating actions
  - Walking around objects (plants) on the ground
  - Requesting help
  - Accepting wet clothing or dirt on hands/clothes
- Since this is an activity that the family does at least twice a day in several different gardens and water is a huge interest for Joey, he would have many opportunities for practice, which would increase the likelihood of success and attainment of outcomes.

### Coaching As a Style of Interaction

A coaching style of interaction is a manner or approach that the team uses to interact with parents, caregivers, and each other. Based on adult learning principles, it is a way build the family's confidence and competence in being able to enhance their child learning and development within the typical activities of the family. The Early Interventionist's role as a coach is to "identify the parent's priorities for their child's development, determine what they already know and are doing in relation to their child's development, share new information and ideas, and then work together to support the child's participation and expression of interest within everyday activity settings to provide opportunities for learning" (Rush & Shelden, 2011).

Research has found coaching to be an essential tool used to directly support families of young children as they generalize interventions into their child's daily routines. It is a critical relationship-based process used to support parents and caregivers within the cultural context of the home and community (Kucharczyk et al., 2012). The Early Intervention coach works to build a relationship with the parent, explore and build on the parent's ideas for supporting their child, supplement the parent's information, and support parents in carrying through strategies with their child in their daily life.

Coaching happens within the context of an activity and is based on use of reflective practices. While the parent works with their child, the coach is there to support them, gather their thoughts and ideas, share information and strategies based on research, model strategies, have the parent try the strategies and reflect on how well they did or did not work. A coach cannot coach if nothing is happening between the parent and child. For instance, a soccer coach does not coach by just talking about soccer. He/she coaches the team while they are actually playing soccer. And so it is with coaching in the context of Early Intervention. The parent or caregiver is doing an everyday activity with their child and the early intervention coach is there to support them.

One characteristic of coaching in Birth to Three is creating a Joint Plan. This is an agreement between the coach and caregiver for what activity (including strategies) the caregiver will work on between visits and what will be the plan for the next visit. (Rush & Shelden, 2011). For a family with a child with Autism, the early intervention team member who has been determined to be the main interventionist coaching the family will help the family develop a Joint Plan on approximately a weekly basis. Joint plans need enough time for the parents and/or caregivers to work on them yet be timely enough to make sure a plan is in place for what specific activity the family would like to focus on during the next coaching visit. All families and caregivers should be regularly developing Joint Plans with their early interventionist(s) as part of their early intervention supports since what happens between visits is critical for attainment of outcomes.

In addition to working intently with the family, at times the early interventionist may also work in a more focused manner with the child to support development of prerequisite skills that are necessary for a child to be successful in an everyday activity related to attainment of outcomes.

### What might it look like for a family with a child with Autism?

• Anne, the Early Intervention teacher, and Maria, the mother of a child with autism, have made a previously agreed-upon plan that included a "between visit" plan that Maria and her son would focus on bath time and several strategies they had practiced to support learning during this activity. The "next visit" plan for today's visit was to play with the child's sister in the backyard, flying a kite. Anne arrives at the house and reviews the Joint Plan with Maria. Maria and Anne discus how the strategies worked or did not work during bath time the previous week and Maria states that she would like to do another visit at bath time in the future as she is still having some difficulty. They decide to go ahead with the plan for today's visit to fly a kite with the child's sister. Anne reviews the activity with Maria ahead of time in order to decide on some strategies that Maria may try to support her son's learning and to set the activity up for the best chance of success.

During this activity Maria, her son and his sister all engage in flying the kite. Anne observes and asks Maria some questions to help her analyze why certain behaviors are happening and come up with some ideas together to address this. As possible, Maria and Anne debrief during the activity on what is going well, where strategies and support

are still necessary, and try new ideas. Anne models strategies if necessary and gives Maria the opportunity to practice. After the activity is over they reflect together on the activity and determine their new Joint Plan. Maria decides that for her "between visit plan" she will work on kite flying again this week and use some of the strategies she tried on this visit to support her son's learning (i.e. using headphones to decrease the noise from the wind which is difficult for her son to handle, using pictures to help with the various transitions, using turn-taking strategies with his sister, and a word or sign that lets Maria know if he wants to continue or stop). Maria decides that she can use these same strategies whether they are kite flying, playing on the swings, or in the sandbox. Maria decides that she would like the "next visit plan" to focus on bath time as she would like more support with this activity.

• A family has a son with autism and they are being supported in the home by several professionals including a Speech Pathologist, a Teacher/Developmental Therapist, and a Developmental Therapy Associate. While coaching as a style of interaction is encouraged with all interventionists during visits, it is decided that the Joint Plan will be developed on the weekly visits with the Speech Pathologist. The Speech Pathologist and family structure their visits similar to what is described in the example above including development of Joint Plans. It is important that the information regarding the Joint Plan is shared with all interventionists so that they also address and support progress on the plan during their sessions.

### **Primary Service Provider Approach to Teaming**

In the field of Early Intervention, a Primary Service Provider approach to teaming is the

recommended manner of support for families. (Workgroup on Principles and Practices in Natural Environments, 2008) This approach designates one team member as the main liaison to the family. This primary service provider would be the team member most frequently supporting the family and would also be acting as the service coordinator. The primary service provider uses natural learning environment practices and coaching in their work with the family. Although the primary provider is the main liaison with the family, he/she and the family are also supported by a full team representing all disciplines during regular team meetings and joint visits. (Shelden & Rush, 2013) For some families who have a child with autism, the primary service provider approach as described above will be the best way to provide support, attain outcomes, and not overwhelm the family and child with multiple interventionists. For other families, supports may look different. Because all supports and services are individualized for each child and family in the Birth to Three System, this is possible. Some families and children may benefit from more intense supports and services. Supports provided in this manner will still include designation of one team member who will act as the family's team lead and will be responsible for working more intently with the family during their daily activities. Ideally this interventionist will also act as the family's service coordinator. In addition to use of natural learning environment practices, the family's team lead uses coaching to build family capacity and works cooperatively with the family to develop joint plans. Families will be working with the team lead to develop and review their joint plans approximately on a weekly basis. Additionally, these families may be receiving regular support from other interventionists who work during daily activities with the family to

support their child but may also work, at times, in a more focused manner with their child. These more focused efforts to support pre-requisite skills for the child should be for the purpose of increasing the child's ability to be successful in participating in the regular, everyday activities of the family. This increased participation and use of strategies during everyday activities will allow for skill development and behavior change for the child and is the goal of early intervention.

### What might it look like for a family with a child with Autism?

- Kaiden has been followed by a general early intervention program through the Birth to Three System and has recently been diagnosed with Autism. His family has strong ties with their team and does not want to change programs. Kaiden and his family are supported by a Speech Pathologist who also serves as the primary service provider and service coordinator. She works regularly and frequently with the family in the context of their everyday activities to help the family support Kaiden and address their desired outcomes. Kaiden also attends childcare several days per week and the Speech Pathologist provides support to the childcare teacher in order to address outcomes for Kaiden. The family and the Speech Pathologist are supported on joint visits as needed by secondary service providers: an occupational therapist and a behavior specialist. The family and primary service provider also have access to a full team of professionals, if additional expertise is necessary.
- Oliver enters the Birth to Three System with a diagnosis of Autism and has not received supports in the past. His family is anxious to get supports and services started and feel they have much to learn. The family prioritized functional outcomes for Oliver that include increasing his participation and success during two challenging activities: bath time and mealtime.
- The family receives support from several professionals: a teacher/developmental therapist who functions as the family's team lead and service coordinator, a behavioral specialist, a developmental therapy associate, an occupational therapist and a speech pathologist. The developmental therapist works with the family during many activities, including the priority areas of bath and mealtime. She and the family work together develop strategies to increase Oliver's opportunities for learning during these activities and to develop the joint plan approximately on a weekly basis. All other interventionists are informed of the joint plan and use this information during their work with the family and child during the week. While all interventionists use natural learning environment practices during their visits, the developmental therapist who is this family's team lead is the primary person using coaching with the family.

The behavior specialist, occupational therapist, and speech pathologist also make visits to support the family and team in use of strategies during regular activities that will allow for skill development and behavior change in Oliver. In addition to working with the family to support their child, the developmental therapy associate works in a

more focused manner with Oliver to build some pre-requisite skills that will help him be more successful participating in bath time, mealtime, and other daily activities. As Oliver is able to more appropriately participate during the activities in the family's everyday life, there will be many more opportunities for learning to take place.

#### DETAILED GUIDANCE FOR KEY PRACTICE ISSUES

### Strategies for Designing Individualized Family Service Plans

The IFSP is a process that uses a written plan to (a) document current levels of development, (b) identify functional outcomes for the child and family, and (c) specify early intervention supports and services needed by the eligible child and family. The IFSP process is family directed and developed jointly by the family, other individuals of the family's choice, members of the assessment team (for the initial IFSP), the service coordinator, and appropriate early intervention service providers. While the general process for the development of an IFSP is well documented, the following bullets describe some key ingredients that should characterize all IFSPs:

- Family information, including their resources, concerns and priorities for their child as identified by the parents through interviews, assessments and informal contacts with the service coordinator, child care staff, doctors, nurses and other family members
- A child's present physical, cognitive, communication, social emotional, and adaptive development levels and needs, obtained from a multidisciplinary evaluation
- Functional outcomes expected to be achieved for the child and their family in the following six months to a year and some strategies to meet those outcomes
- Specific supports and services a child and family will be receiving based on what is felt necessary to support the family in attaining their outcomes for their child
- Where the services will be provided within a child's natural environments (e.g., home, child care). If the services will not be provided in the natural environment, the IFSP must include a statement justifying why not and strategies for moving the services back into their natural environment
- How often a child will receive each service and how long each session will last
- Who will pay for the services, if someone other than Birth to Three is paying
- Name of the service coordinator overseeing the implementation of the IFSP
- Steps to be taken to support a child's transition out of early intervention and into another program when the time comes

Other supports the family may want to explore in order to assist them in meeting their child and family outcomes.

The IFSP needs to be reviewed, and updated if appropriate, at least every six months and is rewritten annually. The IFSP process must be fully explained to the parents in order for them to be able to participate in its development a meaningful way. A parent or guardian must give written consent before supports and services can start and is free to disagree with some services while giving consent for other services to begin.

Creating an IFSP that meets the needs of infants and toddlers and families affected by ASD is, in many cases, a complex and evolving process. The available research base for early intervention service delivery to very young children with ASD is limited. The scientific-based practices are evolving as early intervention providers and researchers use ongoing data systems to guide the developing body of knowledge about how to determine what supports and services, methodologies, intensities and frequencies yield meaningful behavioral change in children under the age of three years. It is recommended that early intervention teams ask themselves the following questions to guide the IFSP planning process for children with ASD in order to support the delivery of services that are individualized, evidenced-based and comprehensive (this list is also provided in Appendix 6 for teams to use):

- Question 1. Have multiple child and family assessments been used to document the infant or toddler and family needs identified in the IFSP that are:
  - a) Specific (observable, measurable, and valued by adult family members)
  - b) Functional (related to specific skills that help the child access everyday life)
- Question 2. Are there evidence-based strategies in place on the IFSP that:
  - a) Address family priorities and each area of need identified by the team?
  - b) Match functional outcomes that focus on participation during everyday activities in order to address the defining characteristics of ASD (communication, social skills, and behavioral concerns)?
  - c) Specifically address the child and family being successful with daily routines (e.g., dressing, feeding, bedtime, community outings, etc.)?
  - d) Include strategies to equip family members with the information and skills needed to provide consistency in intervention when early intervention providers are not present?
- Question 3. Has the IFSP team carefully considered the following, taking into account the child's developmental availability for intervention and the family's dynamics and available resources:
  - a) what early intervention services are needed to implement the evidenced-based practices and support family in carrythrough:
  - b) who will deliver the services;

- c) where the services will be provided, and
- d) when and how frequently the services will occur.
- Question 4. Are the proposed providers fluent with the evidence-based practices to be delivered? Do they have a protocol for judging that the intervention is correctly implemented, If not, what plans are in place to provide training, supervision or coaching for those providers?
- Question 5. Is there a plan in place to use a primary provider service model or, where multiple providers are seeing the child, a plan to meet frequently to communicate, plan logically consistent services and review progress?
- Question 6. Do the planned strategies include ongoing data collection (see section on Monitoring Progress, page 46) and clear decision-making guidelines regarding the continuation or modification of the plan that results in progress for meeting child and family outcomes?

Together, the practice principles discussed in the previous section with the straightforward answers to these questions will help to ensure that plans are sufficiently comprehensive, designed to produce functional outcomes in essential real world settings, are using evidence-based practices, and are delivered in a competent, coordinated and data-based fashion. In order to maximize the child's skill generalization across persons, settings, and time it is essential to first consider the child's planned learning opportunities delivered by adult family members and/or adults in the home and other community settings prior to determining the number of service hours on the IFSP.

For children with ASD, Birth to Three suggests using tools to help the parents identify and communicate their child's current levels of functioning around common everyday experiences at home and in the community. One example is the *About Our Child* assessment tool, (Strain, 2002) (see Appendix Six) that aids parents or other caregivers in identifying skills their child currently demonstrates in common everyday activities and routines. Additionally, the tool helps to identify skills that parents would like their child to learn in these areas. The *About Our Child* document which can be left with parents to complete on their own starts by asking parents or other caregivers to list what the child can do in the following areas:

- 1. Play Skills such as appropriate toy play, sharing, taking turns, playing by themselves (independence) and playing with other children.
- 2. Language Includes skills such as communicating wants and needs, following directions, listening skills, understanding concepts (e.g., in, on, up, etc.)
- 3. Adaptive Skills such as dressing, hand washing and toilet training.
- 4. Meal Time Skills such as eating with utensils, eating a variety of foods, using a cup and sitting at the table for meals.

- 5. Bath Time Skills such as sitting in the tub, washing body parts, brushing teeth, combing hair.
- 6. Cognitive Includes skills such as understanding simple stories, identifying pictures of objects, letters and numbers, shapes, colors, matching, sorting and making choices.
- 7. Motor Covers gross motor skills like running and jumping, rolling, catching and throwing a ball and fine motor skills including opening containers, turning door knobs, holding crayons and markers, using scissors and playing with material like play dough.
- 8. Community Activities Skills such as sitting in a cart at the grocery store, riding in a stroller, playing at a playground and riding in the car.
- 9. Behavior Behaviors that interfere with learning, that the parent(s) would like the child to do less often, are aggressive, self- injurious or deal with sensory sensitivities.

After parents have a chance to list skills their child demonstrates across these areas; parents are asked to list new skills they would like their child to learn in each of these areas. Because parents spend time with their child doing these things on a daily basis it can provide assessment teams valuable information regarding the child's functional skill set throughout the day which can be used alongside any additional formal or informal assessments the team has conducted. Ideas generated through the *About Our Child* can be shaped directly into functional outcomes and strategies on the IFSP. Moreover, the form is a good starting place for building an intervention that is contextually relevant to the everyday activities that families experience. The form may be completed by the family or other caregivers themselves or through interview with the family by a service coordinator or provider.

A second recommended tool to gather family information is through the use of the *Routines-Based Interview* (McWilliam Casey & Sims, 2009). The RBI is a part of a functional intervention planning process and helps determine what skills or behaviors a child must learn to be successful in daily routines. This protocol is an excellent supplement to About Our Child as it more directly pinpoints the daily routines that will serve as the context for service delivery. The RBI also meets IDEA standards as a parent interview, a required component of the IFSP process.

#### EVIDENCE-BASED INTERVENTIONS AND MEASURING OUTCOMES

There are literally hundreds of intervention methods that have been used to improve the core symptoms of ASD. Some methods are highly effective, some less so, still others are ineffective. What seems certain is that regardless of demonstrated effectiveness, many methods are vigorously marketed to providers and families. The guiding principle that children and families should be provided with evidence-based practices has led directly to the following set of recommendations based upon the National Autism Center's National Standards Project Phase 2 (NSP) (2015). Moreover, these practices are also in line with those recommended by the National Professional Development Center (NPDC) on ASD (2014). Of course, in a rapidly changing field, recommended

practices at one point in time should always be revisited as new data become available (Please see Appendix Five to see a side-by-side comparison of NSP 2 and NPDC).

The NSP Phase 2, by far the most comprehensive and rigorous review of the scientific literature on children with ASD to date, was designed with three purposes in mind:

- 1. To identify the level of research support currently available for educational and behavioral interventions used with infants and toddlers with ASD. Knowing levels of research support is an important component in selecting interventions that are appropriate for individuals on the autism spectrum.
- 2. To help parents, caregivers, educators, and service providers understand how to integrate critical information in making intervention decisions. Specifically, evidence-based practice involves the integration of research findings with (a) professional judgment and data-based clinical decisionmaking, (b) values and preferences of families, and (c) assessing and improving the capacity of the system to implement the intervention with a high degree of accuracy.
- 3. To identify limitations of the existing treatment research involving infants and toddlers with ASD.

# **Established Interventions in the National Standards Project (NSP)**

Details regarding the NSP methodology for identifying interventions and rating them can be found online through the National Autism Center's website.

Fourteen interventions were identified as *Established* (i.e., they were established as effective) for individuals with ASD. Established Interventions are those for which several well-controlled studies showed the intervention to produce beneficial effects. There is compelling scientific evidence to show these interventions are effective; however, even among Established Interventions, universal improvements cannot be expected to occur for all individual children with ASD. The NSP Phase 2 also categorized other interventions as *emerging* (i.e., some tentative evidence of effectiveness) or *un-established* (i.e., no data upon which to recommend use).

The NSP identified the following interventions to be established:

- 1. Behavioral Interventions
- 2. Cognitive Behavioral Intervention Package
- 3. Comprehensive Behavioral Treatment for Young Children
- 4. Language Training (Production)
- 5. Modeling
- 6. Natural Teaching Strategies
- 7. Parent Training
- 8. Peer Training Package

- 9. Pivotal Response Training
- 10. Schedules
- 11. Scripting
- 12. Self-management
- 13. Social Skills Package
- 14. Story-based Intervention

For information on other levels of effectiveness see the full NSP report at <a href="National">National</a> <a href="Standards Project Phase 2">Standards Project Phase 2</a>.

Of the fourteen established interventions three were specifically found to have sufficient evidence for NSP2 to confidently state they were effective interventions for 0-3 year old children. These interventions are:

- Comprehensive Behavioral Treatment for Young Children
- Naturalistic Teaching Strategies
- Parent Training Package

Eight interventions were found to be effective for children ages three years and older. These interventions are:

- Behavioral Interventions
- Language Training (Production)
- Modeling
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Scripting
- Story-based Interventions

Cognitive Behavioral Intervention Package, Social Skills Package and Self-management rely on complex language and cognitive skills are not included in these guidelines as they will likely not be used for many children under the age of six years. However, given the heterogeneity of ASD, practitioners may reasonably consider the eight intervention methods found effective for children three years and older may include high-functioning children under three. For this reason we have included them in this guideline.

#### Are These Strategies Enough?

While the wide diversity and unique needs of children with ASD must always be considered, the eleven interventions detailed below represent a wide range of strategies sufficient to address all the core symptoms of autism in young children. Importantly, these interventions have been implemented successfully by a broad range of providers, families, and in some cases, other children. The recommendation is that teams become proficient at delivering these interventions, plan on delivering these interventions first, and then examine Emerging Intervention options only after data indicate less than desired outcomes using these interventions.

#### The Eleven Interventions: Description and Application

Below is a general description of the eleven interventions, their implementation for infants and toddlers with ASD and readings that offer more procedural detail. Following this general description are examples of intervention use with case studies of children and families.

#### Effective Interventions for Children 0-3

1. Comprehensive Behavioral Treatment for Young Children(CBTYC)

CBTYC programs involve intensive early behavioral interventions that target a range of essential skills such as communication, social and pre-academic skills. Deficits in these areas are considered defining symptoms of ASD. The interventions in CBTYC are described as applied behavior analysis (ABA) or Early Intensive Behavioral Intervention (EIBI). The goal of ABA is to teach new skills, promote generalization of these skills and reduce challenging behaviors with systematic reinforcement (Weitlauf et al., 2014). Early and Intensive Behavioral Intervention (EIBI) is an evidence-based intervention using principles and procedures from ABA to teach adaptive behaviors to young children with ASD.

CBTYC programs look to increase skills in the following areas:

- Play
- Communication
- Social skills
- Vocal language
- Self-management skills
- Motor skills

CBTYC typically involves intensive service delivery. However, it is difficult to accurately predict intensity and duration of services for very young children. Amount of hours will vary by family and child but typically would involve over 20 hours per week. This amount might represent a combination of professional and family involvement working directly working with the child. Data based decision- making target the symptoms of ASD. To ensure that the treatment interventions include accurate and appropriate data recording a Licensed Behavior Analyst (LBA) or other highly qualified individual is needed for frequent data monitoring and modification of strategies. This increases the likelihood of making continuous progress.

Instruction is individualized and often includes the following strategies:

- Discrete trial teaching
- Incidental teaching
- Errorless learning
- Behavioral momentum
- Shaping
- Modeling

# Recommended Readings:

Leaf R. & McEachin (1999). A work in progress: Behavior management strategies and a curriculum for intensive behavioral treatment of autism. New York: DRL Books, LLC Lovaas, O. I. (2002). Teaching individuals with developmental delays: Basic intervention techniques. Austin, TX: Pro-Ed.

Maurice, Catherine, Green, Gina & Foxx, Richard M. (2001). *Making a difference: Behavioral Intervention for autism.* Austin, TX: Pro-Ed.

Maurice, C., Green, G., & Luce, S. (Eds.) (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals*. Austin, TX: Pro-Ed.

# 2. Naturalistic Teaching Strategies (NTS)

Naturalistic Teaching Strategies (NTS) are a compilation of strategies that are used to teach children skills in their home, school and community. The emphasis is on following the child's interests, lead or pace when presenting learning trials. More child-centered than the massed trial teaching of an ABA approach, strategies are developed by incorporating children's motivations, interests and favored activities. Trials are less structured and incorporate functional mediators; the cues or prompts that are used to teach a new skill/behavior. The skills are easily transferred across different settings where the skill/behavior is used. This embedding of new skills into a toddler's natural environment and daily activities encourages generalization of skills and allows the adult to use their insights about a toddler's interests and expand upon them to reach target behaviors.

NTS programs look to increase skills in the following areas:

- Interpersonal and play
- Learning readiness
- communication

The following are guidelines to consider when using NTS:

- Observe the child to find out what motivates him or her then structure teaching strategies around those interests
- Use materials the child is likely to encounter on a daily basis
- Teach skills in a variety of situations and settings. For example, teach skills in the home, childcare, the grocery store a park.
- Provide consequences that are found in the environment and have a direct relationship with the activity being completed.
- Provide loosely structured teaching session that vary and are based on the child's interests on that day (National Standards Project 2).

Instruction is highly individualized and might include the following intervention strategies:

- Pivotal response training
- Focused stimulation
- Joint attention
- Early Start Denver Model
- Incidental teaching

- Milieu teaching
- Embedded teaching
- Responsive education
- Prelinguistic milieu teaching

#### Recommended Readings:

Charlop-Christy, M. H. (2008). How to do incidental teaching. Austin, TX: PRO-ED. Thompson, T. & Odom, S. (2011). Individualized autism intervention for young children: Blending discrete trial and naturalistic strategies. Baltimore, MD: Paul H. Brookes.

#### 3. Parent Training Package

The Parent Training Package focuses on interventions that highlight parents' and caregivers' integral role in providing a therapeutic environment for their family members with ASD. Parent training interventions are classified based on their theoretical framework and are placed on a continuum from pure behavioral interventions to sociopragmatic interventions. Behavioral interventions are characterized by a high level of structure in which a therapist prompts the child's behavior. When the child responds correctly, the therapist reinforces the child's behavior. Sociopragmatic interventions are characterized by following the child's lead through spontaneous activities and using those activities to enhance the child's learning (Beaudoin, Sebire, & Couture, 2014). Several interventions incorporate strategies from both behavioral and sociopragmatic interventions. Behavioral strategies such as repetition can be combined with activities chosen by the child in natural settings (Vismara, Colombi, & Rogers, 2009).

Parent Training Package programs look to increase skills in the following area:

Interpersonal and play

Behaviors decreased through Parent Training Package programs include:

- General symptoms
- Problem behaviors
- Restricted, repetitive, nonfunctional behavior, interests or activity

Parent training can take many forms including:

- In vivo individual training
- Group training
- Support groups with an educational component
- Training manuals
- Therapist –guided parental coaching during parent-child interactions
- Therapist-guided programs offered in groups or one-to-one

Examples of skills parents learned to use include:

- Strategies to develop imitation skills
- Commenting on the child
- Expectant waiting to elicit communication
- Appropriated sleeping routines
- Joint attention
- Development of play dates activities

#### Recommended readings:

Ingersoll, B. & Dvortcsak, A. (2010). *Teaching social communication to children with autism: A* 

practitioner's guide to parent training / A manual for parents (2 volume set). New York, NY:

The Guilford Press.

Rogers, S. J., Dawson, G., & Vismara, L. A. (2012). An early start for your child with autism: Using

everyday activities to help kids connect, communicate, and learn. New York, NY: The Guilford Press.

#### **Effective Interventions for Children 3-22**

Behavioral Interventions.

• The Behavioral Intervention category is comprised of interventions described as antecedent interventions and consequent intervention. Typically, these interventions involve the modification of situational events that typically precede the occurrence of a target behavior. Prompting is part of a complex behavioral intervention consisting of two or more components. In the latest NSP prompting has been moved from a "stand alone" evidence based intervention to being grouped with other behavioral interventions. The following are examples of Behavioral Interventions:

#### A. Using one identified component:

Joint Attention Intervention
 Chaining
 Differential Observing Response

Forward Chaining
 Function-based Intervention
 Repeated practice

Reinforcement Schedule
 Imitation Training
 Standard Echoic Training

#### B. Using two identified components:

• Extinction + Reinforcement Function-based Intervention + Prompts

A. Sign Extinction + Differential Reinforcement of Alternative Behavior (DRA)

# B. Stimulus Fading + Positive Reinforcement

# C. Using three identified components:

- Choice + Task Interspersal + Positive Reinforcement
- Discrete-trail Training + Natural
- Consequence + Error Correction
- Most to Least Prompting + Natural Consequences + Activity Interspersal
- Preteaching + Prompting + Positive Reinforcement

#### D. Using four identified components:

- Combined Task Direction + Contingent Reinforcement + Physical Prompts + Stimulus Fading
- Modeling + Prompting + Reinforcement + Redirection + Abolishing Operation Component
- Prompt Delay + Auditory Scripts + Manual Prompts + Behavioral Rehersal + Tokens

Video Modeling + Photo Prompts + Contact Desensitization + Shaping + Differential Reinforcement of Other Behavior (DRO) + Escape Extinction

Language Training (Production)

Language Training (Production) targets the ability of the child with ASD to produce verbal communication through spoken words.

Language Training looks to increase skills in the following areas:

- Interpersonal and play
- Communication

Strategies in individualized programs may include:

- · Modeling verbalizations for the individual with ASD to imitate
- Various prompting procedures including verbal, visual, gestural prompts
- Cue-Pause-Point
- Using music as part of language training
- Reinforcement for display of targeted verbal response

#### Modeling

Modeling relies on a family member, professional or peer to demonstrate a target behavior with the expectation that the child with ASD will imitate the target behavior.

Modeling looks to increase the skills in the following areas:

- Cognitive
- Academic
- Communication, interpersonal, personal responsibility and play

Behaviors that are decreased are:

- Problem behaviors
- Sensory or emotional regulation

There are two types of modeling; live and video. Live modeling occurs when a person demonstrates the target behavior in the presence of the child with ASD. The following are basic strategies to assist in providing live modeling:

- Clearly outline in writing the target behavior to model
- Ensure that individuals modeling the target behavior are all consistently modeling the same thing. It can be helpful to practice together prior to the modeling to be certain each person provides the same model
- Obtain the child's attention prior to the modeling
- Develop a plan to fade or stop the use of modeling. This encourages the child to independently display the target behavior

Video modeling occurs when you pre-record a person demonstrating the target behavior. Anyone who can correctly and independently perform the task can model the behavior in the video. This includes the child with ASD.

The following are basic strategies to assist in using video modeling with children with ASD:

- Make sure the child is paying attention to and interested in the video
- Point out important steps to the child throughout the video.
- Be sure to make a video that is visually appealing and interesting to the child

#### Peer Training Package

Peer Training Packages involves teaching typically developing peers a variety of ways to interact with children with ASD. The goal is for the child with ASD to acquire social-communication skills through naturalistic learning opportunities with their peers. Children with ASD typically rely on adults for prompting and guidance. Peer training Packages carefully and systematically teach typically developing peers ways of engaging children with ASD in positive and extended social interactions. Peers assume the "teaching" role in a natural and developmentally appropriate way.

Peer Training Packages looks to increase the skills in the following areas:

- Learning readiness
- Communication and interpersonal

Behaviors that are decreased are:

• Restricted, repetitive, nonfunctional behavior, interests or activity

Factors to consider when designing a Peer Training Package include:

- Age and skill level of both the typically developing child and the child with ASD
- Peers should be chosen who are socially skilled, regularly available, willing to participate and able to imitate a model
- Activities should address the interests of both the peer and the child with ASD to ensure high motivation
- Skills taught to peers should include: how to get the attention of the child with ASD; how to facilitate sharing; how to provide help and affection; how to model appropriate play skills; how to organize play activities
- Training the peers should include interacting with the child with ASD in a structured setting during a familiar activity. This allows the peer to practice in a comfortable environment
- The adult facilitator should use prompts and feedback to facilitate interactions between the peer and the child with ASD.
- Training should occur in multiple settings with multiple children to increase the likelihood that the child with ASD will use their skills.

#### Pivotal Response Treatment

Pivotal Response Treatment (PRT®) targets pivotal areas of a child's development, such as motivation, responsivity to multiple cues, self-management, and social initiations. These skills are pivotal because they are the foundational behaviors upon which learners with ASD can make widespread and generalized improvements in many other areas. By targeting these critical behaviors, PRT® results include improvements in communication, social, and behavioral domains (Koegel, Koegel, Harrower & Carter,1999). The key to PRT® is parent/caregiver involvement and implementation in the natural environment such as the home, community or childcare.

PRT® looks to increase the skills in the following areas:

- Interpersonal
- Learning readiness
- Communication and play

PRT®'s aim is to teach the child with ASD how to respond to various teaching opportunities within in their natural environment and to increase independence from prompting. The pivotal areas targeted in PRT® and the strategies used to enhance these skills include:

• Motivation: enhanced by increasing choice, making learning materials meaningful by building a direct relationship between the target and the reinforcers; incorporating

- both new and mastered tasks into the day; and reinforcing reasonable attempts at those new and mastered tasks
- Self-initiation: involves teaching children to take actions so they can be more independent
- Responding to multiple cues: involves teaching children to responding to the diverse statements of others or to different kinds of materials.

#### Schedules

Schedules can be used for children with ASD to increase their independence and allow them to plan for upcoming activities. A visual schedule is a line of pictures, objects, or words that represent each major transition during the day. A schedule simply identifies the activities that must be completed during a given time period and the order that should be completed.

Schedules look to increase the skills in the following areas:

Self-regulation

Factors to consider when using schedules:

- They can be uses for any activity- play, social interaction, self-care
- The child with ASD must possess the fundamental skill of picture identification
- Often used to teach "first, then" concepts such as first we put on our coat, and then we go outside to play.
- Should be followed by preferred activities.
- Can be presented in multiple formats such a pictures, 3-D objects or personal digital assistance programs.
- Can be as simple as: placing a picture on the board at the time of the activity; pointing to the picture immediately prior to beginning of each step or activity and taking the picture down as soon as the activity is completed and placing the picture in a "done" box.

# Scripting

Scripting (SC) involves presenting the child with a verbal description about a specific skill or situation that serves as a model for the learner. Scripting provides guidance on how to use language to respond in certain situations. The main rationale of SC is to help the child anticipate what may occur during a given activity and improve their ability to appropriately participate in the activity. Scripts are practiced repeatedly before the skill is used in the actual situation. When learners are able to use the scripts successfully in actual situations, the script should be systematically faded. SC is often used in conjunction with modeling, prompting, and reinforcement.

Scripting looks to increase skills in:

- Play
- Communication and interpersonal

Factors to consider when using SC:

- The child should have the necessary skill to be able to imitate a verbal model
- Scripting is typically used with behavioral interventions such as: reinforcement, modeling and prompting
- Scripts should be faded as soon as possible to increase independence and spontaneity

# Story-based Interventions

Story-based interventions identify a target behavior and uses a written description of the situation to describe a situation where specific behaviors are expected to occur. Stories may provide more information to a child to increase perspective-taking skills. Social Stories™ are the most well-known story-based interventions and seek to answer the "who," "what," "when," "where," and "why" of a situation.

Story-based interventions look to increase skills in:

- Communication and learning readiness
- Interpersonal and self-regulation

Behaviors that are decreased are:

Problem behaviors

Factors to consider when used Story-based interventions include:

- The target behavior
- The situations in which the behavior should occur
- Strong listening comprehension skills of the child
- The outcome of performing the behavior. This typically involves including a description of another person's perspective.
- Stories typically include: information on the who/what/when/where/why of the target behavior; being written from an "I" or "some people" perspective; discussion with the child about the story to make sure the child understands the main points; pictures to enhance comprehension of the skills.

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# **Case Studies**

In order to provide the reader with examples of the Established Interventions in action, the following material reviews three case studies. For each case a brief set of descriptive information is offered along with a tabled subset of individualized intervention plans (Table 2) that were developed by the IFSP team using the "About Our Child" protocol (See Appendix Seven) and the Routines-Based Interview. Carlos' team used the content of Table 2 to complete the assessment, outcomes and services and support sections of his IFSP.

#### Case Study 1:

Carlos. Carlos is a 24 month old little boy who lives with his mother, father and three sisters (two older and one infant). Carlos is not using any spontaneous functional language although his parents report hearing him say a few words. He occasionally imitates a sound, usually after his parents have repeated a sound he has just made. Carlos does not indicate his wants or needs or ask for things. If he needs something he often whines and his parents try to figure out what he wants. He also walks to the refrigerator and stands next to it when he wants something to eat or drink. Carlos drinks from a sippy cup and feeds himself with his fingers, but is not using utensils yet.

Carlos does not make consistent eye contact with his parents or siblings and while he occasionally approaches his parents, he generally ignores his sisters unless they initiate with him. They are most successful in engaging him in rough and tumble play. Carlos has limited play skills and interest in toys. He plays, briefly, with some cause and effect toys that make noise or light up but generally spends his time wandering around, taking toys off the shelf, looking at them and then dropping them and moving on. He also shows some interest in shiny toys and mirrors. When wandering, Carlos frequently flaps his hands and occasionally engages in other self-stimulatory behaviors such as staring at his fingers and/or looking at things out of the corners of his eyes.

Based on this information gathered from the RBI and the "About Our Child" the following priorities were identified by Carlos' family; a) help with dressing in the mornings and evenings; b) asking (either using words or with pictures) for what he wants; c) interacting with others (play with children and saying "hi" and "bye" to people), and d) playing with

Table 1: Carlos' "Established Interventions"

	Priority	Outcomes	Setting and	Methodologies and Strategies
Dressing/Diaper Changes	Carlos will help dress himself.	Carlos will assist with dressing by pulling his pants up and down.	Home with mom or dad.	Antecedent Package: Most to least prompting (use physical prompting initially, then fade to partial physical, then to verbal cues), Providing choices of what to wear.
Snacks and Meals	Carlos will ask for what he wants.	Carlos will request a snack by using pictures or words.	Home and childcare  Parents, childcare providers siblings, peers and therapists	Visuals: Have pictures of his favorite food and drink items velcroed to the refrigerator door.  Naturalistic Teaching & Visuals: When Carlos stands by the refrigerator prompt him to look at the pictures and select what he wants. Once Carlos selects a picture model the verbal response "I want cereal" and immediately follow-up with the delivery of the requested item. Provide small snack portions to allow for multiple requesting opportunities.
Greetings and Farewells	Carlos will say "hi" and "bye" to people.	Carlos will respond to adult and peer greetings by waving.	Parents, childcare providers siblings, peers and therapists	Antecedent Package: Provide least to most prompting to respond(if Carlos does not respond to the greeting then verbally cue him to wave, if he does not respond provide physical assistance with the verbal cue). Before entering childcare remind Carlos that he is going to "wave hi" to the teacher and his friends.  Peer Mediated: Childcare providers will remind two or three peers to come and greet Carlos each day.

	Priority	Outcomes	Setting and Participants	Methodologies and Strategies
	Carlos will play with toys like other kids his	Carlos will play appropriately with cause and effect toys, such	Home and childcare	Naturalistic Teaching & Pivotal Response Training: Provide multiple, desired toys for Carlos to play with. Follow cues to determine his favorite toy.
Play Time	age.	as his "See and Say," for 10 minutes.	Parents, childcare providers siblings, peers and	<b>Modeling:</b> Adults and peers will model how to use the toy Carlos has selected.
	Carlos will play with other children.	Carlos will accept toys from peers.	therapists	Peer Mediated: Have peers play with the chosen toys along with Carlos. Peers will provide assistance to Carlos to use toys appropriately. Peers will offer (share) play materials with Carlos
Clean Up	Carlos will play with toys (including cleaning up)	Carlos will help clean up toys after playing with them.	Home and childcare  Parents, childcare providers, siblings, peers and therapists	Antecedent Package: Have clear plastic containers for each toy clearly labeled with pictures of the item.  Provide least to most prompting to participate in cleaning up (adults will start with a verbal prompt and proceed to partial physical and full physical prompting only as needed).
TV Time	Carlos will ask for what he wants.	Carlos will request one of his favorite videos	Home with mom, dad, sisters.	Antecedent Package: Carlos' family has pictures of five of Carlos' favorite videos.  Peer Mediated: One of Carlos older sisters will present him with two video choices.  Naturalistic Teaching: When appropriate, parents will follow Carlos' lead prompting him to request a video when he shows interest.

#### Case Study 2:

**Nick.** Nick is a 32 month-old boy of recently divorced parents who have joint custody. He lives at home with his mother but spends Friday, Saturday and Wednesday nights with his father. Nick communicates effectively using three and four word phrases to request and comment. Nick also has some perseverative language and at times he recites scenes from favorite TV shows and movies. When he is doing this he is very hard to distract and redirect to something appropriate.

Nick appears to show interest in other children and watches them play although he seems to have trouble interacting with them. His parents report that he likes to play "his way" and attempts to redirect him generally result in Nick getting frustrated. When other children have toys or materials he wants he typically tries to take them by force but doesn't usually use aggression. He simply tries to take the toy out of their hand and say things like "My Thomas!"

Nick's parents also report a good deal of frustration with his ability to follow routines. Because of the recent separation, Nick's routine is constantly changing and they report he has a difficult time with this. Bed time is especially difficult and his mom reports getting Nick to stay in his room and go to sleep is a nightly battle.

Based on this information gathered from the RBI and the About Our Child the following priorities were identified by Nick's family; 1) using sentences when asking for things and reducing his scripting; 2) playing with other children and sharing toys; 3) following routines; and 4) staying in his room at bedtime.

Table 2. Nick's "Established Interventions"

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	Priority	Outcomes	Setting and Participants	Strategies and Methodologies
Meals and Snacks	Nick will use sentences to ask for what he wants.	Nick will ask for the food that he wants using complete sentences.	Home and childcare,  Parents and childcare providers	Naturalistic Teaching: Allow Nick to choose and request what he wants for breakfast. Prompt Nick to verbally ask for the desired food, "I want yogurt, please", when given choice of foods.
Meals	Nick will follow a routine.	Nick will help clean up his dishes after eating.		Schedules: Use picture cues (sink) to remind Nick to bring his dish(es) to the sink.
	Nick will play cooperatively with other children.	Nick will request a turn with a toy during each playtime with others.	Home or Community with peers	Naturalistic Teaching: Give peers one of Nick's favorite toys. Prompt Nick to request the toy, "I want truck, please," while putting out his hand or pointing to the toy.
Play Time		Nick will give a toy to a peer when requested during each playtime with others.		Peer Mediated: Adults will cue one or two peers to request toys from Nick.  Antecedent Prompting: Adult will provide Nick with least to most prompting (use verbal prompting initially then partial physical assistance, then full physical assistance only if necessary) to give toys to peers and wait for another turn.
	Nick will participate in activities throughout	Nick will be engaged in at least two activities during	Home or childcare	Antecedent Prompt: Interrupt Nick, redirect to current task using most-to-least prompting. Praise after completion.
the Day	the day.	the day without reciting scenes.		Peer Mediated: Use peer to cue Nick to look at the toy.
Throughout the Day	Nick will participate in daily tasks.	Nick will take of his coat and shoes and wash his hands after he comes inside from playing outside.	Home with mom or dad	Schedules: Use pictures of the three tasks that Nick has to perform: 1) take off coat, 2) take off shoes, 3) wash hands. Provide most to least assistance.

	Priority	Outcomes	Setting and Participants	Strategies and Methodologies
Bed Time	Nick will follow the bedtime routine	Nick will complete his bedtime routine each night.	Home with mom or dad.	Behavior Intervention Package - PBS Antecedent prompt: Provide countdown to bedtime, 10 minutes, 5 minutes, 2 minutes. Provide least to most prompting to complete each step of the bedtime routine.  Schedules: Show Nick his bedtime schedule and review the bedtime routine, 1) PJs picture, "We are going upstairs to put on PJs," 2) Toothbrush picture, "then we are going to brush your teeth so they stay nice and healthy and shiny," 6) Book picture, "then you get to pick a book, and 4) Sleep picture, "then it will be time to turn out the light.
	Nick will sleep in and stay in his own bed.	Nick will sleep in his bed throughout the night.		Consequence Strategy (Reinforcement): Provide praise for getting through each step of the routine. Once Nick is in bed he can pick which story he wants to hear. Use these books only for bedtime routine.  Consequence Strategy (Redirection): If Nick leaves his room, matter-of-factly redirect him back to bed. Limit attention (eye contact, talking to him) to only what is necessary. Use positive language, (i.e., "you need to stay in bed.").

# Case Study 3:

**Hannah.** Hannah is a 30 month-old girl who lives with her mother and father. She was just diagnosed with ASD although her parents had expressed concerns to their pediatrician starting at around 18 months.

Hannah has good use of nouns to label and request objects, can use some verbs in two to three word combinations and also has a variety or rote phrases that she uses mostly out of context or to calm herself (e.g., "We don't bite", "I know what you mean" or "Don't poke eyes"). Hannah demonstrates what her parents call selective hearing, at times responding well to their requests and at other times appearing to not hear them at all.

Hannah seeks out sensory input and likes to play with items like play dough and shaving cream and also likes activities like swings and jumping on the trampoline, but she demonstrates little functional play with traditional age appropriate toys like dolls or blocks. In social situations, Hannah, at times, approaches other adults, although she seems more hesitant with men than women. She generally shows little interest in other children her age, however, when peers initiate an interaction with her she often is aggressive trying to scratch or bite them. Hannah's parents are hesitant to bring her to play with other children or take her to places other children go because of the likelihood of her biting another child.

Hannah gets very upset when her routine changes or she is asked to stop doing something she enjoys. At these times she generally falls to the ground, screaming or crying. In these situations when she is frustrated Hannah occasionally demonstrates self-injurious behavior including biting or scratching her arm and poking her eyes with her thumbs.

Based on this information gathered from the RBI and the About Our Child the following priorities were identified by Hannah's family; 1) using sentences when asking for things and expressing herself when upset; 2) playing with toys and other children; 3) transitioning from one activity to another; 4) completing everyday routines and 5) decreasing self-injurious behavior.

Table 3. Hannah's "Established Interventions"

	Priority	Outcomes	Setting and Participants	Strategies and Methodologies
Dressing and Diaper Changes	Hannah will calmly transition to diaper changes.	Hannah will remain calm while transitioning from the previous activity to diaper changing.	Home with mom or dad	Antecedent Package: Give Hannah a two minute warning before the diaper change. Use least to most prompting for diaper changes and dressing.
Dressir	Hannah will complete an everyday routine.	Hannah will help dress herself each morning.		<b>Schedules</b> : Use Pictures of each article of clothing and a visual schedule for what Hannah needs to put on for dressing.
Transitions	Hannah will move from activity to activity with getting upset.	Hanna will successfully end one activity and move on to the next throughout the day,	Home or community	Schedules: Use pictures of daily activities/routines as a visual schedule. If Hannah protests during a transition use least-to-most prompting to have her check her schedule and review what she needs to do next.
Meal Time	Hannah will be able to tell us what she wants to eat.	Hannah will request foods using 3+ word sentences during meal time.	Home or community with parents or other adults	Naturalistic Teaching: When Hannah requests food or drink, prompt her for a sentence by saying "I" and using wait time. After two prompts accept her 1 or 2 word request.
Play Time	Hannah will play cooper- actively with others.	Hannah will take turns in play with a peer or adult.	Home or community with parents, peers and teachers	Modeling: Adults and peers will model appropriate play for Hannah. Give play direction and use least-to-most prompting.  Use preferred materials (sensory) and commenting to encourage joint attention around play materials.

	Priority	Outcomes	Setting and Participants	Strategies and Methodologies
	Hannah will interact with other children.	Hannah will independently say "hi" to a peer in response to the peer's initiation.	Community Center playgroup with mom, teacher, and five peers	Peer Mediated: Peers at the playgroup will be prompted to say "hi" to Hannah. Hannah will be verbally prompted by the teacher to respond by saying "hi" to the peer.
		Hannah will accept an item from a peer.		In response to Hannah's "Hi", peers will give Hannah a small play dough container or other preferred sensory materials.
	Hannah will show that she has the skills that other children her age have.	Hannah will identify 5 colors while at playgroup.		Naturalistic Teaching: Once Hannah has two or three play dough containers, the play group leader will use them to teach Hannah colors.
Play Group	Hannah will have aware- ness of her environ- ment.	Hannah will identify where things are at playgroup through the understanding of 10 prepositions, such as beneath, over, under, etc.		<b>DTT:</b> One of Hannah's IFSP team members (speech pathologist) will meet her at the playgroup on a daily basis. The SLP will join Hannah in her routine and will work on expanding vocabulary by asking Hannah and her peers to expressively identify prepositions in the environment.
	Hannah will participate in playgroup activities without screaming or injuring herself or others.	Hannah will follow simple one-step directions during activities at playgroup  Hannah will remain calm when approached by a peer		Positive Behavior Interventions and Supports: Give Hannah short, one-step directions, and to allow at least 5 seconds for her to respond.  Teach peers to approach Hannah slowly making sure that she sees them coming toward her. Peers will give Hannah preferred sensory materials.  If Hannah attempts to bite an adult will interrupt her, show her a picture of a stop sign and redirecting her to a different activity (such as completing a puzzle).  Once calm she will be offered to engage in a preferred activity with the peer or adult that triggered the aggressive behaviors.

	Priority	Outcomes	Setting and Participants	Strategies and Methodologies
	Hannah will	Hannah will	Hannah and	Antecedent Prompts: At around 7:30, Hannah's dad
	successfully	transition from	dad at home	will give her a 5 minute warning for getting ready for
	follow her	after dinner		bedtime.
	bedtime	activities to		
	routine.	bedtime		
<b>9</b>		activities.		
Bed Time				
-		Hannah will		Schedules and Antecedent Prompts,: Use pictures of
		brush her teeth.		bedtime activities/routines as a visual schedule. If Hannah protests during a routine use least-to-most prompting to have her check her schedule and review what she needs to do next.

# **Monitoring Progress**

The link between achieving good outcomes for infants and toddler with ASD and their families and the use of ongoing data collection is clear and undeniable. Every Established Intervention described above has only been used in conjunction with ongoing data collection. Within the context of early intervention for infants and toddlers with ASD careful progress monitoring is essential because:

- No practice is universally effective and thus there is a professional and ethical imperative to detect less than needed effects and change methods in a timely fashion.
- Many of the behaviors targeted for change (e.g., tantrums, self-injury, repetitive speech) with this population engender strong emotions in both families and providers by their presence or absence. Thus, it is essential to have methods for the objective measurement of behavior over time.
- Many Established Interventions rely on incoming data to make individualized modifications and accommodations to reach maximum effectiveness. That is, the best version of Incidental Teaching, for example, to teach language to Aaron is slightly different than the best version to teach language to Karen. Only by using ongoing data systems can providers hope to make these small but incredibly important variations for each child and family. Involvement of the family in reviewing data is important to ensure behavior changes are generalized across people and settings.

The challenge is to select measurement methods that yield meaningful data while at the same time not being too burdensome to all involved. In recent years a variety of relatively simple behavior rating scales have been utilized by parents and providers to achieve these dual purposes (Dunlap et al., 2010; Strain & Schwartz, 2009).

On the following pages is an overview of sample rating scales that have been used to track a wide variety of behavioral outcomes.

For use with general cognitive, adaptive, and self-help skills a "Prompting Hierarchy Scale" is recommended. The categories in the hierarchy are:

- 4 = Child can complete the skill independently or when given a group direction. 3 = Adult points/gestures/models/or verbally directs the child to perform skill.
- = Adult provides partial physical assistance to complete skill, but child can do some independently.
  - 1 = Adult provides 100% physical (hand over hand) assistance to complete skill. 0 = Child refuses to perform skill; walks away; ignores adult; says "No"; tantrums. N/A = No data for that session.

Objective	D		٥/	/0	/0	۵/	/0	/0	/0	0/	/0	σ/	/0	/6	ò	Š	ì	õ
Rem ove socks and shoes	0	4 3 2	4 3 2	4 3	4	4 3	4 3 2	$O_2^3$	4 2	4 3 2	<u></u>	ф	0	φ	Þ	Ó	Q	<b>→</b>

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Level: 3 Criteria: 5 sessions

4 = Child performs skill independently or when given a group direction. No adult intervention is needed 3 = Adult points/gestures/models/ and verbally directs child to perform skill

= Adult provides partial physical assistance to complete skill but child can do some independently 1 = Adult provides 100% physical (hand over hand) assistance to complete skill

0 = Child refuses to perform skill, walks away, ignores adult, says "No", tantrums ND = No data for that session

The contemporary level or criterion for each objective is set one level above the child's current capability. For example, if the objective is to "remove socks and shoes", and the child can currently take off his socks and shoes with partial assistance, then the level to be achieved is set at Level 3. Each time the child attempts the task a tick mark is placed by the level at which the task was performed. At the end of the day, providers or parents circle the level at which more tick marks were placed. If two levels receive the same number of tick marks, then the lower level is circled because the goal is for mastery. Once the child is at Level 3 for several (3-

5) consecutive days the team should shift the criterion to Level 4 – independent performance.

For use with objectives where the basic goal is to have the child comply with a necessary routine such as diapering the following type of hierarchy scale is recommended. Just like the previous scale, an initial performance level is set one step above the child's baseline performance and work continues until "independent" performance is achieved.

Objective														
Hannah will cooperate with diaper changing routine	4 3 Q	4 4 3 3 0 2	4 4 0 3 2	0	0	4 3 O 2	4 © 2	4 3 2	2	3 2	3	0	3 0 2	$\begin{vmatrix} 4 \\ 3 \end{vmatrix}$

4 = Hannah independently stays on changing table while being changed.

= Adult needs to provide repeated verbal prompts and visual cues (pictures) to get Hannah to stay on the table. 2 = Adult provides gentle physical assistance (a hand on Hannah's chest) but Hannah also lies still part of the time. 1 = Adult provides constant physical redirection (repeatedly laying her back down) for Hannah to stay on changing

0 = Hannah refuses to stay on changing table, tantrums, bites, scratches. ND = No data for that session

For use with objectives that involve verbal language production the following type of hierarchy scale is recommended. This is, of course, a version of a prompting hierarchy, but one specific to verbal behaviors where physical prompting is not possible.

Objective Date	ò	ò	/σ	à	ā			Ď	Ď	ð	(0	/o	/ο	/o
Requests breakfast Level: 3 Criteria: 5	4 3 2 1	4 3 2 0	4 3 2 1 0	4 3 2 1 0	4 3 2 1 0	4 3 2 1 0	2 1 0	4 3 2 1 0	2 1 0	4 2 1 0	1 0	$ \begin{array}{c}                                     $	3 2 1 0	2 1 0

- 4 = Nick requests items using 2-3 word sentences independently. No adult support is necessary. 3 = Adult shows Nick the breakfast item and provides a first word "I..." prompt.
- 6 = Adult models the desired response for Nick "I want waffle".
  - 1 = Adult accepts an easier response from Nick "Waffle", or the use of a picture exchange or point. 0 = Nick refuses to request any of his favorite items, walks away, tantrums.

ND = No data for that session

For inappropriate or challenging behaviors we recommend tracking the behaviors based on a specific, observable dimension of the behavior and developing a unique key specific to the behavior.

Behavior: Screaming Date	9/		0/	/0	/0	/0	۵/	/0	۵/	۵/	/0	/0	1	1
Screams Frequently	4 3 2	\$ 4 3 2	2 w t	4 3 2	5 4 3 2	5 4 3 2	5 4 3 2	5 3 2	5 3 2	5 4 3 2	5 4 3 2	5	5 4	5

**Key:** Screaming to protest (loud, inappropriate voice): 5 = 16 or more

times

4 = 9-15 times

- 6 = 5-8 times
- 6 = 2-4 times
  - 1 = 0-2 times

# **Making Smart Decisions about Data Systems**

There are two sets of decisions that are crucial in using data. The first has to do with the frequency or intensity of data collection. While it is imprudent to offer fixed, theoretical guidance the Birth to Three System suggests the following considerations. First, if target behaviors are considered crucial to safety and well being (e.g., self-injury, running into street, hurting others) then the team should consider maximizing data collection resources accordingly. Second, anytime a new skill is targeted or a new tactic is implemented then the team should consider these events as occasions for more intensive data collection.

A second set of decisions center on the adoption of guidelines under which decisions are made regarding changes to intervention approaches. The goal here is to have a reliable system of data review in place such that children and families are not needlessly exposed to ineffective or less than optimal interventions. Many of the most widely researched and replicated models of early autism services (e.g., LEAP; Project Data, Walden Preschool, Princeton Child Development Center, etc) employ a very similar decision making system. Specifically, the operational rule is that the intervention team must meet to discuss potential modifications to any intervention after two weeks (10 successive data-days) of data indicating no progress or regression. In many cases, the outcome is not to abandon an approach but to see if it is being implemented faithfully, or if it needs to be "tweaked" to address some unique child need or preference.

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# **APPENDICES – INDEX**

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# **Appendix One**



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.

# **Appendix Two**

To be designated as a program that <u>serves children with a diagnosis of Autism Spectrum</u>
<u>Disorder (ASD)</u> the program must make the following assurances to the Office of Early
Childhood

The program	m assures the lead agency that they have the following in place:
	The person with direct supervision of the program and staff must have at least three
,	years of experience administering a program for children with autism spectrum
	disorders and families under Part C of IDEA
	The program has a history of providing services to children with autism spectrum
	disorders and their families for at least three years or, the requirement listed above is
	documented
	The program has the ability to provide all eligible families with evidenced-based
	practices as identified by the most recent version of the National Standards Project:
-	National Standards Project Phase 2
	The program has ongoing training in the use of empirically validated autism specific
	curricula and practices as identified by the most recent version of the National
	Standards Project: National Standards Project Phase 2
	The program is familiar with and adheres to the set of principles that reflect both the
	science of early intervention and a core group of values referred to in the CT Birth to
	Three Autism Guidelines as the 12 guiding principles
	The program has at least one LBA on staff who uses objective data to plan,
	implement, and evaluate the effectiveness of the interventions and is on the IFSP
	The program has the ability to provide adequate LBA supervision as identified by the
	Behavior Analyst Certification Board (BACB)
	The staff providing services have the ability to develop outcomes for all children
	based on increasing functional participation during daily activities.
	The staff providing services have the ability to support families as they work with
	their child during daily activities and that routinely develop a two-part joint plan with
	all families
I,	assure that this program meets the requirements stated above
	be listed as having the designation for a program that serves children with autism
-	isorders (ASD).
_	et the lead agency know immediately if there are any changes that would make the
program in	eligible for this designation.
Program Na	ame
i iogiaiii ive	**************************************
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# **Appendix Three**

# Modified Checklist for Autism in Toddlers, Revised, with Follow-Up $(\text{M-CHAT-R/F})^{\text{TM}}$

Diana L. Robins, Ph.D. Deborah Fein, Ph.D. Marianne Barton, Ph.D.

Acknowledgement: We thank the M-CHAT Study Group in Spain for developing the flow chart format used in this document.

For more information, please see <a href="www.mchatscreen.com">www.mchatscreen.com</a> or contact Diana Robins at DianaLRobins@gmail.com

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#### Permissions for Use of the M-CHAT-R/F<sup>™</sup>

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of the M-CHAT-R/F must follow these guidelines:

- (1) Reprints/reproductions of the M-CHAT-R must include the copyright at the bottom (© 2009 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.
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- (4) If you are part of a medical practice, and you want to incorporate the first stage M-CHAT-R questions into your own practice's electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request a licensing agreement.

#### Instructions for Use

The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from <a href="http://www.mchatscreen.com">http://www.mchatscreen.com</a>. Associated documents will be available for download as well.

#### **Scoring Algorithm**

For all items except 2, 5, and 12, the response "NO" indicates ASD risk; for items 2, 5, and 12, "YES" indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

**LOW-RISK**: **Total Score is 0-2**; if child is younger than 24 months, screen again after second

birthday. No further action required unless surveillance indicates risk for ASD.

MEDIUM-RISK: Total Score is 3-7; Administer the Follow-Up (second stage of M-CHAT-R/F) to get

additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk

for ASD. Child should be rescreened at future well-child visits.

**HIGH-RISK**: **Total Score is 8-20**; It is acceptable to bypass the Follow-Up and refer immediately for

diagnostic evaluation and eligibility evaluation for early intervention.

## M-CHAT-R<sup>TM</sup>

Please answer these questions about your child. Keep in mind how your child <u>usually</u> behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** <u>or</u> **no** for every question. Thank you very much.

1.	If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2.	Have you ever wondered if your child might be deaf?	Yes	No
3.	Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4.	Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)	Yes	No
5.	Does your child make <u>unusual</u> finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6.	Does your child point with one finger to ask for something or to get help?  (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Yes	No
7.	Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8.	Is your child interested in other children? ( <b>FOR EXAMPLE</b> , does your child watch other children, smile at them, or go to them?)	Yes	No
9.	Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? ( <b>FOR EXAMPLE</b> , showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10.	Does your child respond when you call his or her name? ( <b>FOR EXAMPLE</b> , does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11.	When you smile at your child, does he or she smile back at you?	Yes	No
12.	Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13.	Does your child walk?	Yes	No
14.	Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
	Does your child try to copy what you do? ( <b>For Example</b> , wave bye-bye, clap, or ke a funny noise when you do)	Yes	No
16.	If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17.	Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18	Does your child understand when you tell him or her to do something?  (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Yes	No
			No
19	If something new happens, does your child look at your face to see how you feel about it?  (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
	(FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will	Yes	No

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

\_\_\_\_\_/ \_\_\_/ Today's date: \_\_\_\_/ \_\_/

Child's birth date:

month day year						month day year				
Sex of child: 1: Boy 2: Girl				Your r	ela	tionship to child: 1: Mother 2: Father 3: Other	er			
Child's ethnicity: 1: White/Caucasian 2: Black/African American			3: <b>Hispanic/Latino</b> 5: <b>Native Ameri</b> an 4: Asian/Pacific Islander 6:							
Other:										
						r-old children. Many statements describe normal is seem too young or too old for your child. Pleas				st
For each statement, please circle the answer th Rarely." Circle 1 to indicate "Somewhat True						child in the LAST MONTH. Circle 0 to indicate "N le 2 to indicate "Very True or Often."	ot True	9 OI	•	
Please choose the answer that best describe 0 = not true/rarely	•					ST MONTH: ue/sometimes 2 = very true/often				
Shows pleasure when s/he succeeds	0	1	2		25.	Imitates playful sounds when you ask him/her to.	0	1	2	
(For example, claps for self).	0	1	2		26.	Refuses to eat.	0	1	2	
<ol><li>Gets hurt so often that you can't take your eyes off him/her.</li></ol>	0	1	2		27.	Hits, shoves, kicks, or bites children (not including brother/sister). (N = No contact with other children)	0	1	2	N
3. Seems nervous, tense or tearful.	0	1	2		<b>∠</b> ŏ.	is destructive. Dreaks of rulls trilligs off purpose.	U	1	<b>Z</b>	
4. Is restless and can't sit still.	0		2			FUILLS TO SHOW YOU SUFFICIENTLY IAI AWAY.	U	1	<b>Z</b>	
5. Follows rules.	0	1	2			HILS, DILES OF KICKS YOU (OF OLDER PARENT).	U	ı	2	
6. Wakes up at night and needs help to fall asleep again.	0	1	2			Hugs or feeds dolls or stuffed animals.	0	1	2	
7. Cries or tantrums until s/he is exhausted.	_	1				Seems very unhappy, sad, depressed or withdrawn.	0	1	2	
B. Is afraid of certain places, animals or things.			_			Purposely tries to hurt you (or other parent).	0	1	2	
What is s/he afraid of?	0	1	2		34.	When upset, gets very still, freezes or doesn't move.	0	1	2	
9. Has less fun than other children.	0	1	2			The following questions are about feelings and bet that can be problems for young children. Some of				
10. Looks for you (or other parent) when upset.	0	1	2			questions may be a bit hard to understand, especia	ally if			
11. Cries or hangs onto you when you try to leave.	0	1	2			you have not seen them in a child. Please do your answer them anyway.	best to			
12. Worries a lot or is very serious.	0	1	2		35.	Puts things in a special order, over and over.	0	1	2	
13. Looks right at you when you say his/her name.	0	1	2		36.	Repeats the same action or phrase, over and over.	0	1	2	
14. Does not react when hurt.	0	1	2			Describe:				
15. Is affectionate with loved ones.	0	1	2		37.	Repeats a particular movement, over and over (like rocking, spinning, etc.).	0	1	2	
16. Won't touch some objects because of how they fee	l. 0	1	2			Describe:	ū	•	-	
17. Has trouble falling asleep or staying asleep.	0	1	2		38.	"Spaces out." Is totally unaware of what's happening around him/her.	n		0	
18. Runs away in public places.	0	1	2		20	Does not make eye contact.	0	1	2	
<ol> <li>Plays well with other children (not including brother/sister). (N = No contact with other children</li> </ol>	ın) O	1	2			•	0	1	2	
Profiler/sister). ( $N = NO$ contact with other children 20. Can pay attention for a long time. (Not including TV		1				Avoids physical contact.	0	1	2	
21. Has trouble adjusting to changes.		1			41.	Eats or drinks things that are not edible, like paper or paint.	0	1	2	

23. Often gets very upset.	0	1	2	2	42. Hurts him/herself on purpose.	•	_	,
24. Gags or chokes on food.	0	1	2	2	For example, bangs his or her head.  Describe:	0	1	2

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#### The Brief Infant-Toddler Social & Emotional Assessment (BITSEA)

(Briggs-Gowan & Carter, 2002) ©

#### 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 <u>not</u> 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 <u>not</u> 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	
Problems		
12-17 months	13	
18-23 months	15	
24-29 months	13	
30-35 months	J	
Competence		
12-17 months		
18-23 months		
24-29 months		
30-35 months		

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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#### **CSBS DP Infant-Toddler Checklist**

Chi	ld's name:	Date of birth:		Date	filled out:					
Wa	s birth premature?	If yes, how many weeks premature?								
Fill	ed out by:	Relationship to child:								
sho eva es 1	cructions for caregivers: This Checklist is designed to identify di naviors that develop before children talk may indicate whether uld be completed by a caregiver when the child is between 6 a luation is needed. The caregiver may be either a parent or anoi hat best describe your child's behavior. If you are not sure, plea your child's age are not necessarily expected to use all the	or not a child w and 24 months ther person who use choose the cl	ill have diff of age to o nurtures the osest respon	iculty learni determine w he child dail	ing to talk. This C vhether a referra ly. Please check al	hecklist for an I the choic-				
En	notion and Eye Gaze									
1.	Do you know when your child is happy and when your chil	ld is upset?		☐ Not Yet	☐ Sometimes	☐ Often				
2.	When your child plays with toys, does he/she look at you to	see if you are v	vatching?	☐ Not Yet	☐ Sometimes	☐ Often				
3.	Does your child smile or laugh while looking at you?		0.5	☐ Not Yet	☐ Sometimes	☐ Often				
	When you look at and point to a toy across the room, does	s vour child loo	k at it?	□ Not Yet	☐ Sometimes	□ Often				
	mmunication	your cima ioo				D 9 (141)				
	Does your child let you know that he/she needs help or wan	its an object our	t of reach?	□ Not Yet	☐ Sometimes	☐ Often				
	When you are not paying attention to your child, does he/					D 4.1.1				
O.	attention?	sile try to get y	our	☐ Not Yet	☐ Sometimes	☐ Often				
7.	Does your child do things just to get you to laugh?			☐ Not Yet	☐ Sometimes	☐ Often				
	Does your child try to get you to notice interesting objects at the objects, not to get you to do anything with them?	—just to get yo	u to look	□ Not Yet	☐ Sometimes	□ Often				
Ge	stures									
9.	Does your child pick up objects and give them to you?			□ Not Yet	☐ Sometimes	☐ Often				
	Does your child show objects to you without giving you the	e object?		□ Not Yet	☐ Sometimes	☐ Often				
	Does your child wave to greet people?	e object:		□ Not Yet	☐ Sometimes	☐ Often				
	Does your child point to objects?			□ Not Yet	☐ Sometimes	☐ Often				
	Does your child nod his/her head to indicate yes?  unds			□ Not Yet	☐ Sometimes	□ Often				
	Does your child use sounds or words to get attention or he	dn 2		□ Not Yet	☐ Sometimes	☐ Often				
	The second secon		11-2							
	Does your child string sounds together, such as uh oh, man		ye, pada:	□ Not fet	☐ Sometimes	☐ Often				
16.	About how many of the following consonant sounds does ma, na, ba, da, ga, wa, la, ya, sa, sha?	your child use:	☐ None	□ 1-2 □	13-4 🗆 5-8	□ over 8				
W	ords		L) NOTIC	D 1-2	7 5-4 13 5-6	D Over 0				
	About how many different words does your child use mean	n in afully								
17.	that you recognize (such as baba for bottle; gaggie for doc		☐ None	□ 1-3 □	14-10 🗆 11-30	□ over 30				
18.	Does your child put two words together (for example, mor					☐ Often				
	derstanding		2 27							
	When you call your child's name, does he/she respond by ke or turning toward you?	ooking		□ Not Yet	☐ Sometimes	□ Often				
20.	About how many different words or phrases does your chil stand without gestures? For example, if you say "where's y tummy," "where's Daddy," "give me the ball," or "come he showing or pointing, your child will respond appropriately	our ere," without	□ None	□ 1 <b>-</b> 3 □	<b>J</b> 4–10	over 30				
Ok	ject Use									
21.	Does your child show interest in playing with a variety of c	objects?		☐ Not Yet	☐ Sometimes	☐ Often				
	About how many of the following objects does your child cup, bottle, bowl, spoon, comb or brush, toothbrush, wash ball, toy vehicle, toy telephone?	use appropriate	ely:		J 3–4 □ 5–8	over 8				
23.	About how many blocks (or rings) does your child stack?	Stacks	☐ None	☐ 2 blocks	☐ 3-4 blocks ☐	5 or more				
24.	Does your child pretend to play with toys (for example, fee stuffed animal, put a doll to sleep, put an animal figure in			□ Not Yet	☐ Sometimes	☐ Often				
Do	you have any concerns about your child's development	t? □ yes	□ no	If yes, ple	ase describe on	back.				
-	, out y contains about your cinias acretopinen	y		3 03, pic	and describe on	- www.				

Communication and Symbolic Behavior Scales Developmental Profile by Amy M. Wetherby & Barry M. Prizant © 2002 by Paul H. Brookes Publishing Co., Inc. All rights reserved.

Information on scoring this instrument may be found at <a href="http://firstwords.fsu.edu/">http://firstwords.fsu.edu/</a>

## **Appendix Four**

## Autistic Spectrum Disorders Screening and Assessment Instruments for Young Children

Screening Instruments	Age Range
The Brief Infant-Toddler Social & Emotional Assessment (BITSEA) ©	12-35 months
Briggs-Gowan, M. & Carter, A., 2006	
PsychCorp	
Pervasive Developmental Disorders Screening Test-II, Primary Care	12-48 months
Screener	
Siegel, B., (2004)	
PsychCorp	
The Modified Checklist for Autism in Toddlers (M-CHAT) and Scoring	16-48 months
Template	
Robins, D., Fein, D., & Barton, M. (1999)	
University of Connecticut, Psychology Department	
www.mchatscreen.com	

Assessment Instruments	Age Range
Autism Diagnostic Interview – Revised ADI-R	MA of 2 or
Rutter, M,. LeCouteur, A., & Lord, C., (2003)	above
Western Psychological Services	
Autism Diagnostic Observation Schedule ADOS	Toddlers to
Lord, C., Rutter, M., DiLavore, P., & Risi, S., (1999)	Adults
Western Psychological Services.	
Childhood Autism Rating Scale (CARS)	Ages 2 years
Schopler, E., Reichler, R., & Renner, B. (1988)	and up
Western Psychological Services	
Communication and Symbolic Behavior Scales DP (CSBS)	Communication
Wetherby, A.M., & Prizant, B., (2002)	age of 6-24
Paul H Brookes Publishing, CO.	months. Can be
<b>3</b> ,	used for children with atypical
	communication
	skills up to 72
	months of age
Gilliam Autism Rating Scales,	Ages 3-22
Gilliam, J., (2 <sup>™</sup> edition 2006)	
Western Psychological Services	
Psychoeducational Profile-Third Edition	Ages 3-5
Shopler, E., Lansing, M., Marcus, L. & Reichler, R, (2005)	
Western Psychological Services	D: (I
Vineland Adaptive Behavior Scales II	Birth – age 90
Sparrow, S., (2005)	
PsychCorp	

# **Appendix Five**

#### **Comparison of NPDC and NSP Practices**

Evidence-Based Practices Identified by	Established Treatments Identified by the National Standards Project (NSP)														
the National Professional Development Center (NPDC) on ASD	Behavioral Interventions	Cognitive Behavioral Interventions	Modeling	Natural Teaching Strategies	Parent Training	Peer Training Package	Pivotal Response Training	Schedules	Scripting	Self- management	Social Skills Package	Story-based Intervention	Language Training	Comprehensive Behavioral Treatment for Young Children	
Antecedent-based Intervention	х												Language training did not	The NPDC on ASD did not	
Differential Reinforcement	х												emerge as a focused	review comprehensive	
Discrete Trial Training	х												intervention by the NPDC on	treatment models.	
Extinction	х												ASD. Components of	Components of The	
Modeling	х		х										Language Training	Comprehensive Behavioral	
Prompting	х												overlap with NPDC identified	Treatment of Young Children	
Reinforcement	x												practices that may support	overlap with many NPDC	
Response Interruption/Redirection	х												language production, such	identified practices.	
Scripting	х								х				as modeling, prompting, and reinforcement.		
Task Analysis	х														
Video Modeling	x		х												
Time Delay	х														
Cognitive Behavioral Intervention		х													
Naturalistic Intervention				х											
Parent Implemented Intervention					х										
Peer-mediated Instruction & Intervention						×									
Pivotal Response Training							x								
Self-management										х					
Social Narratives												х			
Social Skills Training											х				
Visual Supports								x							
Exercise	Exercise was id	entified as an em	nerging practice l	by the NSP.											
Functional Behavior Assessment	The NSP did no	t consider Functi	onal Behavior As	ssessment as a ca	ategory of evider	nce-based practic	e.								
Functional Communication Training	Functional Com	nmunication Trail	ning was identifi	ed as an emergin	ng practice by the	NSP.									
Picture Exchange Communication System	Picture Exchang	ge Communicatio	on System was id	lentified as an en	nerging practice	by the NSP.									
Structured Play Groups	The NSP did no	t consider Struct	ured Play Group	s as a category o	f evidence-based	d practice.									
Technology-aided Instruction & Intervention	Technology-aid	led Instruction ar	nd Intervention v	vas identified as	an emerging pra	ctice by the NSP.									



## **Appendix Six**

## Questions to Guide the Individualized Family Service Plan Planning Process for Children with Autism Spectrum Disorder

The following checklist is provided for early intervention teams to guide the IFSP planning process for children with ASD in order to support the delivery of services that are comprehensive, individualized, evidence-based and of sufficient intensity:

Question	Resp	onse
1. Have assessment strategies been utilized to document the child and family needs IFSP that are:	identified in	the
a) Specific (observable, measurable, and valued by adult family members).	Yes	No
b) Functional (related to specific skills that help the child access everyday life)?	Yes	No
2. Are there evidence-based strategies in place that:		
a) address each area of need identified by the team?	Yes	No
b) include functional outcomes addressing the defining characteristics of ASD (communication, social skills, and behavioral concerns)?	Yes	No
c) specifically addresses the child and family being successful with daily routines (e.g., dressing, feeding, bedtime, community outings, etc.)?	Yes	No
d) include strategies to equip family members with the information and skills needed to provide consistency in intervention when early intervention providers are not present?	Yes	No
3. Has the IFSP team carefully considered the following taking into account the child' availability for intervention and the families dynamics and available resources:	s developm	ental
a) What early intervention services are needed to implement the evidence-based practices?	Yes	No
b) Who will deliver the services?	Yes	No
c) Where the services will be provided?	Yes	No
d) When and how frequent the services will occur?	Yes	No
e) What available funding sources will be accessed?	Yes	No
4. Are the proposed providers fluent with the evidence-based practices to be delivered? If not, what plans are in place to provide training, supervision or coaching for those providers?	Yes	No
5. Is there a plan in place whereby multiple providers, if utilized, meet frequently to communicate, plan logically consistent services and review progress?	Yes	No
6. Do the planned strategies include an ongoing data collection system and clear decision-making guidelines regarding the continuation or modification of the plan that results in progress for meeting child and family outcomes?	Yes	No

### **Appendix Seven**

#### **About Our Child Questionnaire**

Child's Name: Date: Priority Level (low, medium or high) We would like We would like We would like Skills we would like our child to What our child knows or already to work on strategies for Area information this at home teaching this about this learn in this area: does in this area: Play Skills (skills such as appropriate toy play, sharing, taking turns, playing by self, playing with other children...) Language & Communication (skills such as communicating needs, following directions, listening skills, concepts such as in, on, up, down...) Adaptive / Self Help (skills such as dressing, undressing, zippering, buttoning, toilet training, sitting or standing at potty, toileting schedule...) Meal Time (skills such as eating with utensils, eating more of a variety of foods, pouring juice, eating more slowly, table manners...)

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Area	What our child knows or already does in this area:	Skills we would like our child to learn in this area:	Priority Level (low, medium or high)	We would like information about this	We would like to work on this at home	We would like strategies for teaching this
Bath time						
(skills such as sitting (staying) in the tub, washing self,						
combing hair, brushing teeth)						
,						
Community Activities						
(skills such as shopping with family members, eating out in						
restaurants, riding in the						
car)						
Cognitive						
(skills such as understanding cause and effect, identifying						
numbers, letters, colors, shapes; sorting objects)						
snapes, sorting objects)						
Motor						
(skills such as running, jumping, playing ball, coloring,						
building with blocks)						
Behavior						
(Behaviors that interfere with learning or that you would like						
your child to do less often)						

^

### **Appendix Eight**

#### **Additional Resources**

#### 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 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, intellectual disabilities, 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, intellectual disabilities or attention disorders
- 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



## Early Indicators of Autism (Red Flags for ASD) in Infants and Toddlers

Maryann Trott MA, BCBA Autism and Other Developmental Disabilities Division

One of the questions most often asked of the individuals that work in the Autism programs is "How early can you tell if a child has autism?" followed by "What are the signs?"

According to Dr. Lauren Elder who is the assistant director of dissemination science at Autism Speaks, it is a complicated question because of the variation in the way that children develop and the signs of autism are manifested. That said, some of the early behavioral signs may begin to emerge as early as 6 to 12 months. Most professionals who specialize in the diagnosis of autism, however, hesitate to make a definite diagnosis until 18 months. Sometimes, the signs of autism appear to emerge or fade away until about 24 months. Some children may appear to develop in a typical way until about 18 months and then lose skills or regress. Other 18 month old babies may seem be behind developmentally but then "catch up" by the time they are 24 months old. For some infants, behavioral signs may be quite apparent close to the first birthday. In these cases, an experienced professional may make a diagnosis so that the infant will begin to receive early intervention services as soon as possible. One more thing to consider is that some children with autism are not diagnosed until they enter school and begin to struggle with social demands.

Early diagnosis of autism is essential as early intervention can change the way the brain develops. For further information about early screen and diagnosis, see the CDD information brief "The Importance of Early Screening for Autism Spectrum Disorder".



### What are the early signs of autism in babies and toddlers?

Recognizing that every infant is different from every other infant and that some of the "signs" of autism may be present in infants who may have other disabilities or even in infants who may turn out not to have any disability, there are some signs that warrant a discussion with a pediatrician and a possible closer look at the infant's overall development.

#### In the area of language development:

- \* Diminished babbling (especially back and forth babbling that looks like the baby is "talking" to another person).
- \* No single words by 16 months
- \* Odd first words
- \* No two word phrases by 24 months
- \* Limited response to name by 12 month
- \* Repeat words or phrases over and over (echolalia)
- \* Abnormal tone of voice (flat, robotic or sing-song)



#### In the area of nonverbal communication:

- May avoid eye contact or look at people/ things in unusual ways
- \* Little or no joint attention (baby and another person are both interested in the same item or event and both understand that the other is interested). It is not joint attention if the purpose is to get something (non–social) Joint attention emerges about 9 months and should be well established by 18 months
- Less positive affect or joyful expressions (flat or inappropriate expression)
- \* Limited or absent social smile
- \* Infrequent use of gestures such as pointing by about 14 months

#### In the area of social development:

- Limited shared enjoyment including showing something to another person or engaging in back and forth activities such as waving, reaching by 12 months
- \* May prefer to play alone
- \* May resist or avoid physical contact
- Only interacts to get something s/he wants

#### In the area of play

- May be repetitive such as lining things up or spinning things
- May not be interested in functional play (making cars go vroom; pounding with a toy hammer, eating toy food)
- Odd play such as spinning the wheels on a car rather than making the car go
- Plays with toys the same way over and over (and may become upset if others attempt to join in)
- \* "Obsessive" interests
- \* May be more interested in parts of objects
- \* Does not pretend

#### In the area of body use & sensory differences:

- \* Repetitive movements such as hand or finger posturing, flapping, spinning
- Seeks out or avoids certain textures, sounds or movements
- Visual differences (fixating on objects or certain kinds of stimuli such as the light coming through blinds, looking at things in odd ways or tracking such things as fan blades, etc.)
- \* Unusual reactions to food tastes or textures
- \* Unusual response to smells or sounds

#### Other:

- \* Has to follow certain routines
- Gets excessively upset by minor changes on a regular basis
- Very difficult to comfort
- \* May dislike physical contact

Please remember that none of these concerns by themselves, or even several taken together, indicate that a child has an Autism Spectrum Disorder. Also, many of these indicators may be present in children who have other developmental concerns. This is not to say "wait and see." If in doubt or if you are wondering about a baby's development, do not delay. Ask for an appointment with a pediatrician or developmental specialist as soon as possible.

#### About the Author:

**Maryann Trott MA,** is a Special Educator and BCBA who manages several projects for the Autism Programs at the University of New Mexico, Center for Development and Disability, Autism Programs.

#### Tips for Success

- 1. **Get Regular Well-Child Check-ups:** It is important for a child to get regular check-ups with a primary care doctor to monitor development. Be sure to bring up <u>any</u> concerns about a child's progress, and don't hesitate to ask questions.
- 2. **Know what to look for:** Know the developmental milestones for each stage of a child's development and talk to the doctor if the child is not reaching those milestones. Learn the early signs or "red flags" for ASD in young children and request an evaluation if there are concerns.
- 3. **Don't take the "wait and see" approach:** There is no time for the "wait and see" approach when there are concerns about a child's development, and there is no harm done in screening or seeking a referral. Remember, early identification leads to early intervention. The age that intervention begins does matter!

#### Resources

- **1. Autism Video Glossary** <a href="http://autismspeaks.player.abacast.com/asdvideoglossary-0.1/autismspeaks/login">http://autismspeaks.player.abacast.com/asdvideoglossary-0.1/autismspeaks/login</a>
- 2. **Early Childhood Evaluation Program (ECEP): Age 0-3 years** Center for Development and Disability, University of New Mexico <a href="http://www.cdd.unm.edu/ecep/index.html">http://www.cdd.unm.edu/ecep/index.html</a> or e-mail: <a href="https://www.cdd.unm.edu/ecep/index.html">ECEP@salud.unm.edu</a> (505) 272-9846 or Toll Free at 1-800-337-6076
- 3. **Centers for Disease Control and Prevention, Learn the Signs, Act Early** <a href="http://www.cdc.gov/ncbddd/actearly/index.html">http://www.cdc.gov/ncbddd/actearly/index.html</a> <a href="http://www.cdc.gov/ncbddd/autism/signs.html">http://www.cdc.gov/ncbddd/autism/signs.html</a>
- 4. Steiner, A.M., Goldsmith, T.R., Snow, A.V., & Chawarska, K. (2012). Practitioners guide to assessment of autism spectrum disorders in infants and toddlers. *Journal of Autism and Developmental Disorders*, 42:1183-1196.

autism

By 6 months, I don't smile back at you. I don't look at you. I don't coo or babble.

By 9 months, I'm not happy to see you. I don't seek your attention.

By 12 months, I don't wave. I don't point. I don't notice you. I rock back and forth, spin or flap my hands persistently.

**By 14 months**, I don't say anything. I stare at objects. I'm oversensitive to textures, smells or sounds. I resist change at all costs.

By 24 months, I don't say simple words. I don't pretend. I don't have friends. I've stopped talking.

For more information about this resource or to inquire about the Autism Programs call (505) 272-1852 or 1-800-270-1861 <a href="www.cdd.unm.edu/autism">www.cdd.unm.edu/autism</a>

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. 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 that a nutritionist be consulted before beginning any diet therapy, since one could be eliminating a child's only source of important nutrients.