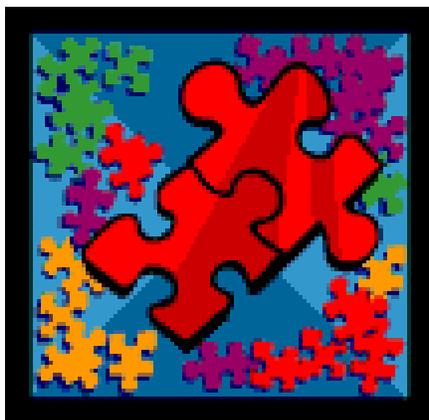




Technical Assistance Manual

Autism Spectrum Disorders

Guidance on providing supports and services to young children with autism spectrum disorders and their families



June 2004

New Mexico Public Education Department
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The State of New Mexico
Autism Spectrum Disorders Technical Assistance Manual
June, 2004

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Foreword

Although we will never fully understand the world of the child with ASD, we can look to adults who are able to talk about their experiences with autism. One such person is Temple Grandin who has authored books on the subject of autism, drawing heavily from her own personal experiences. Here are several excerpts from her book "Emergence: Labeled Autistic" (1989) and her article "My Mind is a Web Browser: How People with Autism Think" (2000):

"Objects that move rapidly also attract the attention of people with autism. When I was younger, I liked to play with automatic doors at supermarkets. I enjoyed watching the rapid opening movement... As a child, my favorite things all made rapid movements. I liked flapping flags, kites, and model airplanes that flew."

"Spinning was another favorite activity. I would sit on the floor and twirl around. The room spun with me. The self-stimulatory behavior made me feel powerful, in control of things. After all, I could make a whole room turn around."

"Birthday parties were torture for me. The confusion created by noisemakers suddenly going off startled me. I would invariably react by hitting another child or by picking up an ashtray or anything else that was handy and flinging it across the room."

"Only by interviewing people did I learn that many of them think primarily in words, and that their thoughts are linked to emotion. In my brain, words act as a narrator for the visual images in my imagination. I can see the pictures in my memory files."

While there are common behaviors and traits in children with autism, we must remember that each young child is unique. Our challenge, in partnership with parents, is to engage the child in activities that will help him/her learn.

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Introduction

Project SET (Specialized Early Teaching for Young Children with Autism) was funded in 2000 to begin training and technical assistance throughout New Mexico for very young children with Autism Spectrum Disorders (ASD) and their families. Project SET is a jointly funded project of the Department of Health - Family Infant Toddler (FIT) Program and the Public Education Department, Special Education Bureau. Project SET is a program of the SouthWest Autism Network at the University of New Mexico - Center for Development & Disability.

In the Fall of 2002, Project SET staff began work on a technical assistance document for the state of New Mexico that would outline recommended practices in intervention for very young children with ASD. Project SET staff researched recommended practices in the field as well as documents produced by other states.

The field of autism is rapidly changing with increased funding for research into causes and treatments of this Autism Spectrum Disorder. This document will focus primarily on behavioral and communication treatment approaches that may be used within early intervention and/or preschool special education. Other treatment approaches that are not covered in this document include biomedical and dietary treatments as well as complementary approaches such as art, music and animal therapy. Information on other treatment approaches can be obtained from the Autism Society of America (www.autism-society.org).

Throughout this document we have included the term "early childhood" to refer to children from birth to 8, however our primary intended audience is for families and providers of children birth to 5. This technical assistance document is intended to be used by personnel in early intervention agencies and local education agencies as well as family members of children with ASD.

Many children with ASD are demonstrating promising outcomes as a result of intensive and specialized intervention. In New Mexico our challenge is to ensure that all children with ASD and their families have access to high quality intervention that meets their individual needs.

Background

What is Autism Spectrum Disorder (ASD)?

Autism, or autistic disorder, is a neurobehavioral syndrome characterized by onset prior to age 3. Characteristics include severe differences in interaction with other people, communication deficits, as well as restricted and stereotyped patterns of interest and behaviors. Increasingly, the term Autism Spectrum Disorder (ASD) is being used to refer to the wide range of symptoms and characteristics in these areas, which vary from mild to severe. Along the continuum, children may exhibit any combination of these behaviors in varying degrees of severity.

Given this broad spectrum of characteristics, the need for individualized interventions becomes critical.

What Causes ASD?

In recent years, much attention and time from researchers worldwide has been given to determine the causes of ASD. Although current research links autism to biological or neurological differences in the brain, much remains unknown about the causes of these differences. Both environmental and genetic causes are being targeted in research. In terms of genetics, it is estimated that there is a 5-8% recurrence risk of having a child with ASD when one child in the family has this diagnosis. There is also a 60% - 90% chance of identical twins both being affected with ASD; in fraternal twins there is a 10% likelihood that both twins will have ASD if one twin is diagnosed. We do know that ASD is **NOT** caused by bad parenting, mental illness or poorly behaved children.

How Often Does ASD Occur?

There appears to be mounting evidence that earlier prevalence rates for ASD may have under-counted children with this diagnosis. Recent studies have revealed 2 to 6 children per 1,000 for the entire spectrum. Given these figures, conservative estimates indicate that there may be approximately 3,600 to 10,800 children and adults with ASD in New Mexico, with an estimated 270 - 810 children under the age of five. We are seeing more and more young children with signs of ASD.

Identification

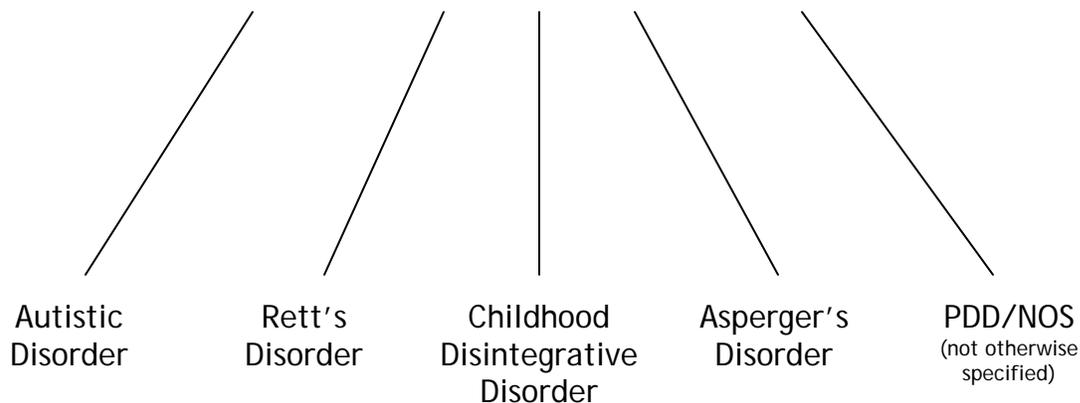
Is Pervasive Developmental Disorder the Same as ASD?

Diagnosis of medical disorders is based on various categories found in a diagnostic manual printed by the American Psychiatric Association (Diagnostic and Statistical Manual of Mental Disorders, DSM-IV). Pervasive Developmental Disorders (PDD) is the official category in the diagnostic manual under which the various autism spectrum disorders are listed. Since the printing of DSM-IV, many in the field refer to PDD as Autism Spectrum Disorders to properly reflect the spectrum nature of this diagnosis. The following specific diagnoses are included under the category of PDD:

- ◆ **Autism, also called Autistic Disorder**
Onset for autistic disorder is within the first 36 months of life. Children may be initially perceived as deaf with significant or absent language and social communication skills. Unusual behaviors such as stereotyped movements are common after about 3 years of age.
- ◆ **Pervasive Developmental Disorders - Not Otherwise Specified**
In PDD-NOS (also referred to as atypical autism), the child has difficulties in social interaction and other areas consistent with a diagnosis but does not meet the full criteria for a diagnosis of autism.
- ◆ **Asperger's Disorder**
Although early cognitive and language development may appear to be normal, social deficits become prominent as the child enters preschool and fails to respond appropriately to peers. Generally, children with Asperger's Disorder have unusual interests that are pursued with intensity.
- ◆ **Childhood Disintegrative Disorder**
With childhood disintegrative disorder, there is a prolonged period of normal development followed by marked regression in multiple areas and development of many features that are reminiscent of autism.
- ◆ **Rett's Disorder**
Very early growth and development is normal but is followed by a deceleration in head growth, development of marked mental retardation, and unusual hand-washing stereotypies and other features.

All of these diagnosis share common features of ASD and may be diagnosed separately. The chart on the next page illustrates the spectrum of Autism.

PERVASIVE DEVELOPMENTAL DISORDERS



Explanation: Given the low occurrence of both childhood disintegrative disorder and Rett's disorder, early childhood providers may not see many children with these diagnoses. Children with Asperger's syndrome are generally not referred for early intervention services because they have typical language and cognitive skills; Asperger's Disorder is generally not diagnosed until the child is in preschool, as the social deficits become apparent, therefore, an early interventionist in a birth to 3 program may not have much contact with these children. Of children on the autism spectrum, early childhood providers will be most likely to see children who will later carry a formal diagnosis of atypical autism or autistic disorder. Many of the children with ASD begin receiving early intervention or school services because of developmental delays, including communication delays. It is imperative that early childhood providers be aware of some of the early signs of possible ASD and make appropriate referrals for a correct diagnosis.

What are the Early Signs of ASD?

Because of delays in development, the majority of young children with ASD will receive early intervention services prior to receiving a formal diagnosis. Often they have significant social communication/ language delays that are further delayed than the rest of their development. In the communication area, early warning signs of ASD are as follows:

- ❑ No babbling, pointing or gesturing by 12 months.
- ❑ No single words by 16 months.
- ❑ No 2 word spontaneous phrases by 24 months.
- ❑ No response to name.
- ❑ ANY loss of language or social skills at any age (see example on next page).

Example: Jennifer is a two and a half year old child referred for evaluation for ASD. Her mother stated that around 18 months of age, she had approximately 10 words, such as “mama”, “dada”, “juice”, etc. She stated that around 2 years of age, she stopped using these words, and now is no longer talking.

The Checklist for Autism in Toddlers (CHAT) is a screening instrument designed to detect the core features of autism in children as early as 18 months. The checklist was modified recently (M-CHAT). The checklist consists of 23 yes-no questions; the authors recommend that any child who fails three or more items on the entire M-CHAT or two or more of the “critical” items should receive a comprehensive evaluation. The critical items on the M-CHAT include the following:

- Does your child take an interest in other children?*
- Does your child ever use his/her index finger to point, to indicate interest in something?*
- Does your child ever bring objects over to you (parent) to show you something?*
- Does your child imitate you (e.g., if you make a face-will your child imitate?)*
- Does your child respond to his/her name when you call?*
- If you point at a toy across the room, does your child look at it?*

See Appendix A for the complete M-CHAT.

Early Indicators for Screening of Autistic Spectrum Disorders

Developmental indicators from birth - 60 months in the areas of sensory-motor, speech-language, and social domains have been outlined by B.J. Freeman at UCLA. These are indicators and not diagnostic criteria; the presence of a number of these indicators does not necessarily mean the child will have ASD.

Age	Sensory-Motor (restricted repertoire of activities)	Speech-Language (cognitive development)	Social (relating to people and to objects)
Birth - 6 months	<ul style="list-style-type: none"> ▪ Persistent rocking ▪ Inconsistent response to stimuli 	<ul style="list-style-type: none"> ▪ No vocalizing ▪ Crying not related to needs ▪ Does not react differentially to adult voices 	<ul style="list-style-type: none"> ▪ No anticipatory social responses (when sees or hears mother) ▪ Does not quiet when held ▪ Poor or absent eye to eye contact ▪ Fails to respond to mother’s attention and crib toys.
6 - 12 months	<ul style="list-style-type: none"> ▪ Uneven motor development ▪ Difficulty with responses 	<ul style="list-style-type: none"> ▪ Babbling may stop ▪ Does not imitate sounds, gestures or expressions 	<ul style="list-style-type: none"> ▪ Unaffectionate, difficult to engage in baby games ▪ Does not initiate baby

	<ul style="list-style-type: none"> to textures (e.g., problems transitioning to table foods) ▪ Failure to hold objects or attachment to unusual objects (or both) ▪ Appears to be deaf ▪ Preoccupation with fingers ▪ Over or under reaction to sensory stimuli (or both) 	<ul style="list-style-type: none"> ▪ Does not give objects when requested to do so. 	<ul style="list-style-type: none"> games ▪ Does not wave “bye-bye” ▪ No interest in toys ▪ Does not show distress when mother leaves room ▪ Absent or delayed social smile ▪ Does not repeat activities that he/she enjoys ▪ Does not extend toys to other people ▪ Does not differentiate strangers from family
12 - 24 months	<ul style="list-style-type: none"> ▪ Loss of previously acquired skills ▪ Hyper or Hyposensitivity to stimuli ▪ Seeks repetitive stimulation ▪ Repetitive motor mannerisms appear (e.g., hand flapping, whirling) 	<ul style="list-style-type: none"> ▪ No speech or occasional words ▪ Stops talking ▪ Gestures do not develop ▪ Repeats sounds non-communicatively ▪ Words used inconsistently and may not be related to needs 	<ul style="list-style-type: none"> ▪ Withdrawn ▪ Does not seek comfort when distressed ▪ May be over distressed by separation ▪ No pretend play or unusual use of toys (e.g., spins, flicks, lines up objects) ▪ Imitation does not develop ▪ No interest in peers
24 - 36 months	<ul style="list-style-type: none"> ▪ Unusual sensitivity to stimuli and repetitive motor mannerisms continue ▪ Hypersensitive or Hyposensitive (or both) 	<ul style="list-style-type: none"> ▪ Mute or intermittent talking ▪ Echolalia (e.g., repeats television commercials) ▪ Specific cognitive abilities (e.g., good rote memory, superior puzzle skills) ▪ Appears to be able to do things but refuses ▪ Leads adult by hand to communicate needs ▪ Does not use speech communicatively 	<ul style="list-style-type: none"> ▪ Does not play with others ▪ Prefers to be alone ▪ Does not initiate ▪ Does not show desire to please parents
36 - 60 months	<ul style="list-style-type: none"> ▪ Repetitive behaviors may decrease or occur only intermittently 	<ul style="list-style-type: none"> ▪ No speech ▪ Echolalia ▪ Pronoun reversal ▪ Abnormal tone and rhythm in speech ▪ Does not volunteer information or initiate conversation ▪ May ask repetitive questions 	<ul style="list-style-type: none"> ▪ Foregoing characteristics continue but may become interested in social activities ▪ Does not know how to initiate with peers ▪ Upset by changes in environment ▪ Delay or absence in thematic play

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Who Can Make A Diagnosis of ASD?

Parents and early childhood providers are often the first ones to realize that a child may exhibit characteristics of an autism spectrum disorder, since characteristics of autism occur before 36 months of age. Given the increased awareness of ASD, early childhood providers should discuss with parents the aspects of the child's development that is atypical or different. They should also be able to respond appropriately to a parent's question "Does my child have autism?" by knowing the early signs of ASD as well as the signs that rule out ASD. Although the majority of early childhood personnel are not qualified to make a diagnosis of autism, they should be able to refer families who wish to pursue this diagnosis to the appropriate specialists.

Developmental pediatricians, psychologists, child psychiatrists, or neurologists typically make a diagnosis of autism if they have experience in the area of ASD. Although children are being diagnosed at younger and younger ages, the majority of early diagnoses are made between the ages of 2-3. Diagnosis may be part of a multidisciplinary developmental evaluation; all developmental evaluations should address the child's unique strengths and learning challenges. If a diagnosis is not part of a developmental evaluation, a complete medical and/or psychological evaluation is recommended, with a referral to a specialist in autism. In New Mexico, the UNM Early Childhood Evaluation Program (ECEP) is able to evaluate and diagnose ASD for children before the age of 3.

Explanation: All early childhood providers must have an understanding of early warning signs and be able to assist parents in finding an adequate evaluation/assessment if they wish to pursue the diagnosis. If a child does not have a formal diagnosis but exhibits many of the characteristics, the early childhood providers must still insure that the child's need for intensive interventions are met.

What Evaluations and Assessments are Recommended When a Diagnosis of ASD is Suspected?

The American Academy of Child and Adolescent Psychiatry recommends a complete assessment upon referral for ASD. This assessment should include the following:

History:

- ◆ Review of pregnancy, labor and delivery and early post-natal history.
- ◆ Review of communication and motor milestones.

- ◆ Any aspects of child's development that have been unusual.
- ◆ When and why the family first became concerned with the child's development.

Medical History:

- ◆ Discussion of possible seizures.
- ◆ Vision or hearing impairments.
- ◆ Family history of autism or developmental disorders.

Intervention History:

- ◆ The child's response to intervention.
- ◆ Review of previous evaluations, therapy reports, intervention reports.

Assessment of Child:

- ◆ Observation: It is important to observe the child in a variety of settings; observing the child with the parents and siblings is often useful. Typically, more than one session is needed.
- ◆ Developmental Level: This should include the child's ability in the areas of communication, social interaction and play as well as restricted or unusual interests/behaviors. These behaviors should be evaluated relative to the child's overall developmental level.
- ◆ Cognitive Abilities: This will establish a child's overall level of functioning. It is important to separate verbal from nonverbal performance when possible.
- ◆ Adaptive Skills: This will provide additional information that will assist in establishing priorities for intervention.
- ◆ Speech/Language/Communication Assessments: Actual use of language (both receptive and expressive) should be assessed; articulation and oral motor difficulties should be noted; social use of communication should be assessed at whatever level of communication skills the child exhibits.
- ◆ Occupational and Physical Therapy Assessments: Motor development should be assessed as well as degree of hyper- or hypo-sensitivity or other sensory issues.
- ◆ If the child is not currently receiving services, a determination is made regarding eligibility for the FIT Program or for preschool special education.

Medical Assessment:

- ◆ Physical examination of the child is concerned with a search for a treatable medical condition or for conditions with important implications for the family, e.g. inherited medical conditions such as fragile X syndrome or tuberous sclerosis.
- ◆ Medical history to include immunization history and routine laboratory studies.
- ◆ Audiological and visual examinations: Brainstem auditory evoked response audiometry should be conducted if behavioral audiometry is not definitive.
- ◆ Neurological Assessment: Observation of the child for symptoms of seizures should be conducted.
- ◆ Laboratory Studies: There are no specific laboratory tests for autism; fragile X testing is typically indicated. There is now a DNA test for fragile X syndrome.
- ◆ The presence of dysmorphic features may suggest obtaining genetic screening for inherited metabolic disorders or chromosome analysis.
- ◆ If a medical specialist is not part of the team, a referral should be made. This may be to a community physician with experience in working with children with ASD; a referral could be made to the Center for Development & Disability to assist the local physician with diagnosis or additional testing.

What are the Specific Criteria that a Team Uses to Make a Diagnosis of ASD in a Young Child?

The DSM-IV provides the diagnostic criteria for autism, or autistic disorder, and a diagnosis of ASD is made based on complete or partial fulfillment of that criteria. According to the DSM-IV, the following are the criteria for Autistic Disorder.

Criterion A

A total of six (or more) items from sections (1), (2), and (3) with at least two from section (1) and one each from sections (2) and (3):

- (1) **Qualitative impairment in social interaction, as manifested by at least two of the following:**
 - a) Marked impairment in the use of multiple, nonverbal behavior, such as eye to eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - b) Failure to develop peer relationships appropriate to developmental level.
 - c) A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest.)

- d) Lack of social or emotional reciprocity.

Explanation: In very young children with ASD, impairments in social interaction often take the form of decreased eye contact and/or decreased use of gaze shifting for communication (e.g., looking from a person to an object or activity and back to the person), decreased use of gestures such as pointing, and decreased joint attention (e.g., looking at an object when an adult looks at it). Young children with ASD often have difficulty understanding the concept of taking turns (social reciprocity), even at the level of infant-type “back and forth” games. If they bring an object to an adult, it is usually to have the adult do something (such as open the lid), rather than to show the adult the object for enjoyment. It is difficult to determine a child’s peer relationships if a child is not in a preschool setting or in other ways exposed to peers. Observing the child in a variety of settings or eliciting this information from parents will be important.

(2) Qualitative impairment in communication as manifested by at least one of the following:

- a) Delay in, or total lack of, development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime).
- b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
- c) Stereotyped and repetitive use of language or idiosyncratic language.
- d) Lack of varied, spontaneous make believe play or social and imitative play appropriate to developmental level.

Explanation: Frequently young children with ASD do not consistently respond to their name; lack of a consistent response to name is a reliable discriminator between ASD and other developmental delays. In very young children with ASD, impairments in communication usually take the form of significant delays in expressive language that are not accompanied by attempts to compensate with gestures. If young children are vocalizing, they may use an odd jargon or unusual repetition of sounds or words (echolalia). Some young children with ASD learn language in different ways, sometimes repeating “chunks” of words together, such as sentences they memorize from their favorite video. Young children with ASD often have difficulty imitating motor and verbal activities or play routines, and their play activities are usually more mechanical (e.g., building or lining up blocks, pushing cars back and forth) than symbolic.

(3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
- b) Apparently inflexible adherence to specific, nonfunctional routines or rituals.
- c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping, twisting, or complex whole body movements).
- d) Persistent preoccupation with parts of objects.

Explanation: Very young children with ASD may not develop repetitive mannerisms (e.g., hand flapping) or interest in rituals or routines (e.g., only eating from a green plate) until after age 3, so many young children with ASD may not meet this criteria until they are older. More subtle motor mannerisms, however, have been noted in some young children, such as walking on tiptoes, liking to spin, or a tendency to carry objects around continually. Many young children have difficulty with transitioning from activities or from places. Some children like common objects such as paper, pens, trucks, or trains to an unusual degree.

Criterion B

Delays or abnormal functioning in at least one of the following areas, onset prior to age 36 months: social interaction, language as used in social communication, and symbolic or imaginative play.

Criterion C

The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Explanation: When a child is referred for an evaluation/assessment for the diagnosis of ASD, individuals who have been providing intervention services prior to age 3 can play a critical role in assisting the multidisciplinary evaluation team. Sometimes community based providers/therapists may be a part of the evaluation team and in other instances they will provide valuable information to the team. This may include the child's responses to intervention, what tends to work for the child and what intervention has been unsuccessful. Observation of the child, which should occur in more than one setting, can be completed by those who are already involved with the child. Information regarding the child's developmental levels that are observed on a daily basis will be an important adjunct to standardized tests.

In New Mexico, children birth - 3 who are suspected of ASD can be referred to the Early Childhood Evaluation Program (ECEP) at the UNM - Center for Development & Disability. Children are evaluated by an interdisciplinary team skilled in the diagnosis of learning differences in young children. The team typically consists of a pediatrician, cognitive therapist or psychologist, speech-language pathologist, and a physical or occupational therapist. The composition of the team frequently includes community providers and therapists as well.

For children over the age of three, referrals are typically made to community providers, local educational agencies, or independent practitioners with experience in the diagnosis of ASD in young children. The SouthWest Autism Network's (SWAN) Autism Clinic at the Center for Development & Disability is a multidisciplinary clinic that sees children over the age of three for diagnosis and assessment. Team members consist of a developmental pediatrician, clinical neuropsychologist, speech-language pathologist and a family liaison.

For review of additional Diagnostic Criteria for Autism Spectrum Disorders, please see Appendix B.

National Recommendations for Serving Young Children with ASD

What are the National Recommendations for Serving Young Children with ASD?

Children with ASD present complex intervention needs. Given the broad spectrum nature of ASD, it is unlikely that any one intervention or treatment will benefit all children with ASD. Similarly, no two families of children with ASD are alike; each will have unique strengths, stressors and needs.

The U.S Department of Education's Office of Special Education Programs charged the National Research Council (NRC) to integrate scientific, theoretical, and policy literature and evaluate the scientific evidence concerning effects and features of interventions for young children with ASD. Their specific charge was to suggest recommendations for young children with ASD birth - 8 years of age, which would include early diagnosis, early intervention, preschool and school programs for this age group. The NRC report *Educating Children with Autism* was published in 2001.

Recommendations for Diagnosis and Assessment

NRC Recommendation 1: Children with any ASD (autistic disorder, Asperger's disorder, atypical autism, PDD-NOS) regardless of severity should be eligible for special educational services under the category of autism spectrum disorder as opposed to "other health impaired", "developmentally delayed", etc.

Explanation: It appears the intent of this recommendation is that each state has an accurate estimate of the number of children with ASD and that given their intensive service/educational needs, program planning must take into account the child's unique learning needs. New Mexico special education regulations allow the category of "developmentally delayed" to be used until a child is 9 years of age, however 6.31.2. 10.F (2) (a) NMSA states "the developmentally delayed classification may be used at the option of individual local education agencies, but may only be used for children who do not qualify for special education under any other available disability category." The diagnosis of autism can help the family and team to gain an understanding of the unique and intensive services that are recommended for children with ASD.

NRC Recommendation 2: Children identified with an autism spectrum disorder should have a formal multidisciplinary evaluation to include evaluation of social behavior, language and nonverbal communication, adaptive behavior, motor skills,

atypical behaviors, and cognitive status. Included in this evaluation should be a systematic gathering of information from parents about their concerns and their observations of their child.

Explanation: Expertise and experience are required to assess children with ASD. Most standardized measures are not sufficient to determine an appropriate plan for children with ASD. Multidisciplinary teams need expertise and time to pool their collective information and to use the information gathered from parents to address the unique learning needs of these children.

NRC Recommendation 3: Younger children who receive a diagnosis of ASD should have a follow-up diagnostic and educational assessment 1-2 years after their initial evaluation.

Explanation: Although there is not adequate data to determine the average age for diagnosis for children with ASD within New Mexico, children are generally receiving earlier diagnosis. After children leave the Family Infant Toddler (FIT) Program, they generally enter public schools. There is no system-wide follow up within New Mexico for a diagnostic evaluation for young children other than educational assessments they may receive in the public school settings. This should be addressed to insure that early diagnoses are accurate and that developmental changes in young children be documented and utilized to continue to develop appropriate programming strategies.

NRC Recommendation 4: All professionals having contact with young children should have information about the patterns of behavior seen in very young children with ASD. They should also have an understanding of the importance of early diagnosis and intervention.

Explanation: The Department of Health - Family Infant Toddler Program as well as the Public Education Department - Special Education Bureau have made a concerted effort to provide information to all professionals through their funding of projects (e.g., Project SET of the SouthWest Autism Network) designed to provide training, technical assistance and consultation regarding young children with ASD. The need for this training will continue to grow as more and more children are diagnosed. Early intervention agencies and local education agencies should avail themselves of training and technical assistance opportunities.

Recommendations Regarding Family Role

NRC Recommendation 1: Parent perspectives and concerns should actively shape the educational planning.

Explanation: This recommendation is based on the principle of family centered practice that applies to working with all children. Parents of children with ASD know their child best and have unique perspectives about their children. Children with ASD frequently demonstrate skills in the home setting that they may not show in other settings; professionals need to be cognizant of this and be certain that outcomes/goals include the generalization of skills learned in one setting to other settings. New Mexico has a strong history of family centered practice. Involving the family in the development of the IEP/IFSP and in the intervention process is key to successful planning. Professionals must listen to the concerns and priorities of each family and pay attention to cultural differences.

NRC Recommendation 2: Parents should have access to information about the nature of autism spectrum disorders, range of alternatives within best practices in early education, sources of funding support and their child's rights.

Explanation: Several organizations within the state can assist parents with information and support, including the SouthWest Autism Network and Parents Reaching Out. The LINC resource library at the UNM - Center for Development & Disability has an extensive collection of books and videos available to families and community providers.

NRC Recommendation 3: As part of the early intervention, families should be provided with opportunities to learn specific techniques for teaching their child and reducing challenging behaviors. These may include:

- ◆ Teaching sessions.
- ◆ Ongoing consultation for problem solving.
- ◆ In-home observations.

Explanation: Many families are able to provide some of the active engagement time with their child, but will need training and consultation in order to carry out recommended teaching techniques. Much of this can be conducted by the early childhood staff working directly with the parent, however it may sometimes be beneficial for parents to attend a group training session.

NRC Recommendation 4: Mental health support services should be provided to families that are experiencing stress. These services should be extended to include families of children at least up to age 8.

Explanation: Although not specifically mental health support services, support groups for families do occur throughout the state through the SouthWest Autism Network's regional parent coordinators. These support groups meet to discuss community issues, access to services, and general family support. Regional parent coordinators also provide one to one support for families. There are currently six regional parent coordinators located throughout the state. Early intervention and public schools can refer parents to the SouthWest Autism Network for access to these regional parent coordinators. One reason that parents frequently contact SWAN is for support related to the stress of raising a child with ASD. Parents ask for assistance with sleep and feeding issues most frequently, often needing a supportive listener who is familiar with the uncertainties of raising a child with ASD. Parents Reaching Out is another parent information center that provides parent networking, training and resources for families.

Recommended Characteristics of Effective Programs

Although there are a variety of interventions that are effective for children with ASD, there is general consensus regarding features of effective programs for young children with ASD. Specific programs have services that are tailored to the child's unique learning profile as well as to family's preferences and needs. The following features are critical and recommended as part of effective programs.

NRC Recommendation 1: Entry into intervention programs as soon as an ASD diagnosis is considered.

Explanation: Clearly, this suggests that early diagnosis is important as is early intervention. The NRC committee does not recommend entry into intervention only after a diagnosis is confirmed but as soon as it is considered. If a diagnosis of ASD is considered, the child should receive intervention that highlights these critical features.

NRC Recommendation 2: Active engagement in intensive instructional programming for a minimum of a full school day, 5 days (at least 25 hours) a week, with a full year of programming. This will vary given an individual child's chronological age and developmental level, and the desires of the community.

Explanation: Young children with ASD require intensive engagement with adults in activities that promote their learning. By definition, children with autism tend to spend little time engaged in purposeful and appropriate activities and more often are disconnected from their surroundings and people around them. Intervention therefore, should be aimed at increasing the amount of time that the child is engaged throughout the day in order to meet the outcomes / goals identified in the IFSP/IEP.

While recognizing the need for intensive engagement for young children with ASD, New Mexico does not recommend a specific number of hours. The precise number of hours, specified on the IFSP/IEP, will vary depending on: the child's age; severity of autistic symptoms; rate of progress; the child's health and/or tolerance for the intervention; and on the family's circumstances. The IFSP/IEP must be developed based on the unique needs of the child rather than on the basis of child's disability alone, as required by regulation. It is not possible to accurately predict the optimal number of hours that will be effective for any given child.

While engagement can include time spent by family members and other caretakers, IFSP/IEP teams should be aware of not overburdening families. The IFSP/IEP team in partnership with the family and other community providers must develop a comprehensive plan that delineates who will provide the intervention as well as when and where it will occur. The plan should consider the needs of the child and family with regards to health care, behavioral health, family support and training, as well as respite. The implementation of a plan that is coordinated and crosses a variety of agencies has also been recommended by a statewide advisory group and is reported in "Health Care Systems and Persons with Autism in New Mexico" (2004).

Children with autism benefit from predictable and regular intervention according to an established schedule. Intervention should occur year round and the IFSP/IEP should address vacations, holidays and other variations in the schedule in advance.

It is recommended that the number of hours and the location where services are provided be reviewed and revised periodically. The child's progress should be reviewed in order to determine if the intensity of hours should be increased or decreased.

NRC Recommendation 3: Planned teaching opportunities around brief periods of time (15-20 minute intervals for younger children) with one to one adult time and small group instruction to meet individualized need.

Explanation: This program feature suggests that a proactive, planned approach to teaching young children with ASD is essential. The NRC committee recommendations include both one to one instruction with an adult and small group instruction.

The family and other IFSP/IEP members need consider the setting(s) where services may be delivered. This may include “natural environments” such the child’s home, childcare settings, family home providers, public parks and other community setting, as well as classroom settings for preschoolers. It is recommended that children with ASD be included in settings with typically developing peers as much as possible, while at the same time recognizing the child’s need for one to one instruction.

The Autism Society of America, citing the NRC recommendations, suggests that local agencies be responsible for establishing a clear mechanism to determine the appropriate natural environments for service delivery with consideration of the concerns, priorities and resources of the child’s family. In addition, other considerations should include the age of the child, developmentally appropriate activities, the outcomes/goals and strategies/objectives on the child’s IEP/IFSP, the need for generalization across multiple settings and the evidence of best practices, including intensity and length of services. Given the type of outcomes/goals that need to be addressed for young children with ASD, the ASA recommends that, where possible, services begin in the home and then extend to childcare centers, play groups and preschool programs.

NRC Recommendation 4: Inclusion of family component, including parent training.

Explanation: Parent training is again mentioned in this feature. As was mentioned earlier, parents require opportunities to learn how to support their child’s development, information regarding recommended programming and regarding their rights. Early intervention agencies as well as preschool programs should insure that parents have access to this training. Parents also require support and networking with other families.

NRC Recommendation 5: Low student/teacher ratio (no more than 2 young children with ASD per adult in the classroom).

Explanation: This program feature speaks to the need for intensity of intervention/education for both early intervention and special education. A low student/teacher (developmental specialist) ratio allows for one to one teaching as well as work within small groups. Since children with ASD may have educational assistants who are working with them, this feature also raises training issues for those in instructional settings.

NRC Recommendation 6: Ongoing program evaluation and assessment of the child's progress to insure that program is meeting the child's individualized needs.

Explanation: This program feature is important for all those working with young children with ASD; it implies that children with ASD are expected to make progress and learn. Frequent program evaluation is necessary to be certain that the child is responding in a positive manner to the intervention.

Recommendations Regarding Intervention/Educational Services

The most appropriate outcomes/goals for children with ASD are similar to those for all children: personal independence and social responsibility. The NRC Committee recommended that both the IEP and the IFSP are the vehicles for planning and implementing appropriate intervention and education strategies/objectives. All outcomes/goals and strategies/objectives for children with ASD should be observable and measurable; they should be expected to be completed within one year and add significantly to the child's participation in education, community and family life. The following are recommended goals for young children with ASD.

- ◆ Social skills to include imitation, social initiations, responses to adults and other children, play skills both parallel and interactive play with others.
- ◆ Expressive verbal language, receptive language and non-verbal communication skills.
- ◆ Functional communication system, which may include pictures, photos, communication devices.
- ◆ Increased engagement and ability to participate in developmentally appropriate tasks, including ability to attend to the environment.
- ◆ Ability to respond to an appropriate motivation system.
- ◆ Fine and gross motor skills that are age appropriate.
- ◆ Cognitive skills such as basic concepts of cause/effect, early problem solving skills and pretend play skills.
- ◆ Replacement of challenging behaviors with more conventional and appropriate behaviors, such as teaching the child to take his mother's hand instead of running into the street.

- ◆ Independent skills necessary for successful participation in preschool and school programs: completing tasks independently, following instructions, requesting help.

See Appendix C for sample basic skills for young children with ASD.

All outcomes/goals should be assessed in an ongoing fashion to determine the child's response to intervention and to refine the child's program as necessary.

Recommendations for Effective Intervention Outcomes/Goals

The NRC committee's recommendations for effective treatment outcomes/goals were again based on empirical findings. These recommendations dovetail with the committee's finding of effective programs. The committee recommended the following:

NRC Recommendation 1: Based upon a child's individualized outcomes/goals, services should be implemented as soon as a diagnosis is suspected*. A child's and family's needs and strengths should be considered as a schedule of services is developed. These services should include a minimum of 25 hours per week, 12 months a year—this time should be when the child is systematically engaged in developmentally appropriate strategies/objectives.

**In New Mexico, services will be determined by the IEP/IFSP team after criteria for eligibility and need for services have been established.*

Explanation: The key words in this treatment outcome/goal are that the child is "systematically engaged in developmentally appropriate strategies/objectives". The recommendations are clear that young children with ASD, to be systematically engaged, need repeated, planned teaching opportunities organized around 15 - 20 minute intervals of time. With regard to the intensity of service, a combination of inclusive playgroups, day care, home visits and other options should be explored. The key to this combination is to be certain that in all settings, the child is engaged in developmentally appropriate learning activities.

NRC Recommendation 2: A child must receive sufficient individualized attention on a daily basis to achieve objectives; this individualized attention may include individual therapies, developmentally appropriate small group activities, direct one to one contact with teaching staff/parents/family.

Explanation: These treatment outcomes/goals speak to the need for a coordinated system of supports, interventions and education.

NRC Recommendation 3: Ongoing assessment of child's progress towards meeting strategies/objectives must be documented.

Explanation: Professionals working with the child must collect data that is useful and meaningful in order to determine how well the child is meeting outcomes/goals and when modifications to strategies/objectives may be necessary.

NRC Recommendation 4: Children should receive intervention and instruction with typically developing peers to the extent that this leads to specific educational outcomes/goals.

Explanation: This recommendation clearly states the value of inclusive community settings including child day care settings, preschool settings, and playgroups to "the extent that this leads to specific educational outcomes/goals."

The NRC committee recommends that certain kinds of intervention should have priority. These include the following:

- ◆ Functional, spontaneous communication should be a primary focus. Programming for young children should be based on the assumption that the child will learn to speak. Teaching both verbal language and alternative modes of functional communication should be investigated.
- ◆ Social instruction should occur across a variety of contexts, with adults and peers.
- ◆ Teaching of play skills should focus on play with peers as well as the appropriate use of a variety of toys.
- ◆ Outcomes/goals for cognitive development should also be emphasized, such as generalization and maintenance of new skills. Rates of acquisition of new skills should be documented. Methodology for teaching new skills may differ from those used for generalization and maintenance.
- ◆ Positive, proactive approaches should be used to address challenging behaviors.
- ◆ Functional academic skills should be taught, as appropriate to the child.

Treatment and Intervention Strategies

Children with ASD have a wide variety of complex intervention/education needs. Typically, a single strategy will not work for all children, nor will all skills be easily taught by a single method. Children with ASD are unique individuals and therefore our teaching approaches and intervention must be individualized to meet their needs. Similarly, early childhood personnel must work with the family and design a program that both addresses their concerns and priorities as well as fitting with their family life. Effective intervention includes helping the family to learn approaches and techniques that they can use with their young child that can promote his/her development.

Reinforcement

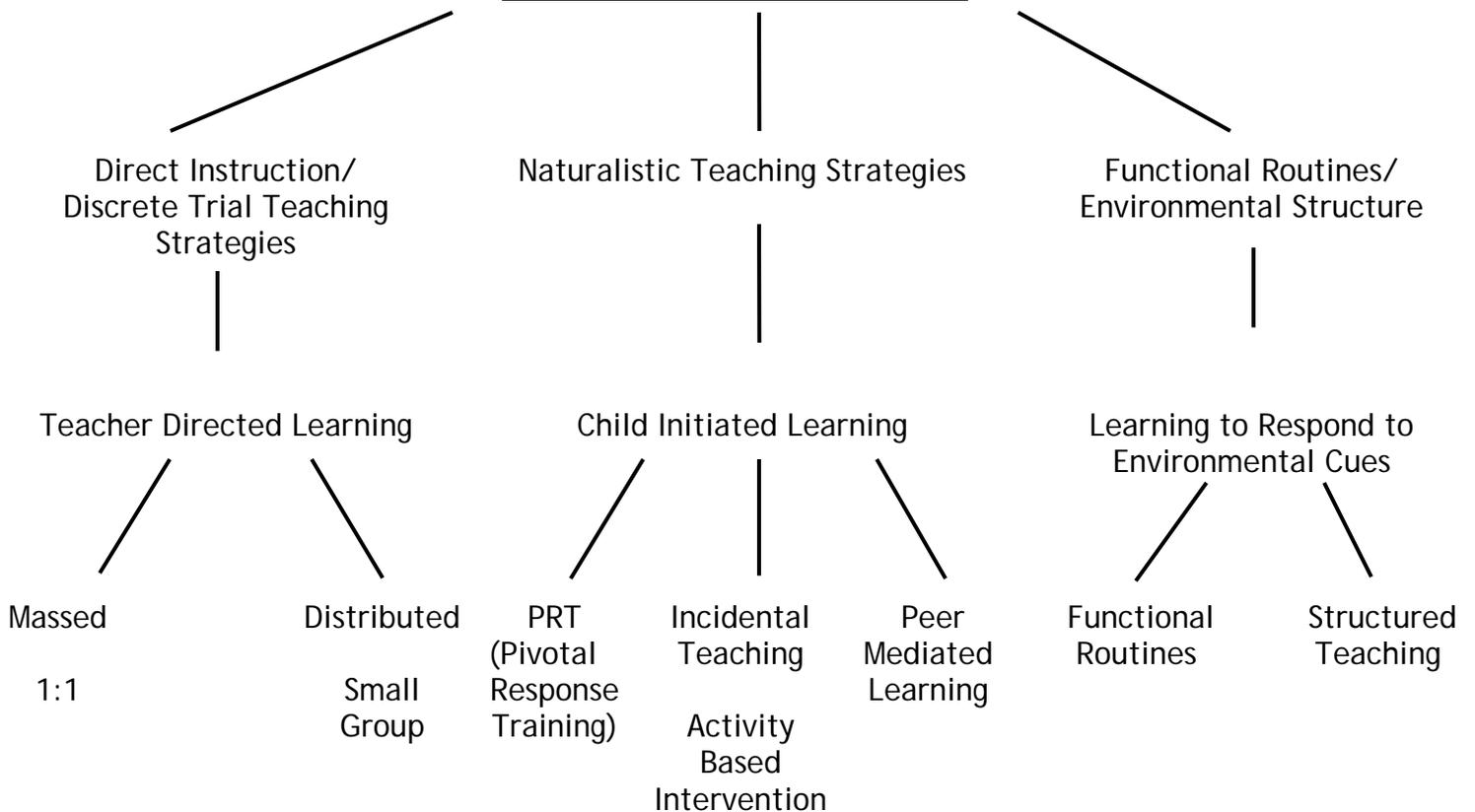
As with any teaching strategy, reinforcement is the key factor in success. Early childhood personnel need to take time to address what motivates children with ASD perhaps more than any other children. Parents know best about what their child likes and what motivates him/her. Early childhood personnel who work with the parents to identify reinforcements and rewards before implementing a teaching strategy will be more successful in effectively engaging the young child with ASD.

Applied Behavior Analysis

Teaching strategies from the field of Applied Behavior Analysis (ABA) are most often utilized for teaching children with ASD. These approaches have proven effective for a variety of children with ASD and range from teacher directed learning strategies, such as direct instruction/discrete trial teaching strategies to child initiated learning strategies which are classified as naturalistic teaching. The teaching of functional routines within environmental structure is another area of ABA.

The next chart illustrates the connection of the applied behavior approaches.

Applied Behavior Analysis: ABA



Direct Instruction/Teacher Directed Learning

Direct instruction refers to teaching strategies, which are adult directed, and one to one. They are highly structured and systematic and generally require repetitive practice with reinforcement given for correct responses.

Discrete Trial Training

Discrete trial is a 3 part teaching strategy that utilizes a behavioral sequence to maximize learning in students with ASD and other similar developmental disabilities. Discrete trials let the student know immediately if he/she has responded correctly or incorrectly. Discrete trials also help the teacher maintain consistency in all phases of the learning process and make assessment of progress earlier. Discrete trials have been proven to be effective when teaching new skills to children with autism.

The discrete trial consists of the following three distinct parts:

- ◆ The instruction (also called the Sd or discriminative stimulus), should be short and easy to understand such as “do puzzle,” “hands down,” etc.
- ◆ The second part of the discrete trial is the child’s response or action in response to the Sd.
- ◆ The third part is the consequence following the response or the reinforcing stimulus. The reinforcing stimulus may be food, privileges, praise, affection, attention, tickling, preferred activities, etc.

The strengths of discrete trial or direct instruction are that it often produces rapid, efficient learning and that it breaks down tasks into small, teachable steps. Some areas of concern include poor generalization and the need for one to one instruction. It is also a technique that requires some specialized training.

Example: Mary is a 2-1/2 year old child with a diagnosis of ASD. She moves around constantly making it difficult to get her attention. The teacher leads Mary to her carpet square and says, “Sit down.” Mary starts to leave the area; the teacher redirects her back to the carpet square, shows Mary her favorite ball and says, “Sit down.” Mary sits on her carpet square and the teacher gives her the ball and says “Good sitting.” The discrete trial had the following three parts:

“SIT DOWN” → Mary sits → “GOOD SITTING”, Mary given ball as reinforcer

Naturalistic Teaching/Child Initiated Strategies

These strategies that are child initiated include pivotal response training, incidental teaching/activity based intervention, and peer-mediated learning.

Pivotal Response Training

Pivotal response training was developed by Drs. Robert and Lynn Koegel at the University of California-Santa Barbara in the 1980s. PRT was developed in an effort to increase generalization of skills in children with ASD and to find target behaviors that would produce simultaneous changes in many other behaviors. Teaching occurs in natural environments with the following outcomes/goals: to teach responsiveness in social and learning opportunities; to increase independence; and to allow the child with ASD to participate in inclusive settings.

Pivotal behaviors are those that seem important in a wide area of functioning. Positive changes in pivotal behaviors should result in positive effects on many other behaviors.

Such behaviors include responding to multiple cues, (the “yellow car”, not just a single cue “car.”) A child who can respond to multiple cues is able to discriminate and attend more effectively to the environment. Another pivotal response behavior is

self-initiation. By learning to ask questions spontaneously, rather than just respond to them, a child is able to initiate with a variety of adults and peers. Teaching a child to use a pivotal word, such as "Look," to actively engage others and gain knowledge, rather than trying to teach labels for everything is an example of PRT. The main differences between direct instruction/discrete trial are a) teaching is by child choice, b) behaviors have natural consequences, and c) the child is motivated by the teaching object, not an unrelated reinforcer.

The differences between discrete trial and pivotal response are illustrated in the following example:

Objective: Naming objects/pictures
Direct Instruction: The teacher presents picture of bus; asks the child: "What is it?"
The child responds: "Bus."
The teacher response: "Great!" and hands the child a top as a reinforcer.

Objective: Naming objects/pictures
Pivotal Response: The teacher brings item of interest to child's eye level and says: "Top."
The child imitates and says: "Top."
The teacher says: "Great!" and hands the child a top as a reinforcer

The benefits of PRT are that it can be provided in most inclusive settings, it produces generalized improvements in other areas, and it was specifically developed for children with ASD. An area of concern is that the teaching strategies may not be well specified.

Incidental Teaching

Incidental teaching has been explored by Dr. Gail McGee at Emory University in Georgia. Incidental teaching is a naturalistic strategy in that a child's interests are assessed and instruction is child directed and child focused. The child is provided the opportunity to explore whatever interests him/her in the classroom or environment. The teacher uses the child's expressed interests as an opportunity to determine what skills should be taught. The teacher must capitalize on the opportunity and turn it into a teachable moment. The focus for teaching is the development of social and communication skills. Skills are taught within ongoing activities.

The strengths of incidental teaching are its usefulness in natural settings, the emphasis on maintenance and generalization of skills, and its ability to utilize typically developing peers. Some of the concerns are that the child must have some necessary pre-requisite skills and should have goal directed behavior. It also requires an observant teacher who is able to detect and respond to even subtle cues of interest given by the child with ASD.

Example: During free play, the teacher notices Johnny playing with a pretend car wash set; as he pushes the car inside the car wash, the teacher models the word "in." Johnny echoes the word, the teacher responds with "Yes, car in."

Activity Based Instruction

Activity based instruction refers to instruction that is embedded within an activity. There is shared teacher/child control and instruction occurs within natural environments. Activities are typical and developmentally appropriate.

The strengths of activity based instruction are that generalization is promoted and that discrete trials of instruction may be embedded into typical activities. Some areas of concern are that activities may not be motivating for the child or that the child may not be focused on the activity. This strategy also requires some pre-requisite skill on the part of the child and by its nature may provide fewer learning opportunities.

Example: After finger painting, Maria follows the other children to the sink to wash her hands. The teacher points to the steps of hand washing, which are posted through pictures by the sink. This is a natural activity in which the instruction is embedded.

Peer Mediation/Coaching

Peer mediation refers to the "coaching" of typically developing peers to help increase the social, language, or play skills of children with ASD. The use of peers is important as children with ASD typically tend to communicate more with adults than with their own peer group. Adults are able to predict and adapt their communication style to the child with ASD, whereas peers may require some coaching on how to respond to, initiate, and maintain communication with children with ASD. As peers learn these adaptations, adult contact decreases and the peers are able to provide more natural social examples to the child with ASD. Peer mediation generally consists of a combination of 1) coaching the peer and 2) shadowing the child with ASD.

The adult focuses on teaching the peer 1) how to understand the communication attempts of the child with ASD, 2) how to initiate and respond to the child with ASD, and 3) how to maintain an interaction with the child with ASD. The peer may practice where to stand, how to give or take an item, how to show something to the child or how to tap the child's arm to gain attention. Peers are taught how to persist if the child with ASD does not respond, how to wait for a response, and how to ignore certain behaviors.

The adult facilitates the interaction by modeling and prompting the child with ASD. It is important to distinguish for the child with ASD whether the adult is interacting with him/her or modeling for him/her. If the adult is face to face with the child with ASD,

the child may respond to the adult rather than to the peer. However, if the adult stands behind the child with ASD and then prompts the peer to say something, the child with ASD is more likely to understand he/she is supposed to direct the message to the peer. In addition, visual and non-verbal cues can be given to the peer from the adult if needed.

The use of peer mediation/coaching has much obvious strength. It maximizes and encourages inclusion in all settings, and is a naturalistic strategy for teaching social and communication skills. Some concerns may be the coaching of the typical peer and providing sufficient practice for the child with ASD.

Example: The developmental specialist selects the sister (Carol) of a child with ASD (Billy). She models how to complete a picture exchange with Carol. After practicing with Carol, the developmental specialist coaches her to receive a picture of a cookie from Billy with some assistance. She encourages Carol to give Billy the cookie. After several tries, the developmental specialist is able to move away from the children as the exchanges continue.

Functional Routines/Environmental Structure

Functional Routines

Functional routines are those routines that are meaningful to the child and family and occur naturally in a home or school setting. Instruction in these routines must be systematic and planned to be successful. Early childhood personnel have a great opportunity to support families in teaching these functional routines within the home environment.

The steps in teaching functional routines include the following:

1. Identifying skill, routines/activities, settings - The same skill may be practiced in several different activities and in many settings. Examples of functional routines that may be targeted for teaching include dressing, getting ready for bed, mealtimes, bathing, etc.
2. Creating a teaching plan - This includes developing strategies/objectives, where activity will be taught, what materials will be needed, steps involved, prompts, teacher's response to both correct and incorrect performance.
3. Developing a data system - This will provide ongoing assessment of the child's progress and may include the percent correct, number of steps independently completed, prompt level to be successful.

4. Teaching within natural routines - Identify who will teach, i.e., parents, early childhood providers, therapists, etc. Discuss how to prompt and how to reinforce and talk specifically about how the skill will be taught, perhaps through role play.
 - a. Use a variety of behavioral teaching techniques to teach the child, such as more physical handling of the child, less verbal prompting, shaping approximations, errorless learning, and frequent use of rewards early on.
 - b. Incidental techniques are also used, such as observing natural learning opportunities and creating situations where the child may be motivated to initiate and respond.
 - c. Structured teaching techniques may also be useful, such as the utilization of visual schedules of routines, visual cues for completion of tasks, and teaching the child when an activity is finished.
 - d. Developmentally appropriate teaching is also important in teaching functional routines. Skills taught should be developmentally appropriate; language used should be at a level understood by the child and the activity should be fun for the child.
5. Monitoring Progress - Data collected should be reviewed regularly to determine if change is necessary for the child.
6. Expanding Skills - Skills should be expanded to encourage more independence, to practice in another environment or to learn a more complex skill.

Structured Teaching

Developed by the Division TEACCH in the Department of Psychiatry of the University of North Carolina School of Medicine, structured teaching is generally considered to be a strategy that attempts to understand the child's unique learning challenges and to develop environmental supports to compensate. It is individualized and begins with a thorough understanding of the child and his/her strengths and needs.

Generally, structured teaching refers to five broad categories of strategies. These include:

- ◆ Physical structure: This includes physical classroom structure and where materials, furniture etc. are placed.
- ◆ Daily Schedule: This refers to the child's individual schedule, which tells him/her what activities will occur, and in what order.
- ◆ Individual Work Systems: This is the child's systematic way to receive and understand information. The work system allows the child to work independently by visually answering the questions: what work, how much work, when it is finished and what happens next.

- ◆ Visual Structure: This allows the child to use visual methods to complete tasks by providing visual instruction, visual organization and visual clarity.

PECS - Picture Exchange Communication System

The Picture Exchange Communication System (PECS), authored by Andy Bondy and Lori Frost, was originally developed for use with preschool children with autism and other pervasive developmental disorders, as well as for other children with communication disorder who have no functional verbal speech. It came out of the need for an alternative to motor and/or vocal imitated speech. The PECS approach involves a child giving a picture of a desired object to a communicative partner in exchange for that item. By doing this action, the child initiates a social and communicative exchange with a concrete, reinforcing outcome. Some of the many benefits of this approach include: 1) it can be used with very young and/or children with significant cognitive delay, 2) it emphasizes spontaneous communication with others, 3) it is taught using the visual modality, which is usually a strength for children with ASD, and 4) it is easily generalized across settings and people. Although some people believe that PECS reduces the likelihood of a child using verbal speech, in fact, the opposite is true according to research findings. When a child begins to communicate by using a picture exchange system and the verbal label is paired with the desired item, the child will, over time, usually decrease dependence on the picture and express himself/herself verbally with the label of the desired item.

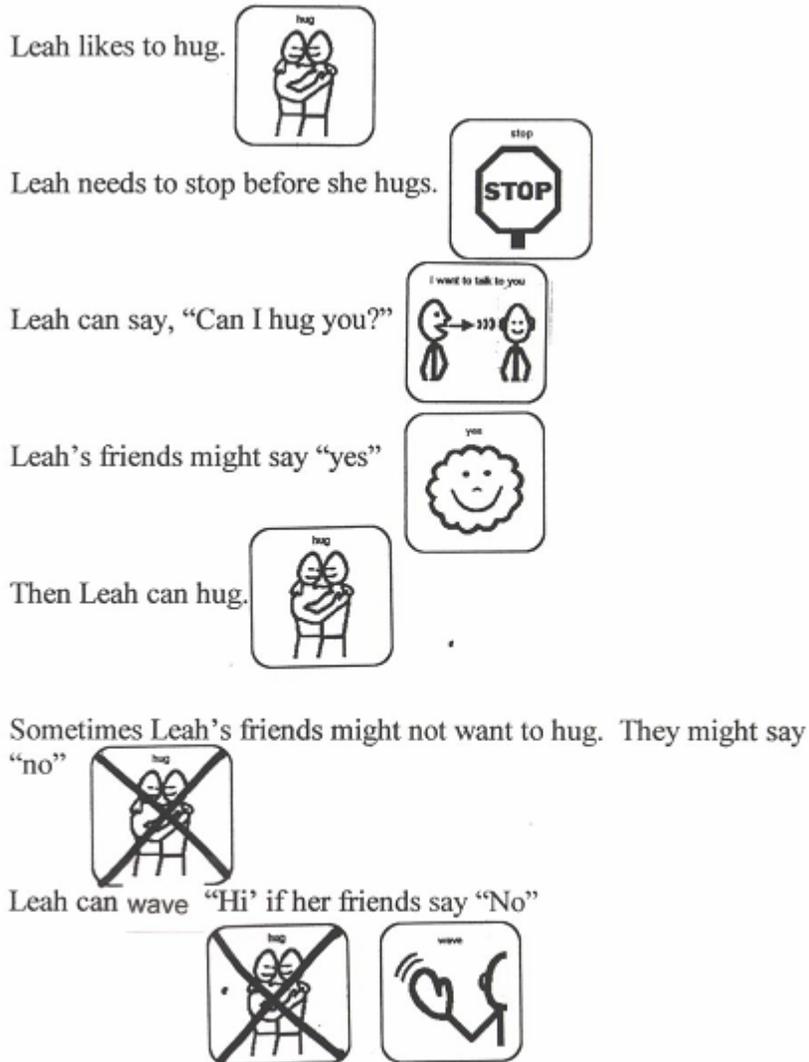
Example: Suzi gains access to objects by grabbing them. The therapist shows Suzi a picture of her favorite object, which is a videocassette case. The therapist puts the picture cue in front of the videocassette case. When Suzi reaches for the case, the therapist guides her hand towards the cue and Suzi picks up the picture cue. The therapist places her open hand next to the cue and assists Suzi to release the picture cue into her open hand. Suzi is immediately given the videocassette case.

Social Stories

Social stories were initially designed by Carol Gray. Social stories are meant to describe any situation, through pictures and/or words, that may require the child to pick up on relevant social cues and/or give correct responses. They can be targeted for specific social skills and can often help children with ASD adapt to changes in routine. Social stories are designed to describe a situation (who, what, where, when) with a description of desired behavior and/or acceptable coping strategies that can be used by the child. It is important to develop a social story at an appropriate developmental level for every child (i.e., a child with ASD who is reading words may not need pictures, etc.) They are written in present tense and should include 2 to 5 descriptive and/or perspective sentences for every one directive statement. The strength of this approach for teaching children with ASD is that it is geared to address abstract or difficult social situations and gives the information (i.e., visual and/or verbal) in a manner that the child can understand. Some limitations of this approach

are that it can be time-consuming and that it is often used for behavior management instead of its intended purpose.

Example:



Summary

Autism spectrum disorder affects as many as 1 in 500 persons throughout the United States. Providing effective and intensive early intervention services for young children with ASD is a daunting task. There are multiple interventions that have been shown to make dramatic improvements in the lives of children with ASD. The field of applied behavior analysis has given us many of these strategies, such as discrete trial training, pivotal response teaching, and using functional routines within structured teaching. In addition, social stories and the picture exchange communication system have provided children with ASD the opportunity to receive information and communicate with others in a way that makes sense to them. Reinforcement is critical in implementing any of these strategies and should be individualized. Providing supports such as visual schedules and environmental structure are also important in providing a comprehensive program for each child.

Intervention with young children with ASD involves an understanding of how their sensory systems impact their ability to relate to the environment. An effective program takes into account how sensory issues and communication skills account for the types of behavior that we see in young children with ASD.

Early intervention providers and educators need increased support through training, technical assistance and consultation at a state and local level to effectively address these difficult issues. Issues related to autism spectrum disorder require intensive intervention and coordination among all people involved in a young child's life. By working together, we can effectively shape New Mexico's future in how we serve children with ASD and their families.

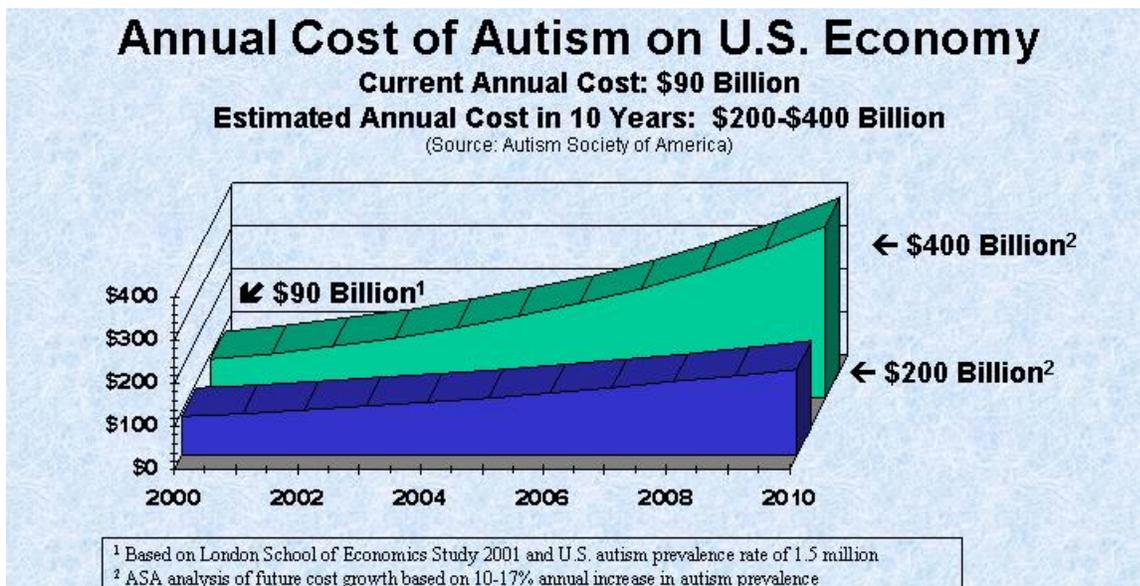
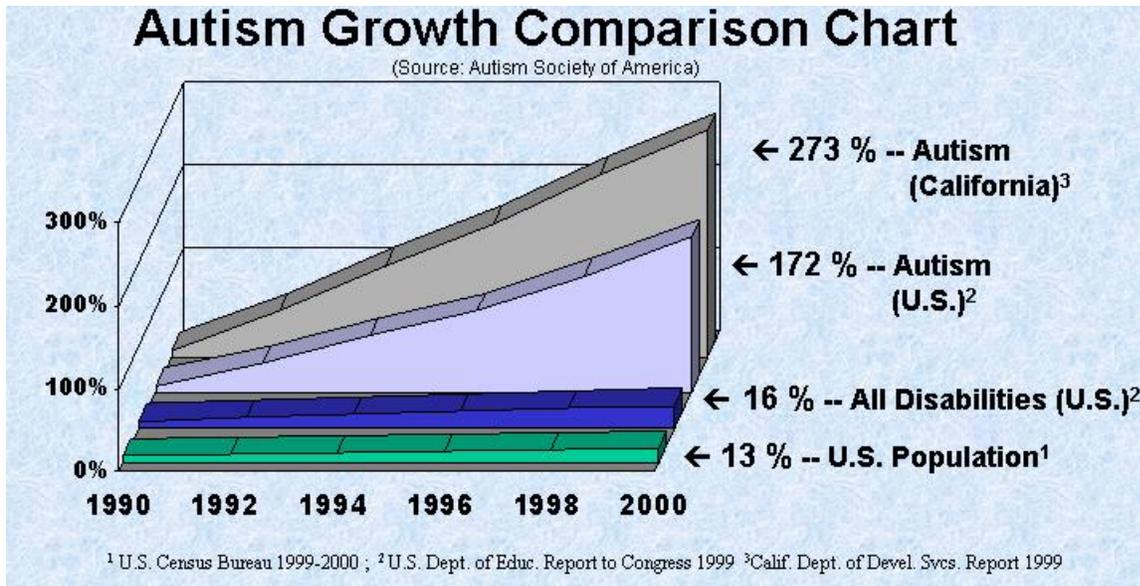
It has been demonstrated through scientific research that children with ASD will not gain skills without this degree of intervention (Sheinkopf & Siegel, 1998). New Mexico early intervention providers and local education agency - preschool program will be challenged to meet the intensive engagement hours that have been demonstrated to be effective with children with autism spectrum disorder. Communities will have to work together across disciplines and agencies in order to meet the individualized needs of children and their families. Plans therefore will need to address health care, behavioral health, family support and training, as well as the family's need for respite.

In addition, New Mexico continues to be challenged to ensure an adequate number of qualified early childhood personnel trained specifically in teaching children with ASD. New Mexico is moving ahead with training for both early intervention and early childhood education personnel.

It is important that New Mexico addresses the growth and cost of providing appropriate services to children with ASD if we are to avoid the pitfalls that other

states have experienced, such as costly due process litigation and contentious relationships.

The growth of ASD nationally has increased to an alarming rate of 172%, compared with just 16% for all other disabilities. In addition, the projected cost of ASD to the US economy will be from 200 to 400 billion dollars, compared with 90 billion at the present time. The children and families of New Mexico deserve access to high quality, intensive interventions for ASD. The starting point has to be with the early intervention and early childhood programs throughout New Mexico.



Appendix A

The Modified Checklist for Autism in Toddlers (M-CHAT): An Initial Study Investigating the Early Detection of Autism and Pervasive Developmental Disorders
Diana L. Robins, Deborah Fein, Marianne L. Barton, and James A. Green

M-CHAT

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

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

Contact the authors for more information on receiving copies of the English or Spanish M-CHAT.

Appendix B

Diagnostic Criteria for Autism Spectrum Disorders

Autistic Disorder (299.0)

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - a) Marked impairment in the use of multiple, nonverbal behavior, such as eye to eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b) Failure to develop peer relationships appropriate to developmental level
 - c) A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d) Lack of social or emotional reciprocity
 2. Qualitative impairment in communication as manifested by at least one of the following:
 - a) Delay in, or total lack of, development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime)
 - b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c) Stereotyped and repetitive use of language or idiosyncratic language
 - d) Lack of varied, spontaneous make believe play or social and imitative play appropriate to developmental level
 3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b) Apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping, twisting, or complex whole body movements)

- d) Persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder

Rett's Disorder (299.80)

- A. All of the following:
 - 1) Apparently normal prenatal and perinatal development
 - 2) Apparently normal psychomotor development through the first 5 months after birth
 - 3) Normal head circumference at birth
- B. Onset of all of the following after the period of normal development:
 - 1) Deceleration of head growth between ages 5 and 48 months
 - 2) Loss of previously acquired purposeful hand skills between 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand wringing or hand washing)
 - 3) Loss of social engagement early in the course (although often social interaction develops later)
 - 4) Appearance of poorly coordinated gait or trunk movements
 - 5) Severely impaired expressive and receptive language development with severe psychomotor retardation

Childhood Disintegrative Disorder (299.10)

- A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play and adaptive behavior.
- B. Clinically significant loss of previously acquired skills before age 10 years in at least two of the following areas:
 - 1) Expressive or receptive language
 - 2) Social skills or adaptive behavior
 - 3) Bowel or bladder control

- 4) Play
- 5) Motor Skills

C. Abnormalities of functioning in at least two of the following area:

- 1) Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity.
- 2) Qualitative impairment in communication (e.g., delay or lack of spoken language, inability to initiate or sustain conversation, stereotyped and repetitive
- 3) Restricted, repetitive and stereotyped patterns of behavior, interest, and activities including motor stereotypes and mannerisms.
- 4) The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

Asperger's Disorder (299.80)

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

- 1) Marked impairment in the use of multiple nonverbal behaviors, such as eye to eye gaze, facial expression, body posture, and gestures to regulate social interaction.
- 2) Failure to develop peer relationships appropriate to developmental level
- 3) Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing or pointing out objects of interest to other people)
- 4) Lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behaviors, interests and activities, as manifested by at least one of the following:

- 1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in either intensity or focus
- 2) Apparently inflexible adherence to specific, nonfunctional routines or rituals.
- 3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
- 4) Persistent preoccupation with parts of objects

- C. The disturbance causes clinically significant impairment in social, occupational or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years.)
- E. There is no clinically significant delay in cognitive development or in the development of age appropriate self help skills, adaptive behavior (other than in social interaction,) and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism) (299.80)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairments in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes “atypical autism” presentations that do not meet the criteria for Autistic Disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Appendix C

Basic Skills Needed by Young Children with Autism Spectrum Disorder (ASD)

Behavioral Control

- *Command Compliance*
- *Task Compliance*

Attention Skills

- *Ability to attend to and makes sense of:*
 - *Individual Stimuli*
 - *Relevant Stimuli*
 - *Familiar adults and children*
 - *Other adults and children*
 - *Speech*
 - *Gestures*
- *Ability to shift attention from one person/item/activity/input to another*
- *Ability to attend to more than one stimulus at a time*
- *Demonstration of joint attention to person and object*

Imitation Skills

- *Motor*
- *Verbal*
- *Social*

Language Skills

- *Understands:*
 - *The function and power of communication*
 - *A few familiar verbal commands*
 - *Representational meaning*
 - *Visual system*
 - *More verbal or visual commands*
- *Functions:*
 - *Request*
 - *Protest*
 - *Call for attention*
 - *Make choices*
 - *Ask for help*

- *Label*
- *Greet spontaneously*
- *Comment*

Social Skills

- *Awareness of others*
- *Physical proximity*
- *Turn-taking*
- *Models behavior of others*
- *Ongoing back and forth interactions*
- *Initiation of social interaction*

Play Skills

- *Awareness of materials and activities*
- *Appropriate play with toys*
- *Expansion of areas of interest*
- *Participation in imaginative/symbolic play*
- *Participation in interactive/reciprocal play*
- *What objects in the environment does he/she gravitate toward?*
- *Toy use - Appropriate or idiosyncratic*
- *Non-toy use - Appropriate or idiosyncratic*
- *How long does he/she stay with an object or activity in play?*
- *What does he/she do with a new toy?*
- *Does his/her play indicate potential reinforcers?*

Attention Skills Questions

- *What is the child's range of attention span?*
- *What items/activities does he/she attend to longest?*
- *What items/activities does he/she attend to briefly?*
- *Does he/she pay attention to talking? To verbal directions? To gestures? To modeling of an action?*

Communication Questions

- *Does he/she use single words, phrases, sentences?*
- *Does he/she seem to understand what is said?*
- *Does he/she respond to questions that are yes/no?*
- *Does he/she respond to why, what, where, when, or who?*
- *Does he/she respond to open-ended questions?*
- *Does he/she request, protest, comment, call attention, ask for help?*

Organization/Orientation in Space

- *What does he/she do with his/her body?*
- *How long does he/she stay in one position?*
- *How long does he/she stay still?*

Organization in the Environment

- *Does he/she do better in some places than others?*
- *Does he/she do better in some circumstances than others?*

Modified from training information, Project SET, 2003

Appendix D

Sample Educational Outcomes/Goals for Young Children with ASD

Social Skills

Proximity - Tony will accept proximity of others within 2-5 feet, without escape during home and school activities with support.

Non-verbal turn-taking - With an 1) adult, 2) peer, Andrew will participate in 3 turn taking exchanges during motivating activities, 3 out of 4 opportunities over 2 weeks.

Responding to social initiation - With an 1) adult, 2) peer, John will acknowledge a social initiation (i.e., wave, "Hi", "bye") with eye gaze, wave, and/or verbalization, 3 out of 4 opportunities over 2 weeks.

Functional Communication

Requesting

Mary will point to request a desired item in the environment, 3 out of 4 opportunities over a two-week period.

Juan will request using a single picture exchange for desired items, 3 out of 4 opportunities over a two-week period.

Michele will use a functional sign (i.e. more, finished) to request continuation or completion of an activity, 3 out of 4 opportunities over a two week period.
Lonnie will verbalize to request a desired item or activity, 3 out of 4 opportunities over a two-week period.

Expressive Language

Mary will verbally request or reject items or activities in the environment 3 out of 4 opportunities over a 2-week period.

Claire will request using a PECS constructed sentence (i.e., "I want____") for desired items 3 out of 4 opportunities over a two-week period.

Receptive Language

Mary will follow familiar and unfamiliar one step directions, 3 out of 4 opportunities, over a two-week period.

Tom will answer simple questions (what, where) from staff and/or peers, 3 out of 4 opportunities, over a two-week period

Play Skills

Michael will participate in functional cause and effect play activities during free time, 3 out of 4 opportunities over a two-week period.

John will participate in object and/or action imitation (i.e. trains, songs) with 1 adult, 2 peers, involving sequencing of a routine, 3 out of 4 opportunities over a two week period.

Evan will participate in facilitated, symbolic play activities during free time, 3 out of 4 opportunities over a two-week period.

Pre-Academics

Joan will transition, during home and school activities, with visual supports, transition objects and routines, 3 out of 4 opportunities over a two week period.

Tony will sequence a three-step activity with visual supports, 3 out of 4 opportunities over a two-week period.

Johnny will independently use an individual visual schedule to make transitions throughout the day, 3 out of 4 opportunities over a two-week period.

Appendix E

Case Studies

Jesus - 2 years, 8 months

Jesus has been in services for the past five months, receiving a one hour home visit a week by a developmental specialist, an hour of speech therapy in the home per week and a half hour visit, once a week by an occupational therapist. So far, there has been little to no progress noted by the team.

Jesus can be characterized as primarily self-directed, with frequent avoidance of social situations, task demands, or communication with others. He spends much of his time running back and forth from the couch to the TV while watching his favorite video, Bob the Builder. In addition, his parents report that he spends much of his time seeking out activities such as swinging, jumping from tall objects, and "crashing into things."

Jesus's communication is characterized primarily by whining or crying when he does not receive a desired item, pushing people out of his space when they attempt to interrupt his gross motor play, and having frequent meltdowns around transitions. He has no functional verbal language or gestures and does not appear to hear when you are talking to him. Sometimes when Jesus gets upset, he will bite his wrist. His parents state that this generally occurs around transitions, when he is asked to follow a direction, or over stimulating situations.

His parents continue to ask the providers how to deal with his behaviors, and feel that Jesus is generally just being stubborn. They state that "he really understands what they want; he just doesn't want to do it. You know, he's just being a typical two-year old." They have gone along with early intervention services, mainly because of pressure from a family friend. They feel that he may have some slight delays, but the majority of his problem is just behavior. They feel that as he matures, he will grow out of some of his difficult behaviors and his language and social interaction will improve.

A team meeting is scheduled with his parents to discuss goal planning, the lack of progress, and the need for further evaluation to prepare for his transition to the three and four year old program.

Suggestions for talking with Jesus' family:

- Discuss *specific* behaviors to help the family see that Jesus is showing *differences* in his development as well as delays

- Discuss Jesus's behaviors in terms of his learning style being different than other children
- Allow the family to process information and suggest further evaluation by a team qualified to look at Jesus's behaviors in terms of ASD
- Do NOT say that you think Jesus has ASD
- Discuss lack of progress in terms of how it forces the team to look at other possible interventions, evaluations for other possible diagnoses
- Acknowledge that some of Jesus's behaviors may be related to stubbornness, but that there may also be differences in terms of how he processes information

Kaitlyn - 3 years, 2 months

Kaitlyn has received services for 3 months. She receives two home visits a month from a developmental specialist, two visits a week for a half an hour from an SLP at a center based program, and twice monthly home visits from an OT. So far, there has been little to no progress reported by the team.

Kaitlyn can be characterized as generally self-directed, although she has demonstrated an emerging understanding of contingency (i.e., first this, then that). She spends much of her time engaged in solitary, stereotypic play with Pooh figures. Her parents report that Kaitlyn has times where she will seek out sensory input from others by pushing her head into their midsection. At other times, they report that Kaitlyn would spend hours swinging outside if allowed to do so. They state that some days she is unreachable when engaging in these activities, whereas other days, she can come out of them rather easily.

Her communication is primarily verbal single words or short phrases that are usually functional, to make a request. She will respond socially in situations that make sense to her, such as saying "Hi" and "Bye" to people. Her mother reports that it seems like Kaitlyn communicates better after having periods of gross motor play, but that sometimes, she is just "stubborn." Her parents are concerned about some of her behaviors, such as grabbing items from others, pushing away her 4 year old brother when he gets too close to her, and a high-pitched squeal that surfaces when she is told "No."

A team meeting is scheduled to discuss her lack of progress, goal planning, and the possibility of bringing her into a preschool classroom setting for several days a week. As a part of this possible transition, the EI team is meeting with the 3 and 4 year old staff to discuss strategies. What do you suggest?

Suggestions for talking with Kaitlyn's family:

- Discuss pros and cons of bringing her into a preschool classroom setting
- Discuss lack of progress in terms of *differences* that you are seeing in *specific behaviors*, not just general feelings by the staff

- Discuss her sensory and communication difficulties in terms of her different learning style and ways that she processes information
- Discuss the need for further evaluation in order to help her more effectively
- Do NOT say that she has ASD

Daniel - 4 years, 4 months

Daniel has been receiving services from the public school system for the past year after being diagnosed with ASD at age 3 years, 4 months. During this time, the school staff has noted many improvements in Daniel's communication, social interactions and transitioning ability.

Daniel currently goes to a three day preschool for four hours a day. At preschool, he receives speech therapy and occupational therapy services in the classroom for an hour a week. In addition, he receives outpatient speech and occupational therapy through private insurance, twice weekly for an hour each in co-treating sessions.

Daniel primarily uses three and four word phrases and sentences to express his wants and needs. He does little commenting or protesting verbally, and usually resorts to non-verbal communication when stressed. Because he is verbal, the staff has been reluctant to use PECS, feeling that it might prevent him from progressing in terms of his verbal communication. Daniel can follow familiar and unfamiliar one step directions and familiar two step directions with minimal to moderate visual cueing.

The school staff has noticed that Daniel has started to engage in escape behaviors during circle time and snack time. They are concerned because he is not able to verbalize his problems, and instead acts out by hitting and pinching other children and staff. When redirected to another environment, he calms quickly, but refuses to reenter the activity.

The school staff states that they try to reason with Daniel during these times, but he just "doesn't seem to hear us." A team meeting is planned with the outpatient SLP and OT and the school staff and therapists. What do you think should be the focus of the meeting?

Suggestions for talking with Daniel's family:

- Discuss Daniel's strengths and how that should drive intervention
- Discuss Daniel's needs in terms of a different learning style
- Discuss the need for further evaluation
- Do NOT say that Daniel has ASD
- Discuss that just because Daniel is verbal, does not mean that he always is able to process verbal information in a meaningful way
- Discuss alternative strategies (i.e., visual supports) in the classroom to help him process information more effectively

Frequently Asked Questions

What causes autism?

At this time, there is no known cause for autism. Most experts believe that there is a genetic basis for the disorder.

Is there a 'cure' for autism?

There is no cure for autism, however, with intensive intervention, children with autism are much more likely to have success later in life. As children grow and develop, so does their autism. As adults, they have often learned coping skills to help address their difficulties associated with this disorder.

How young can a child be diagnosed with autism spectrum disorder?

Although previously it was believed that children under three years of age could not be diagnosed, we now have the ability to accurately diagnose children under the age of two due to a better understanding of behavioral characteristics associated with ASD.

My child is two and a half and doesn't speak, will he ever talk?

Although there are no definitive statistics regarding this issue, most children with ASD develop some level of meaningful verbal communication during their lifetime.

What therapy services will my child benefit from?

An individualized plan will be developed that will detail the services and supports that are unique for your child and family. Speech therapy, occupational therapy, physical therapy and sensory integration therapy and developmental instruction are generally believed to be appropriate services for children with ASD. Hippotherapy has been effective for some children with ASD, as well as some specific diet therapies. Each child with ASD is different, so not all therapies will be effective for every child.

How much therapy does my child need?

The national recommendation is for 25 hours of 'engagement', which is the time your child maintains attention to an activity or a person that promotes learning. You and your IFSP/IEP will decide on the when and where your child will receive the engagement they need. This will likely vary from child to child depending on their

age, their autistic symptoms, how they are progressing, their tolerance for the intervention, as well as on your family situation.

If my child uses pictures to communicate, won't this prevent verbal communication?

In fact, research from years of picture communication systems, such as PECS, has proven just the opposite. Pictures often serve as a bridge for later verbal communication. Attaching a verbal label to a picture often helps children with ASD associate words with objects, leading later on to verbal communication. When a child learns the words for meaningful objects, they often start to communicate more verbally, because it is faster and easier than exchanging a picture to get their needs met.

Which approach is the best for intervention with my child with ASD?

There is no one approach that is successful for every child with ASD. Generally speaking, a combination of different approaches is usually most effective. Some effective approaches for teaching children with ASD include PECS, TEACCH, discrete trial training, pivotal responses training and structured teaching.

Does my child need to be in a group setting with other children, or should I just have her just receive individual intervention / therapy until she gets older?

Although every child with ASD is unique, there is often a benefit to having a child engaged in a program with other children, even at a young age, for at least a portion of her intervention. Individual intervention / therapy is important, and may often help a child reach a level of functioning that enables her to benefit from a group or preschool classroom setting.

Should my child with ASD be on medication to help with behavior?

Most behaviors are directly related to communication and/or sensory difficulties. It is usually more effective to address behavior through teaching strategies. Medication may be helpful for some children in some cases, usually in addition to behavioral therapies.

How long will a person with ASD live?

People with ASD have the same life expectancy as people without autism.

How do I discipline my child with ASD?

It is important to remember that children with ASD process information differently. Often, using visual supports can help a child process information more effectively.

Making sure that your child understands what is expected of him/her is important in considering discipline.

Should I treat my child like I would a typical child?

A child with ASD is not a typical child, so he/she needs to be treated with his/her differences in mind. He/she will need additional support and intervention in order to learn, however, it is still important to have hopes and goals for your child.

How do I explain my child's disability to their sibling(s)?

Probably from a position of "This is how ___ understands the world or his/her environment." Kids don't need to know diagnosis. Brothers and sisters like to know how they can support their sibling's learning. Siblings like to be involved but shouldn't be made to feel responsible.

How do I deal with my concerns that I am not doing enough for my child with ASD?

Parents can often feel overwhelmed after a diagnosis of ASD for their child. It is important to remember that you are a parent FIRST, and a teacher AT TIMES. Sometimes parents feel intimidated or inadequate. It is important to remember that you know your child best and others in your intervention team need to hear what you have to say. Do not feel intimidated because you may not be trained in a specific area of intervention. The support that you as a parent provide along with other intervention / therapy is extremely important.

Where can I go for support?

Parents often find it helpful to talk to other parents of children with ASD. It can be reassuring to know that other parents are feeling some of the same things you are or are dealing with some of the same issues. The following organizations (listed in the Resources section) can help connect you with other parents of children with ASD: the SouthWest Autism Network; Parents Reaching Out (PRO); and Parents of Behaviorally Different Children (PBDC). You can contact with other parents over the phone, through e-mail or in person.

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Resources

The following is a list a New Mexico and national resources related to children with ASD.

<p>The Autism Research Institute (ARI) 4182 Adams Avenue San Diego, CA 92116 Voice 619-281-7165 Fax 679-563-6840 www.autism.com/ari</p>	<p>A hub of a worldwide network of parents and professionals concerned with autism. ARI conducts and fosters scientific research designed to improve the methods of diagnosing, treating, and preventing autism.</p>
<p>Autism Society of America 7910 Woodmont Avenue, Suite 650 Bethesda, MD 20184-30315 1-800-3-autism www.autism-society.org</p>	<p>A leading source of information and referral on autism. Today, over 20,000 members are connected through a working network of over 200 chapters in nearly every state.</p>
<p>Cure Autism Now 5455 Wilshire Blvd., Suite 715 Los Angeles, CA 90036 1-888-8AUTISM www.cureautismnow.org/</p>	<p>An organization of parents, physicians, and researchers, dedicated to promoting and funding research with direct clinical implications for treatment and a cure for autism.</p>
<p>Early Childhood Evaluation Program Center for Development & Disability University of New Mexico 1-800-337-6076 (toll free) 505-272-2756 (Albuquerque)</p>	<p>Information on interdisciplinary team evaluations for children eligible for early intervention services.</p>
<p>Family Infant Toddler Program (FIT) Long Term Services Division New Mexico Department of Health 1-877-696-1472 (toll free) www.health.state.nm.us/ltsd/fit</p>	<p>Information regarding early intervention services for children birth to age three and their families in New Mexico.</p>
<p>Families for Early Autism Treatment (FEAT) P.O.Box 255722 Sacramento, California, 95865-5722 (916) 843-1536 www.feat.org/</p>	<p>An organization of parents and professionals, designed to help families with children who have received the diagnosis of Autism or Pervasive Developmental Disorder (PDD NOS).</p>

<p>LINC (Library and Information Network for the Community) University of New Mexico 1-800-827-6380 (toll free) or 505-272-0281 (Albuquerque)</p>	<p>Information on the largest collection of autism books, videos and other resources in New Mexico.</p>
<p>Long Term Services Division Developmental Disabilities Programs 1-877-696-1492 (toll free) www.health.state.nm.us/ltsd</p>	<p>Information about the New Mexico Developmental Disabilities Waiver, respite and other services and supports for families of children with autism.</p>
<p>New Mexico Autism Society 505-332-0306 (Albuquerque) www.nmautismsociety.org</p>	<p>State chapter of Autism Society of America; provides a forum to meet other family members. Group meets monthly which includes an educational program.</p>
<p>OAR - Organization for Autism Research 2111 Wilson Boulevard, Suite 600 Arlington, VA 22201 (703) 351-5031 http://www.autismorg.com/</p>	<p>An organization formed and led by parents and grandparents of children and adults with autism.</p>
<p>Parents for Behaviorally Different Children 1-800-273-7232 www.pbdconline.org</p>	<p>An organization formed by families of children and adolescents with neurobiological, emotional and behavioral differences that provides advocacy, support and training.</p>
<p>Parents Reaching Out 1-800-524-5176 (toll free) or 505-247-0192 (Albuquerque) www.parentsreachingout.org</p>	<p>A statewide parent organization that provides parent training, information and referral, advocacy and parent-to-parent support.</p>
<p>Public Education Department Special Education Bureau 505-827-6541 www.ped.state.nm.us/seo</p>	<p>Information regarding preschool and kindergarten and elementary school special education services.</p>
<p>SouthWest Autism Network 1-800-270-1861 (toll free) or 505-272-1852 (Albuquerque) To access Project SET directly (505) 272-3012 (Albuquerque)</p>	<p>Information about Autism Diagnostic Clinic, resources, family support, and training information. Project SET also provides technical assistance to IFSP and IEP teams for young children with ASD</p>

GLOSSARY

ASA (Autism Society of America) - organization dedicated to providing people with autism and their families with information and support.

ASD (autism spectrum disorder) - spectrum of disorders involving a variety of diagnoses and functioning levels that includes PDD/NOS, Asperger's Disorder, Autistic Disorder, Rett's Disorder and Childhood Disintegrative Disorder.

Asperger's Disorder - disorder characterized by autistic behaviors, but differs in that language development is generally seen as more typical with no clinically significant delays.

Autistic Disorder (sometimes referred to as early infantile autism, childhood autism or Kanner's autism) - disorder characterized by markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests manifested before age 3.

Childhood Disintegrative Disorder (also called Heller's syndrome, dementia infantilis or disintegrative psychosis) - disorder characterized by marked regression in multiple areas of functioning following a period of at least two years of apparently normal development.

Child-initiated teaching - methods of teaching that involves a teacher reading a child's motivations and/or cues in order to determine what to teach and how to reinforce.

Discrete Trial Training - a teacher directed method of teaching that involves three distinct components, an antecedent (such as an instruction, "do this"), a behavior (whatever act the child performs immediately after the instruction), and a consequence (positive, negative reinforcement from the trainer).

Discriminative Stimulus (Sd) (also called the antecedent or instruction) - information provided by the trainer to the student to perform a certain behavior.

Dysmorphology - a branch of clinical genetics concerned with the diagnosis and interpretation of patterns of three types of structural deficits - malformation, disruption, and deformation.

Engagement - is the time the child sustains attention to an activity or a person that promotes learning.

Echolalia - repetition of speech. There are two forms of echolalia, immediate and delayed. Immediate echolalia occurs when a child repeats the speech and often the

tone and cadence of another person right after it occurs. Delayed echolalia occurs, for example, when a child repeats speech heard from movies, TV, etc., long after it has occurred.

Functional routines - routines that are meaningful to the child and family and occur naturally within the home or school settings.

Generalization - transfer of skills taught in a particular environment to a wide variety of other environments.

Hypersensitivity - heightened sensitivity to one of the senses beyond that which would be exhibited by neurotypical persons.

Hyposensitivity - decreased sensitivity to one of the senses below that which would be exhibited by neurotypical persons.

IEP - Individualized Education Plan - plan specifically designed for a child over age three that addresses the individual learning styles and unique developmental challenges for that child in a variety of developmental areas.

IFSP - Individualized Family Service Plan - plan that involves the child under age three, the family and the service providers to meet specific outcomes/goals set forth by the IFSP team to help improve the functioning levels of the child and the family in a variety of developmental areas.

Incidental Teaching - a method of teaching that involves a teacher capitalizing on a teachable moment, where a child is engaged with a desired object (i.e. when a child is playing with Pooh on the slide, teaching the child the words to go with the actions, "up", "down").

Inclusion - process of including students with disabilities with typically developing peers in order to maximize learning potential.

Naturalistic teaching - methods of teaching that involve capitalizing on activities that a child is motivated by and engaged in to teach a variety of skills and concepts.

PDD/NOS - disorder with severe and pervasive impairment of development of reciprocal social interaction or verbal and non-verbal communication or stereotyped behaviors, but the criteria are not met for a specific pervasive developmental disorder, sometimes called atypical autism.

PECS (Picture Exchange Communication System) - a method of teaching communication that involves an exchange of a picture in order to obtain a desired object or activity.

Peer Mediation/Coaching - a method of “coaching” of typically developing peers to help increase the social, language or play skills of children with autism.

Pervasive Developmental Disorders - disorders characterized by severe and pervasive impairments in reciprocal social interaction skills, communication skills, and the presence of stereotyped behavior, interests and activities.

Pivotal Response Training - a child initiated method of teaching that involves teaching a child a pivotal behavior that will have a wide effect on a variety of other behaviors (i.e., teaching a child to say “Look” and point when an item is desired.)

Project SET - (Specialized Early Teaching for young children with autism)- UNM/SWAN project that is funded by the New Mexico State Department of Education and the Department of Health Family Infant and Toddler Program to provide training, technical assistance and consultation to providers and families for children with ASD throughout New Mexico from birth to age 5.

Reinforcement - any object, activity or act that is designed to have a positive effect on a child’s behaviors.

Rett’s Disorder - disorder marked by the development of multiple specific deficits (i.e. stereotypic hand movements, such as hand wringing or washing) following a period of normal functioning after birth to 5 months of age.

Sensory Integration - the integration of information perceived by the senses into messages to the brain and body.

Social Stories - method of teaching that involves a description of a situation through pictures and/or words to help make abstract concepts more concrete.

Structured teaching - a strategy that attempts to understand the unique learning challenges of a child and to develop environmental supports to help compensate for these challenges.

SWAN (Southwest Autism Network) - UNM programs housed at the Center for Development and Disability that provides support and information for people with autism and their families. Several programs comprise the Southwest Autism Network, including Project SET, Family and Community Education in ASD, Autism Diagnostic Clinic and fee for service training and consultation.

Teacher-directed teaching - methods of teaching that involves the teacher deciding what will be taught and what will be used for reinforcement (i.e., discrete trial training.)