STATE OF NEVADA, DIVISION OF HEALTH
BUREAU OF EARLY INTERVENTION
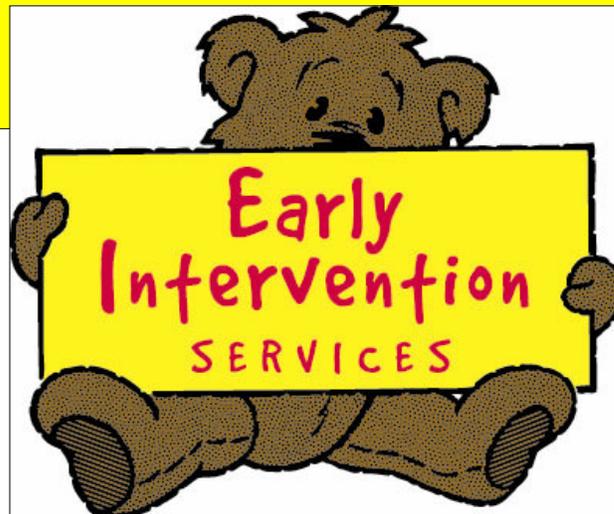SERVICES DRAFT 1/6/06

Serving Children with Autism
Effective Practice Guidelines

Nevada

Effective Practice Guideline Modules Include:

- Service Coordination
- IFSP Development
- Screening and Monitoring (SAM)
- Evaluation and Eligibility
- Transition
- Serving Children with Autism

Module 6

Introduction

Serving Children with Autism: Effective Practice Guidelines" is the product of collaboration between professionals and parents with knowledge in the field of Autism Spectrum Disorders (ASD). These guidelines provide detailed information to assist in the preparation and implementation of services for children with ASD. Delivery of Nevada Early Intervention Services (NEIS) is based on the unique and individualized needs of the family and child with ASD. Research has shown that appropriate early intervention for children with ASD is critical in minimizing the impact of the development delays associated with this disorder and obtaining successful outcomes. The guidelines in this document will provide both professionals and parents with information on best practices for ASD.

Receiving and understanding information about the nature of ASD and the IFSP process is key to informed decision making by the family. When parent education and training are integral parts of the early intervention process, progress is facilitated and gains are maintained. Family involvement is also a crucial component of the natural support system for children with ASD. In fact, appropriate early intervention services and knowledgeable parents may provide long term benefits for children with ASD, and may reduce the lifetime costs for serving this population. Implementing these sound practices will empower families and enable children with ASD to live up to their potential.

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University of Nevada, Las Vegas
Dr. Matt Tincani, Ph.d
Dr. Amanda Boutout, Ph.d

Technical Assistance Organizations
Stephen Hidalgo, WRRC

Parents
Toni Richard
Flo LaRoy
Jan Crandy

Nevada Department of Education
Dr. Keith Allred, Ph.d.

Nevada Division of Health Care Policy and Finance
Janet Serial-Onosigho

Nevada Division of Mental Health & Developmental Services, Sierra Regional Center
Dr. David Luke, Ph.d
Dr. Don Jackson, Ph.d

Nevada Early Intervention Services South
Judy Austin - SLP
Mike Mikkelsen - PDC
Fatima Taylor - DS
Tiffany Kostelec - DS

Nevada Early Intervention Services North/Rural
Erika Winkler - SLP
Jan Marson - OT
Tomeko Young - DS
Charmaine Rickard - DS
Dr. Lynn Kinman, MD
Randy Figurski - SLP
Pam Drawver - DS
Maureen DeLongis - DS

Nevada Bureau of Early Intervention Services
Connee McCasland
Jessica Medulla
Wendy Whipple

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California Dept. of Developmental Services

Connecticut Birth to Three System

Maine Administrators of Services for Children with Disabilities

New Jersey Early Intervention System

Table of Contents

DEFINITION OF AUTISM SPECTRUM

Throughout this document we will refer to Autism Spectrum Disorders (ASD). This broadly refers to a pattern of behaviors involving three core features – atypical social relatedness, verbal and nonverbal communication and repetitive activities and/or unusual interests such as rituals, stereotyped actions and poor play skills that present before age 3. Although this pattern can vary widely in terms of symptom expression and degree of impairment, the core features are present in each case.   (California Department of Developmental Services, 2002)

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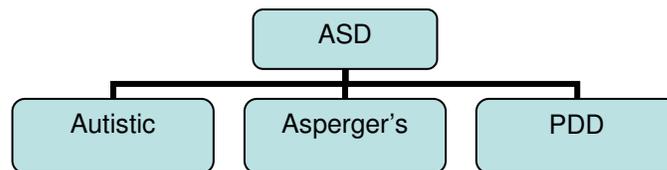
Early intervention providers may note that a child has, "characteristics that are consistent with the definition of autism". There is a continuum of characteristics that may manifest themselves and change over the course of a lifetime. ASD is actually a group of disorders and may occur concurrently with other disorders. This document will define principles and protocol to follow when characteristics of ASD present.

Identifying Characteristics of ASD include:

1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture of mime).

2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.

3. Stereotyped and repetitive use of language or idiosyncratic language.

4. Impairment in the use of multiple nonverbal behaviors such as pointing, eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

5. Lack of varied, spontaneous, make-believe play or social imitative play appropriate to developmental level.

6. Unusual reaction to perceptual stimuli, such as seeming not to hear certain sounds and overreacting to others (e.g., holding hands over ears or "looking through" objects), poor eye contact, or inability to perform certain gross and/or fine motor activities (e.g., walking with peculiar gait, limpness in fingers, inability to hold a pencil appropriately).

7. Extreme distress for no discernible reason because of minor changes in the environment.

8. Lack of intellectual development or delay in certain areas, sometimes accompanied by typical or superior abilities in other areas.

9. Repetitive and peculiar use of toys and objects in an inappropriate manner and/or similar repetitive and peculiar body motions, such as incessant rocking.

10. Impairment or complete lack of relatedness; social inaccessibility to children, parents, and others; lack of social and emotional reciprocity.

11. 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).

12. Hyperactivity or passivity.

13. Short attention span and impulsivity.

14. Apparent insensitivity to pain.

15. Onset of disorder at birth or apparent typical early development followed by deterioration in functioning.

(Rutland Center, Athens, GA (1983); American Psychiatric Association (DSM-IV) (1994))

PRINCIPLES OF INTERVENTION FOR YOUNG CHILDREN WITH AUTISTIC SPECTRUM DISORDER

Principle 1
Early Identification and Intervention is Important

This includes screening, determining eligibility for early intervention services, program planning, and assessment for treatment, conducted by a multidisciplinary team of professionals trained and experienced in the field of Autism. Professionals should not underestimate the importance of a home visit when evaluating a child for an Autism Spectrum Disorder. The primary care physician is often minimally involved in this process and early intervention providers have an obligation to assist in making a diagnosis. Current literature suggests that ASD can be reliably diagnosed in children as young as age two, however, other studies caution against making a diagnosis prior to age three. This document will also address sensitivity issues when being the first entity to approach the subject that their child may have an Autism Spectrum Disorder with families and the appropriate follow-up with families after this concern has been voiced. An evaluation for ASD should provide a classification, as well as provide information about the strengths and learning challenges of the child. It should be helpful in planning for intervention.

This effective practice guide recommends assessment and intervention for families of children with suspected autism spectrum follow evidenced-based practices. The science of assessment and intervention informs us **how** we can move to change things, but the values of the individual, the family and community tell us **what** is worth changing. Family-centered planning is a process for including families in the assessment process and for identifying outcomes and implementing intervention plans based on family, cultural and community values.

The specific challenge for most families whose children are suspected or classified on the autism spectrum is lack of knowledge or misconceptions about the disorder and fear for the future. For this reason, it is critical that families be brought immediately into the process of assessment and intervention planning. The assessment teams attempt to determine the family's need for information about the disorder – even before the assessment is conducted – in order to assist the family in understanding the assessment process and the team's findings.

 The autism teams should work with families to determine their immediate priorities and concerns as well as their vision for their child's future (both short-term and long-term). Families may need information or other supports to become informed consumers of early intervention services. Autism teams need to be sensitive and supportive as families struggle to articulate their concerns. This means taking the time prior to the assessment and prior to developing intervention plans to engage the family in a conversation. This conversation is intended to lead to an assessment process that answers the family's important questions as well as decisions around classification and program planning. The conversation also begins the process of understanding the family's values, concerns and priorities in order to develop an intervention plan that meaningful.

Diagnosis Versus Classification
A diagnosis of autism can only be made by a licensed professional with appropriate training in Autism (e.g. psychologist, physician, licensed social worker, or speech pathologist with appropriate training) who is qualified under state law to make diagnoses.

Additionally, the child must meet the DSM-IV criteria for autism (American Psychiatric Association, 1994) in order for a diagnosis to occur. NEIS recognizes that many children younger than three who exhibit some of the characteristics of autism spectrum disorders do not meet the diagnostic criteria for autism. Moreover, some of the instruments used to make autism diagnoses are not validated for children younger than three. Because children who exhibit the characteristics of autism spectrum disorders, but do not meet the DSM-IV criteria may need immediate intervention, a classification of autism may be given. In contrast to a diagnosis, a classification simply means that the child exhibits the characteristics of autism. A classification of autism will be made according to the guidelines described below.

Components of a Classification Assessment
The components of an evaluation for ASD should include:

1. Relevant developmental, medical, and family history

2. An audiological evaluation

3. Assessment of social skills

    a. Joint attention

    b. Initiation of interactions with adults and peers

    c. Social imitation of adults and peers

    d. Imitation of play skills Verbal imitation

4. Assessment of communication

    a. Pre-language skills including eye contact and gestures

    b. Speech skills: Use of sounds and/or words

    c. Comprehension of language

    d. Functional use of language

    e. Expressive language skills

5. Assessment of interests, activities and play behaviors

6. Assessment of behavior challenges

    a. Presence of stereotypical behavior

    b. Presence of self-injurious behavior

    c. Reaction to transition or change

    d. Specific behavior concerns identified by the family

7. Assessment of the child's sensory profile including

    a.   Activity level

    b.   Reaction to touch, taste and smell

    c.   Reaction to auditory or visual input

    d. Reaction to movement

    e. State regulation (e.g. sleep)

8. Assessment of cognitive skills
   a. Imitation of actions/sounds/words
   b. Problem-solving

9. Assessment of adaptive skills
   a. Feeding skills
   b. Bathing/Dressing skills (personal hygiene)
   c. Sleeping habits

   10. Answers to specific family questions regarding their child's developmental and behavioral challenges.

The NEIS Transdisciplinary Assessment Teams

Best practices indicate that classification teams should be multi-disciplinary. The classification of autism is not required for eligibility. To that end, NEIS evaluation teams shall contain members from various disciplines. These individuals will be experienced in the use of current tools appropriate to the diagnosis of autism and overall child development.

Home Movies/Video Taping Component
As additional information about the child's skills might be helpful in forming a diagnostic picture, the assessment team may want to view home movies or videotapes provided by the family. Additionally, if the child is already enrolled in intervention with a NEIS staff member, the staff member may be asked to videotape one or more of their home visits with the family for review by the autism assessment team.

Home Visit Component
The transdisciplinary assessment team or a member of the team must complete a home visit to view the child in their natural environment. Again, this is for the purpose of providing more observations of the child's developmental skills and symptoms of ASD. If the child is already in services with an NEIS staff member, the assessment team should discuss the child's presenting issues with the NEIS staff member assigned to the case. Review of that staff member's home visits with the family should be conducted.

Clinical Opinion Component
After information is gathered from the above listed sources, the autism assessment team should discuss and interpret the results. Standardized and less formal autism assessment measures, medical information, cognitive functioning, adaptive functioning, and home visit information should all be synthesized into a comprehensive picture of the child. The teams' knowledge of development and ASD should be combined with the clinical tools and familial information gathered to form an accurate clinical opinion of the child. No one tool or home visit should be used to solely make a diagnosis.

MEDICAL EVALUATION
The American Academy of Pediatrics has made recommendations on the role of the pediatrician in the diagnosis and care of ASD. The purpose of the medical evaluation is to assist with determining an etiology when possible and to identify any associated medical conditions if present. The evaluation should be performed by a qualified health care professional with specific clinical training and experience in the diagnosis and treatment of Autism Spectrum Disorders.

The medical evaluation should include:

Birth history (prenatal, perinatal and neonatal history)

Past medical history of the child (illnesses, hospitalizations, surgeries, medications, immunizations, head injuries, allergies)

Family history (3 generation family tree of medical/psychiatric/ developmental history)

Dietary/growth history (diet patterns, bowel habits and growth charts)

Developmental history (milestones, regressions, behaviors, sleep patterns)

Comprehensive Physical and Neurodevelopmental Examination

(Focus on any dysmorphic features, growth patterns, neurocutaneous findings, and neurological exam)

Laboratory and Genetic Testing:

- Routine testing should include a high-resolution karyotype and Fragile X DNA.
- All other testing should be decided based on the clinical history and physical examination.
- Specific neurological testing such as an EEG, brain MRI and trace mineral testing should be considered on an individual basis.

"The American Academy of Pediatrics (AAP) has made recommendations on the role of the pediatrician in the diagnosis and management of ASD (American Academy of Child and Adolescent Psychiatry, 1999). According to the AAP, the purpose of the medical evaluation for children with ASD is to assist with determining the etiology of the disorder, associated medical conditions and any other health conditions that may also be present. Determination of the etiology and associated medical conditions may have numerous important potential benefits, including genetic counseling, family counseling to help the family understand possible treatment options, information about prognosis, potential for prevention (both primary and secondary) and facilitation of the development of a comprehensive database which can be used for epidemiological purposes. Over time, new information, including new clinical genetic syndromes, is expected to be available. It is therefore important for clinicians seeking expertise in ASD to stay involved with the care of children with ASD and to remain informed about current research results." (California Department of Developmental Services, 2002)

Vision

"Questions or observations about the child's functional vision should be asked during the diagnostic process. Since strabismus, hyperopia and myopia are common in children with developmental disabilities, the evaluation of visual function is an important part of the medical evaluation. As part of the physical examination, the clinician should perform an eye examination, documenting the extra-ocular movements and papillary responses as well as the eye morphology. In addition, the child's vision should be screened using acceptable methods for infants, toddlers and preschoolers.

This may be functional vision screening or use of other standardized methods.

If there are concerns from the parent or diagnosticians, a referral to a pediatric ophthalmologist or optometrist should follow during the assessment for intervention planning phase. The procedures used should correspond to the professional standards of the field." (California Department of Developmental Services, 2002)

Hearing
"All children suspected of ASD should have their hearing screened using appropriate methodology and should be referred for a formal hearing assessment if concerns are present. The child should be referred to a pediatric audiologist as part of the diagnostic work-up if hearing screening cannot be performed or if the child fails hearing screening. Since some children with ASD have difficulties with compliance and cooperation with these procedures, it may be necessary to sedate the child to perform auditory brainstem evoked potentials. Newborn screening tests are insufficient for assuring adequate hearing as some children may have hearing impairment due to injury or illness (such as repeated ear infections) in the infancy or toddler years, which was not present at birth."   (California Department of Developmental Services, 2002)

Screening
"Best practice procedures recommend that all children be screened specifically for ASD at ages of 18 and 24 months. Screening at these two periods is recommended because most children who are later diagnosed with ASD display symptoms (excesses/atypical behaviors) and/or lack achievement of core developmental milestones (absence of functional communication and/or symbolic play skills) by the second year of life. Current research literature suggests that a significant number of features of ASD are present by 18 months of age, specifically, verbal and nonverbal communication deficits. In addition, since some children with ASD evidence regression in skills between 15 and 24 months (and rarely after two years), screening at age two years facilitates identifying these children as well. *This is not to suggest that concerns noted earlier by parents or other professional should be dismissed until this time.* Age of onset can vary and is often related to severity of impairment. Optimally, developmental screening specific to ASD would occur at any point at which routine surveillance and/or child observations indicate it is warranted." (California Department of Developmental Services, 2002)

Screening Tools Specific to ASD

- The Checklist for Autism in Toddlers (CHAT)
- The Modified Checklist for Autism in Toddlers (M-CHAT)
- The Pervasive Developmental Disorders Screening Test – Stage 2 (PDDST-II)

Checklist for Autism in Toddlers (CHAT)
- Brief, easy to administer <u>Screening Tool</u> with very high reliability and validity
- Administered at 18 months of age or older
- Should be administered by the NEIS professional if autism spectrum disorder is suspected
- First nine questions (Section A) are asked directly of parent/caregiver

Modified Checklist for Autism in Toddlers (M-CHAT)

- Brief, easy to administer <u>Screening Tool</u> with good reliability and validity
- Administered at 24 months of age or older
- Should be given to the parent to fill out if ASD is suspected
- 23-item checklist in a yes/no format that parents can easily fill out
- Unlike the CHAT, it does not require that a professional observe or administer any items
- A child fails the checklist when 2 or more critical items are failed **OR** when any three items are failed. Yes/no answers convert to pass/fail responses.
- Critical items include questions 2, 7, 9, 13, 14, & 15

Pervasive Developmental Disorders Screening Test –Stage II (PDDST-II)

- Moderately lengthy <u>Screening Tool</u> with good reliability and validity
- Designed to determine the likelihood of global and pervasive developmental disorders in children from eighteen months to three years of age
- 71-item checklist in a true/false format
- Presented in 6-month age intervals
- The parent completes the checklist and it does not require that a professional observe or administer any items
- Attempts to differentiate children with possibility of ASD from children with other developmental issues

If the screening tool indicates the possibility of ASD, the child should be referred for further evaluation. If the parents have specific requests for additional referrals, these should be provided as well (e.g., referral to the nutritionist if the parents are interested in the Gluten-Casein Free Diet, referral to the occupational therapist if there are significant sensory issues, etc.). Staff members may also wish to discuss the child at their weekly team meetings for additional input and support.

Additional community referrals may also be beneficial to families who have a child with autism. These could include mental health or psychological support services if a family member is experiencing depression, neurology services if the family is seeking further medical opinion, and so on.

Evaluation/Classification
Special Considerations for the Birth to Three Population
"Diagnostic criteria for pervasive developmental disorders (American Psychiatric Association, 1994) specify that impairment must be interpreted relative to the child's developmental level. Thus, children with ASD evidence significant differences between nonverbal cognitive ability and social/communicative functioning. This disparity can be difficult to detect in toddlers and older preschool-age children with developmental ages below 12-18 months." (California Department of Developmental Services, 2002)

"Presently, children are being referred for evaluation regarding suspicion of ASD at earlier ages. Although many trained professionals are able to make a definitive diagnosis at a young age, the stability of diagnosis within the spectrum may fluctuate. This is often the case with children who are very young (2 years and under) and for those at the extreme ends of the spectrum. It is not uncommon for a child to meet diagnostic criteria for autistic disorder at age two and then be described at ages three or four as PDD-NOS. Symptoms and behaviors may change considerably with intervention, particularly as language and social skills progress." (California Department of Developmental Services, 2002)

"An accurate assessment of cognitive functioning is crucial for prognosis and intervention planning (Vig & Jedrysek, 1999). Thus, a focus of evaluation and re-evaluation should be to obtain closer approximations to an accurate description of potential in the child. This can be achieved as the child gains experience with more structured learning situations through appropriate intervention." (California Department of Developmental Services, 2002)

Components of a Comprehensive Diagnostic Evaluation for ASD

- Review of Relevant Background Information (i.e., medical records, previous developmental testing, etc.)
- Parent/Caregiver Interview (this could include videotaping of the child and family)
- Comprehensive Medical Evaluation
- Direct Observation
- Cognitive Assessment
- Measures of Adaptive Functioning

(California Department of Developmental Services, 2002)

The Parent/Caregiver Interview

"The parent interview can be either a standardized interview or a more informal gathering of information. Clinicians experienced in the diagnosis of ASD tend to rely more on informal interview questions that are specific to the diagnostic criteria for ASD and are relevant to the child's age and developmental level in establishing a diagnosis. Again this emphasizes the need for clinical and professional expertise in ASD. Standardized interviews, such as the Autism Diagnostic Interview, Revised (ADI-R) (Lord, Rutter, & LeCouteur, 1994), are semi-formal and constrained by administration protocol in gathering information. Such formalities and protocols can provoke anxiety for the parent who is undoubtedly already apprehensive for their young child. Informal procedures often allow the clinician more flexibility in providing examples of specific behaviors for the parents. An informal approach allows for reframing the wording of question to increase comprehension. Parents and caregivers should feel comfortable and relaxed during the interview and confident providing information." (California Department of Developmental Services, 2002)

Informal Parent/Caregiver Interview

"The clinical content of the parent interview should document the following domains:

1. First concerns about the child's development. This included the parents' first concerns as well as concerns of others (relatives, PCP) that may have preceded parental concerns. It is also important to ascertain their interpretation of the events at that time (i.e., family move, illness, daycare experience, etc.).

2. Characteristics of the infant's temperament.

3. Social-emotional milestones. This includes engagement in typical baby games (pat-a-cake, peek-a-boo), eye contact during feeding and games, shared attention, greetings and similar significant events. It is sometimes helpful to provide a reference point (i.e., first birthday) to aid with recall.

4. Sensory abnormalities. It is important for the clinician to provide examples to help discriminate atypical patterns from typical developmental patterns. For example, arm flapping and jumping are common in many preverbal children. For example, children respond to exciting stimuli such as the currently popular children's characters.

5. Feeding and sleep problems or patterns

6. Fine and gross motor development and milestones.

7. Atypical interests and activities.

8. Interest in other children and/or siblings.

9. Patterns of attachment to caregivers.

10. Ability to use nonverbal communicative means such as gesture and facial expression.

11. Communication, including both verbal and nonverbal intent.

12. Preferred activities and play.

13. Other notable characteristics such as loss of skills or deterioration of behavior.

The above list is a guideline for relevant content to include in the parent interview. The sampling of relevant content areas includes dimensions that tend to highlight behaviors within the ASD range and, therefore, reflect atypical development. Consequently, it is important that the clinician be able to interpret responses and ask questions within the framework of typical child development and knowledge of individual family characteristics as well as cultural norms and values. (California Department of Developmental Services, 2002)

The Transdisciplinary Assessment Teams

"Direct observation of the child's behavior is essential to a diagnostic evaluation for several reasons. First, it allows the clinician opportunities to directly observe the child in unstructured situations. After a period of adjustment, children often display typical play behaviors (or lack of) and other behavior anomalies that may be of concern. Observations can also clarify issues that may come up during the parent interview by helping to elicit observation that is more explicit or ascertaining whether such behavior is typical. Parents may have difficulty interpreting questions on screening questionnaires or other information collection procedures. With direct observation, situations can be structured or created to clarify these issues (e.g., by a parent or clinician saying "look" to draw attention to an interesting toy, understanding of the gesture can be assessed). Observation can add additional data to parent report. Parents have the utmost knowledge of their child and, often, the highest degree of adaptation to their child's pattern of communication and behavior. They may not realize how they unknowingly compensate for subtle child deficits (e.g., by standing in front of or close to the child when calling his/her name, thus ensuring eye contact). Finally, observations allow the clinician to observe patterns of interaction with family and unfamiliar adults. Ideally, siblings should be encouraged to attend such diagnostic evaluations to observe these interactions as well. This is not essential, but should be accommodated if appropriate." (California Department of Developmental Services, 2002)

Observation Domains

- Reciprocal turn-taking
- Shared attention
- Social reciprocity
- Pretend play
- Sustained interaction
- Gaze aversion
- Spontaneous giving/showing
- Imitation of novel acts
- Ability to have examiner direct attention
- Use of toys and objects

This list is not exhaustive, but is intended to describe a sampling of behaviors supporting and associated with diagnostic criteria for ASD. Other behaviors to observe include preoccupations and repetitive play, motor stereotypes and sensory preferences. Again, it is critical that all behavior be interpreted within the context of the age and developmental level of the child. Videotapes of other experiences supplement observations and can be helpful either to corroborate behavior observed during formal clinic observations, or to indicate typical behaviors in comfortable, familiar surroundings. (California Department of Developmental Services, 2002)

The Autism Diagnostic Observation Schedule – Generic (ADOS-G)

"The Autism Diagnostic Observation Schedule – Generic (Lord, Rutter & LeCouteur, 1999) is a semi-structured observation and interview measure designed to assess children and adults suspected of having ASD. The instrument is divided into four modules intended for very young children through adults. A module is chosen based upon the age and language level of the individual. asks range from those designed to assess preverbal social/ communicative behaviors in very young, nonverbal children (pretend play, joint attention) to tasks of pragmatic language, social and emotional understanding in verbally fluent adults. Use of this instrument requires extensive training in administration and reliability. Users must also have a high degree of familiarity with ASD." (California Department of Developmental Services, 2002)

The child must have a mental age of 15 months for the ADOS to be appropriately used. For example, if the child shows a mental age of seven months from cognitive or other evaluations, use of the ADOS may not be appropriate.

For the birth to three age range, Module 1 of the ADOS-G will typically be used. It begins with a free play session to allow the child to acclimate to the novel situation. Clinicians will also receive initial impressions of the child's social and communication skills. Module 1 then moves into more structured interactions between the child, parent/caregiver, and clinicians. Each scenario is designed so that the examiners can observe the quality and quantity of the child's social and communicative overtures. Stereotyped behaviors or restricted interests will also be observed during the session. Additionally, the child's play skills and initial, rough estimates of the child's cognitive functioning can be addressed.

The Childhood Autism Rating Scale (CARS)

"The Childhood Autism Rating Scale (Schopler, Reichler, DeVillis & Daly, 1980) is an observational rating instrument for children and adults suspected of having ASD. Fifteen items are rated through observation of the child, and cutoffs are suggested for diagnoses within the autistic spectrum. The CARS, a product of long-term empirical research, provides quantifiable ratings based on direct behavior observation and caregiver report. These ratings are an important element in the systematic diagnosis of autism."   (California Department of Developmental Services, 2002)

Cognitive Assessment

It has been repeatedly established that children with ASD vary widely in their cognitive potential with estimates of 70 to 80 percent functioning in the mentally retarded range (Ballabann-Gill, Rapin, Tuchman & Shinnar, 1996; Lord & Rutter, 1994; Rapin, 1991; Volkmar, Burak & Cohen, 1990).   Among children who demonstrate normal or superior nonverbal skills, a significant proportion demonstrates verbal and/or adaptive skills in the impaired range of functioning." (California Department of Developmental Services, 2002)

It is now recognized that assessment of cognitive functioning is crucial to the differentiation of ASD from other disabilities and to the identification of concomitant impairment in a child with an ASD. Cognitive ability also has an important role in prognosis and intervention planning. An estimation of potential is necessary for the following reasons:

- Functioning level, which includes cognitive and adaptive evaluation, is important for differential diagnosis and intervention planning. A diagnosis of ASD is appropriate when a child shows communicative, social or interest deficits that are inconsistent with overall cognitive functioning. For example, a child of 4 who is functioning at a 12-month developmental level would not receive a diagnosis of ASD if he or she displayed communicative and play behaviors similar to that of other 12-month-old children. It is also extremely difficult to document significant social and communicative deficits below this age level.

- Treatment research generally has supported the notion that response to various treatment approaches has some relation to overall cognitive functioning (Gabriels, Hill, Pierce, Rogers & Wehner, 2001). For example, certain intensive behavioral approaches have been shown to be less successful with children at lower cognitive levels who are unlikely to develop spoken language.

- Degree of cognitive functioning may indicate expected rates of progress. This, of course, is dependent upon the relative degree of certainty with which cognitive impairment can be established."   (California Department of Developmental Services, 2002)

Formal Cognitive Assessment Tools
1. Bayley Scales of Infant Development – II
2. Wechsler Preschool and Primary Scales of Intelligence, Revised
3. Stanford-Binet, 4th edition
4. Mullen Scales of Early Learning
5. Kaufman Assessment Battery for Children

6. Leiter International Performance Scale, Revised

7. Merrill-Palmer Scales of Mental Tests

8. Differential Abilities Scale

9. Child Development Inventory

Adaptive Functioning Assessment

"Adaptive functioning refers to capacities for personal and social self-sufficiency and problem solving in real life situations. For children with suspected ASD, this component is essential because it provides information regarding the child's typical functioning at home or school and may contrast markedly with data obtained through formal assessment procedures. It offers the clinician indications of the child's ability to adapt to environmental demands such as the formal testing situation. Children with autism often demonstrate large discrepancies between their nonverbal cognitive potential and their ability to function successfully in their families and communities. Oftentimes, serious deficits in adaptive functioning are overlooked in treatment planning when children demonstrate nonverbal strengths. Research does not support the assumption that relatively higher cognitive potential will eventually lead to acquisition of adaptive skills. To the contrary, children with autism often continue to demonstrate significant deficits in daily functioning when adaptive skills are not directly assessed and targeted (Carter, Gillham, Sparrow & Volkmar, 1996)." (California Department of Developmental Services, 2002)

"Large gaps between adaptive functioning and intellectual potential elucidate areas to target for intervention and highlight the need for learning to occur in naturalistic situations." (California Department of Developmental Services, 2002)

Adaptive Functioning Assessment Tools

1. Vineland Adaptive Behavior Scales

2. Scales of Independent Behavior – Revised

Documentation and Writing the Report
Results from the various developmental tools administered should be summarized in a comprehensible fashion for the family. Additionally, behavioral observations during the child's visits with NEIS assessment professionals should also be discussed. The report should also include a summary of the child's strengths and needs, as well as possible learning styles (visual, auditory, etc.) If initial intervention strategies were attempted during assessment appointments, the potential effectiveness of the strategies should also be outlined.

Reassessment
Given the rapid change in developmental skills in this population and the need to confirm and expand upon initial diagnostic impressions, best practices indicate that reassessment of the child's skills should be completed on an annual basis, at a minimum. Reassessment of the child's skills allows interventionists to track developmental changes and the efficacy of intervention strategies. Additionally, monitoring of the child's progress may allow an enhanced ability to predict outcome/prognosis.

Principle 2

Assessment and intervention strategies should be evidence based.

A growing body of research supports the use of effective practices for young children with Autism Spectrum Disorders (National Research Council, 2001). Young children with Autism, and their families, have a right to assessment and intervention that is validated by peer-reviewed research. Young children with Autism and their families should not be exposed to practices selected on the basis of practitioner preference, anecdotal evidence, or popularity. Further, practitioners must be trained and qualified to implement assessment and intervention strategies in their respective disciplines.

Approaches to providing services to young children with Autism Spectrum Disorders

There are numerous strategies available to address the needs of young children with autism spectrum disorders (ASD). Often, proponents of a particular approach claim that there is a single "best" way to teach children with ASD, or that their strategy will potentially "cure" ASD. To compound the problem, parents are bombarded with conflicting information about intervention strategies from many sources. Despite the growing body of research on effective intervention for young children with ASD (National Research Council, 2001), there is no single proven way to address the needs of all children with ASD, nor is there substantial research on the long term impacts of any particular intervention strategy. Claims that any single strategy is the "best" way to address the needs of a child with ASD should, therefore, be viewed skeptically.

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

In reality, the intervention strategies that work best for the young child with ASD are those that fit a given child's needs. A good plan will begin with a formal assessment of the child's strengths and needs, and will be individually tailored to meet them. The intensity and strategies used for early intervention will vary considerably across children. One child may require a high level of direct instruction, whereas another may benefit from a more naturalistic approach, or a combination of both. Children with ASD learn in complex ways. Their learning needs, like their autism, transform as they develop. In many cases, focusing exclusively on one approach or method of instruction, which might temporarily produce a desired result, could ultimately restrict a child's growth.

Sometimes, however, there may be a rationale for temporarily putting a significant effort into the development of a specific skill. It is useful to characterize the active ingredients of treatment approaches along a continuum – from traditional behavioral approaches such as discrete trial to more contemporary behavioral approaches that use naturalistic language teaching techniques to developmentally oriented approaches.

Terminology of Behavioral Approaches

There are a variety of approaches described as "behavioral", including applied behavior analysis, discrete trial instruction, the Picture Exchange Communication System (PECS), the analysis of verbal behavior, and positive behavioral supports. Although these approaches share

a common focus on observable behavior, ongoing evaluation of progress, and direct instruction, they differ in critical ways. Each is described below.

Applied Behavior Analysis

Applied behavior analysis describes a variety of strategies, which utilize a natural science approach to teaching children with ASD. There is an emphasis on understanding the functional relationships between environmental events and behavior, without reference to needs, drives, developmental sequences, or other hypothetical constructs. Applied behavior analysts use the tools of direct observation and measurement to understand how a given child's behavior is related to his current and past environments. Thus, it is understood that a child's future behavior can be modified by changing his environment, including one or more of the elements below:

1. Antecedents (what comes before the targeted behavior);
2. Consequences (such as reinforcement); and
3. Setting Events (events that alter the likelihood that an antecedent will evoke a particular behavior, or that alter the reinforcement value of particular consequences).

Since the 1960s, applied behavior analysts have developed numerous research validated strategies to teach persons with ASD and other developmental disabilities. Many of these strategies have evolved into comprehensive programs and curricula for teaching children with ASD. These include the Lovaas or Discrete Trial Instruction (DTI) approach (Lovaas, 1987), the Picture Exchange Communication System (PECS) (Frost & Bondy, 2002), strategies based on Skinner's analysis of verbal behavior (AVB) (Sundberg & Partington, 1998), and naturalistic teaching (Koegel & Koegel, 1995). It is often wrongly assumed that ABA is a specific teaching strategy rather than a broad framework of principles and strategies for changing behavior. In particular, it is popularly believed that the Lovaas or Discrete Trial Instruction approaches and ABA are synonymous. Although each ABA approach shares similarities, there are also critical differences that merit description.

Competencies for Persons Administering Applied Behavior Analysis (ABA) Services

Persons who Supervise ABA Programming

Any person who supervises the design and/or implementation of ABA programs for young children with autism must have training in ABA. Training consists of a graduate degree in education, psychology, or a related discipline with an emphasis in ABA and autism, including coursework and supervised field experience.

The Association for Behavior Analysis accredits graduate training programs in behavior analysis, and maintains a list of graduate training programs on its website (www.abainternational.org). Although a qualified behavior analyst does not necessarily need to complete one of these programs, graduation from an accredited program indicates a minimum level of competence with respect to applied behavior analysis supervision.

The Behavior Analyst Certification Board, Inc. (www.bacb.com) certifies individuals who practice applied behavior analysis. The BCBA credential is not specific to autism or any other disability. There are two levels of certification: Board Certified Behavior Analyst (BCBA) and Board Certified Associate Behavior Analyst (BCABA). To achieve BCBA status, an individual must

possess a masters degree in education, psychology, or a related discipline, must complete specified coursework and supervised experience in behavior analysis, and must pass a written exam. Coursework includes instruction in the concepts and principles of behavior, single subject research methods, application of behavioral principles to teach people with disabilities, and ethical use of behavior change strategies. Individuals who possess the BCBA are qualified to supervise programs if they have specific training and expertise in young children with autism. Individuals who possess the BCABA credential are only required to have a bachelors degree, and work under the supervision of BCBA personnel.

Persons who supervise ABA programming, but who lack formal training in ABA will have a period of three years to attain the board certified behavior analyst credential or to meet the current equivalent coursework and field experience requirements. Both UNLV and UNR offer graduate training programs leading to the BCBA credential, and there are also a number of nationally available distance education programs (see www.bacb.com).

Persons who Implement ABA Programming

 NEIS recognizes that persons who teach or provide direct therapy to young children with autism may possess a variety of experience and training levels. If an individual has no experience implementing ABA directly with young children with autism, the service provider must supply on-the-job training and supervision in ABA.

Discrete Trial Instruction

Among the ABA-based programs for young children with autism developed to date, many are based on the work of I. O. Lovaas and his colleagues at the University of California, Los Angeles. Although the Lovaas approach utilizes a variety of ABA techniques developed in the 60's, 70's, and 80's, it relies heavily on discrete trial training, a highly structured approach in which children with ASD are exposed to a high frequency of teacher directed learning trials. The Lovaas approach gained popularity after the publication of his 1987 research study, in which a number of young children exposed to 40-hours per week of therapy achieved "normal intellectual functioning." The popularity of the Lovaas approach has led many to conclude inaccurately that the term "Lovaas therapy" can be used interchangeably with ABA or other intensive behavioral treatments for autism. Within both broadly defined ABA-based interventions and more specific Early Intensive Behavioral Intervention (EIBI) programs, numbers of techniques are used to accomplish treatment goals. These often include traditional behavioral techniques such as functional assessment, prompting, shaping, and reinforcement, as well as techniques primarily designed for the treatment of autism (e.g., discrete trial instruction).

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

The 1987 study by Lovaas and a follow-up study by McEachin, Smith, and Lovaas (1993)

showed promising results for some children exposed to 40-hours per week of intensive DTI. The results of this research have led some to advocate that all young children with autism should receive 40-hours per week of intensive DTI, and that "recovery" from autism with intensive DTI is possible. The available evidence does not support these claims. First, the 1987 study was subject to a number of methodological flaws, including the absence of random assignment, which limit the generality of findings to children with autism beyond the study (Gresham & McMillian, 1996). Second, despite reports of studies in progress (Smith & Lovaas, 1998), to date there have been no replications of Lovaas's 1987 findings published in peer reviewed journals. Third, most intensive DTI programs are not supervised by Lovaas or his colleagues at UCLA, and may vary considerably from the techniques used in Lovaas's 1987 study. Finally, there is little evidence to suggest that a 40-hour per week DTI program is appropriate for very young children with autism ages 0-2.

Pivotal Response Training

Pivotal Response Training, or PRT, developed by Robert L. Koegel and Lynn Kern Koegel, is a strategy designed to teach key behaviors that are central or "pivotal" to wide areas of functioning (Koegel, Schreffinnan, Good, Cerniglia, Murphy & Loegel, 1988). These key behaviors include motivation and responsivity to multiple cues. PRT was designed to be easily used in natural settings. The reinforcer is contingent upon the behavior, must be delivered as immediately as possible after the desired response, and must be appropriate to the response. An evaluation of the 13 studies done to date, found that 7 of the studies described improvements in communication and behavior, and 9 of the studies described information about improvement in social-emotional behavior (Humphries, 2003). While there has been no research comparing PRT to other methodologies (Lord, 2001), initial evidence appears promising for the effectiveness of PRT on a variety of behaviors.

An example:
Marilyn is blowing bubbles with her son. He suddenly says "music" and points to his toy piano. Marilyn says "good talking" and gives him the toy. An inappropriate response would have been for Marilyn to say "we're blowing bubbles, can you say bubbles"

Picture Exchange Communication System (PECS)

PECS is a strategy for teaching children with autism to communicate by exchanging pictures (Frost & Bondy, 2002). PECS is a broad-based ABA approach, using research supported techniques common to many ABA programs (e.g., fading, prompting, chaining). The conceptual framework for PECS borrows partially from Skinner's (1957) analysis of verbal behavior. Until recently, the support for PECS was primarily anecdotal; however, recent research suggests that PECS is an effective means for teaching functional communication to many non-verbal children with autism (refs.). Further, PECS may have additional benefits beyond functional communication (e.g., increased speech production, decreases in challenging behaviors).

The Analysis of Verbal Behavior (AVB)

Recently, AVB has gained popular attention as a strategy for teaching language skills to children with ASD. AVB derives its name from B.F. Skinner's (1957) book, *Verbal Behavior*, in which he presented a conceptual framework for language grounded in the principles of behavior. Although AVB has been associated with particular teaching strategies advocated by Carbone (2002) and others, including fast-paced discrete trials, errorless learning techniques, and sign language training, AVB is a conceptual approach that accommodates a variety of behavior analytic

teaching procedures. Although there is growing research evidence to support specific teaching techniques based in AVB, there have been no studies on the efficacy of comprehensive AVB programs from young children with autism. Still, AVB shows promise as a framework for teaching language to young children with ASD.

The DIR (Developmental, Individual Difference, Relationship-Based Approach)

DIR stands for Developmental, Individual Difference, Relationship-based approach and was developed by Dr. Stanley Greenspan, M.D. and Serena Weider, Ph.D. It is a comprehensive, interdisciplinary approach that focuses on the emotional development of the child. It takes into account the child's feelings, relationships with caregivers, developmental level and individual differences in a child's ability to process and respond to sensory information. It focuses on the child's skills in all developmental areas, including social-emotional functioning, communication, thinking and learning, motor skills, body awareness, and attention. It is a model of analysis that helps identify the child's and family's profile providing a framework for interventions as part of a developmentally based, comprehensive program of assessment and intervention.

The DIR approach holds that relationships and affect are at the core of learning. Every child is different and must be treated and nurtured differently. Every child can advance and grow. Parents and guardians must play an active and vital role in their child's process of development and discovery. Parents and families, childcare providers, clinicians and educators must all be involved in a multi-faceted treatment approach.

The DIR approach is based on the following principles:
- Developmental - The DIR approach looks at six developmental milestones that children must master, starting from birth, including:
    - Regulation and interest in the world (by 3 months)
    - Engaging and relating (by 5 months)
    - Intentionality (by 9 months)
    - Problem solving, mood regulation, and a sense of self (by 18 months)
    - Creating symbols and using words and ideas (by 30 months)
    - Emotional thinking, logic, and a sense of reality (by 42-48 months)
- Individual Differences -- Each child is unique. The specific biological challenges that a child has will affect how he learns and how he relates to others. Understanding a child's particular pattern of challenges is crucial for helping him. These challenges may include differences the child show in auditory processing, visual-spatial processing, motor planning and sequencing and sensory modulation.
- Relationship-based – The child's developmental challenges and individual differences affect how the child can relate to others and affects the child's relationships. The parents or caregivers also have unique characteristics that may affect their interaction with the child. The approach assists caregivers in developing their relationship with the child, so they can be effective in helping the child to learn and grow. The approach is also concerned that the child is developing meaningful relationships with peers and siblings.

Floor time is the central and vital element of the DIR model. It is spontaneous play in which one follows the child's lead and motivations, opening and closing circles of communication. It is also

continually challenging the child to move up the developmental ladder. Challenges can be gestural or talking according to the child's developmental level promoting problem solving. Floor time needs to be practiced and used with reflective support. Floor time is builds the link between emotion and behavior.

In a review of 200 cases, this approach has been shown to help the vast majority of children to become engaged, trusting, intentional and communicative with a subgroup of children able to develop capacities for high levels of creative and reflective thinking, peer relationships, empathy and academic mastery (Greenspan & Wieder, 1997).

 www.floortime.org
www.icdl.org

Perceptual-Cognitive Approach

The Perceptual-Cognitive theory originated from the belief that children with autism have sensory, perceptual, and thinking differences resulting from brain malfunction. The theory suggests that these children are overly stimulated by the external senses and have difficulty processing sensory information. Given these difficulties, the perceptual-cognitive theory places a priority on teaching in very structured and routinized environments, working toward independence of thought and behavior. Further, cognitive processing problems create the need for caregivers to present information in specific ways, such as providing instructions one step at a time, and limiting extraneous verbalizations. Following are some common strategies for working with children with autism, using the Perceptual-Cognitive theory.

Visual Cues

The Perceptual-Cognitive approach relies heavily on visual cues and supports. One example of these is providing picture or three-dimensional schedule systems depicting the child's activities for the day. The approach teaches children top-down or left-right orientation through these systems. The approach further provides visual cues for common tasks such as washing hands or playing with toys. These visual cues involve picture symbols for each component of the task, posted in sequential order. The goal of visual cues such as these is to fade the necessity for adult prompting, providing the child with the opportunity to practice skills independently, using only the visual cue as a support. Another example of visual cues and supports is the use of color. A learning environment may have specifically colored baskets for different categories of instructional materials, for example yellow for blocks and blue for art supplies. The purpose of color cueing is to aid in a child's processing that different types of materials "go together" as well as to help him or her begin to recognize expectations for different activities without an adult prompt. For instance, if the yellow basket is on the floor, the child will come to expect to build blocks, while if the blue basket is out, he or she will come to expect to sit at the table for an art activity. In this way, independence is fostered.

Routines

Children with autism often have difficulty with changes in routine and with transitions from one activity to the next. The Perceptual-Cognitive approach addresses these challenges through the establishment of routines and through other cueing practices. As much as possible, families should be encouraged to follow a similar routine each day. Though it is not necessary that things happen at precisely the same time each day, the order in which activities take place should vary as little as possible. For example, if brushing teeth, eating breakfast, and getting dressed are common morning activities, the family should do them in the same order day after

day. This provides a sense of structure and safety to the child's world, while providing expectations and predictability. Cues can be added to address transitions. For example, the use of a kitchen timer to signal the end of one activity, if used consistently, will help to prevent common resistance to changes in activities experienced by many families of children with autism. It is also important to prepare the child in advance for changes in routine. The use of the visual schedule system provides the visual support for this preparation.

Attention and Imitation
A final key component to the Perceptual-Cognitive theoretical approach is teaching children with autism to attend and imitate. Because of their perceptual and cognitive difficulties, these can be challenging areas for these children. To address these challenges, caregivers should incorporate attending skills and imitation (both verbal and nonverbal) into the intervention plans for children with autism.

The goal of the Perceptual-Cognitive approach is to provide the child with autism with necessary supports to overcome the perceptual and cognitive processing challenges, while promoting independence and self-reliance. While these supports are necessary for intervention early on, the goal of fading the supports as the child gets older and more independent is key.

TEACCH
TEACCH is an acronym for a curriculum model that was developed in the Division for the Treatment and Education of Autistic and Related Communication Handicapped Children at the University of North Carolina, Chapel Hill. The program's philosophy is to focus on the individual with autism and design a program around that person's interests, skills, and needs. The program is very flexible in that it doesn't ascribe to any one specific treatment technique; rather, it espouses a broad-based intervention approach.

One of the primary aspects of the TEACCH program is called structured teaching. Structured teaching is an attempt to relate to the "culture of autism" and reach an environment that's more comfortable so individuals with autism can understand expectations. Basic components to the structured teaching concepts are organizing a physicals structure, providing a schedule, developing work systems, and using visual materials. These techniques help to make expectations clear and allow an individual with autism to independently engage in tasks without adult prompts. (The Source for Treatment Methodologies in Autism, Gail J. Richard, LinguiSystems 2000)

LEAP Model
The LEAP Model (Learning Experiences: An Alternative Program for Preschoolers and Parents) is a peer-reviewed evidence-based intervention program for children with autism spectrum disorders and their families. This comprehensive program provides a number of support strategies for children with autism spectrum disorders in inclusive preschool settings. It includes a training module for preschool teachers and a home program for parents and children with autism.

The goals of the LEAP program are reflected in its guiding principles (excerpts from the LEAP Outreach Project manual, Lowery & Goudy, 2000):

1. All children (both those with and without developmental disabilities) can benefit from integrated childhood environments.

2. Young children with autism spectrum disorders benefit most from early intervention when intervention efforts are conducted across school, home and community settings.

3. Young children with autism spectrum disorders make the greatest gains from early intervention when parents and professionals work together as partners and are equal members of the instructional team.

4. Young children with autism spectrum disorders can learn many important skills (e.g., social and language skills and appropriate classroom behavior) from typical same-age peers.

5. Young children with autism spectrum disorders benefit most from early intervention when intervention efforts are planned, systematic, and individualized.

Both children with and without disabilities benefit from curricular activities that reflect developmentally appropriate practices.

The LEAP model is distinguished from other eclectic approaches to intervention by the use of specific training modules to help typically developing peers communicate and respond to the communication of children with autism spectrum disorders. The social skills curriculum includes the following five programs:

1. Getting your friend's attention (Attention).

2. Asking for and giving toys (Sharing, part one).

3. Making a sharing request (Sharing, part two).

4. Getting your friend to play with your (Play Organizer).

5. Giving compliments.

These skills are taught and practiced sequentially with each previous skill integrated into the subsequent programs.

Results of a 12-year study of the LEAP model are summarized below (LEAP Outreach Project manual, Lawry & Goudy, 2000):

1. Children in LEAP generally show significant reductions in autistic symptoms after two years of intervention, comparison children do not (Lefebvre &Strain, 1989)

2. Children in LEAP make marked developmental progress on intellectual and language measures, comparison children do not.

3. On observational measures taken in school and at home, LEAP children are far more socially engaged and appropriate.

4. No negative and some positive (e.g., better social skills, fewer disruptive behaviors) outcomes accrue to typical children in the LEAP model.

5. Gains for LEAP children maintain following program participation with 24 of 51 children enrolled in regular education classes (oldest cohort in 10th grade) with no signs of developmental regression.

6. Adult family members who participated in LEAP are significantly less likely than comparison families to show signs of significant stress and depression following the early intervention experience.

The SCERTS Model (Social **C**ommunication, **E**motional **R**egulation, and **T**ransactional **S**upport)
The SCERTS model was developed out of 25 years of research and clinical/ educational practice by Barry Prizant, Ph.D, and Amy Wetherby, PhD, Emily Rubin, Amy Laurent and Dr. Patrick Rydell, a multidisciplinary team of professionals trained in Communication Disorders, Special Education, Occupational Therapy, and Developmental and Behavioral Psychology (Prizant, Wetherby, Rubin, & Laurent, 2003). It is a framework to directly address the core challenges of Autism Spectrum Disorders. The acronym represents the components that are to be addressed; **S**ocial **C**ommunication, **E**motional **R**egulation, and **T**ransactional **S**upport. The focus is on building a child's capacity to initiate communication with a conventional, symbolic system, and to develop self and mutual regulatory capacities to regulate attention, arousal and emotional state. The model is systematic and semi-structured, but flexible. The model involves varying degrees of structure to entice/motivate communication and social engagement, and to support emotional regulation. The SCERTS model is not a curriculum focused solely on training skills in a linear manner. It does focus on enhancing core underlying capacities (joint attention, symbolic behavior, emotional regulation) as well as supporting the development of functional skills, individualized for each child. However, it is flexible enough to incorporate practices from a variety of approaches and teaching strategies.

The SCERTS model has several core values and guiding principles.

- The development of spontaneous, functional communication abilities and emotional regulatory capacities are of the highest priority in treatment efforts.
- Goals and activities are developmentally appropriate and functional, relative to a child's adaptive abilities and the necessary skills for maximizing enjoyment, success and independence in daily experiences.
- All domains of a child's development (e.g. communicative, socio-emotional, cognitive and motor) are interrelated and interdependent.
- All behavior is viewed as purposeful. For children who display unconventional or problem behaviors, there is an emphasis on determining the function of the behavior and supporting the development of more appropriate ways to accomplish those functions.
- Each child's unique learning profile of strengths and weaknesses plays a critical role in determining appropriate accommodations for facilitating competence in the domains of social-communication and emotion regulation. Natural routines provide the educational treatment contexts for learning and for the development of positive relationships. Progress is measured in reference to increasing competence and active participation in daily experiences and routines.
- It is the primary responsibility of professionals to establish positive relationships with children and with family members. Family members are considered experts about their child. Assessment and educational efforts are viewed as collaborative processes with family members.

Principle 3

Services must be individualized for children and families

"Individualization" means that each child and family's services are based on that child's needs, strengths and interests and the family's concerns, priorities and resources. This is different for each child and family because each child and family is different. The development of the intervention plan known as the Individualized Family Service Plan (IFSP) and ongoing changes in the plan will be done with the family. Families have a decision-making role as members of the intervention team. The team will determine who will be involved in the program, when services will take place and what will be the focus of the services. This guideline introduces families to the framework for intervention to guide them in this discussion. Families, including others they choose to participate, will determine how they will be involved in implementing their child's IFSP. Even though the intervention may have a specific curriculum, the daily activities and routines are individualized step by step and customized for each family. (See IFSP Module #4)

IFSP Development

IFSP Outcomes

IFSP teams must develop meaningful, functional and measurable outcomes that promote generalization of skills across settings. Outcomes should not be vague or based on development of isolated skills. Outcomes such as child "will talk" or "will behave" do not provide clear guidance for determining progress. Outcomes should be able to be accomplished within 3-6 months and should affect a child's participation in the community and family life. Outcomes should include the development of social skills, verbal and non-verbal communication, play, fine and gross motor skills, and replacement of inappropriate behaviors

Intervention Methodologies

Nevada Early Intervention Services recognizes that multiple methods and strategies for intervention exist for children with autism. NEIS does not support, endorse or favor one methodology or "name brand method" over another. Families are encouraged to ask questions and consider all possible methods when making decisions for their child.

When developing the IFSP, one of the most challenging decisions the team faces is the type of instructional method that will be effective with a child and family.

The National Research Council (2001) noted that:

- "Intervention research is not yet available to predict which specific intervention approaches or strategies work best with which children. No one approach is equally effective for all children and not all children in outcome studies have benefited to the same degree" (p.64).
- "Children with the same diagnosis, gender, chronological age, and IQ score may well have a range of other different characteristics and may respond differently to intervention treatments (p.197).

To support families' full participation in the decisions regarding instructional methods, service coordinators will provide families with unbiased information on treatment options available for children with ASD. Additional assistance in evaluating choices will be available upon family request. All information will be given to families prior to the development of the IFSP.

Service Providers and Approved Services

NEIS promotes and supports program providers and interventions that have a strong philosophical base supported by professional literature and clinical data and that have developed curricula and instructional strategies.

In making their conclusions regarding nationally known "model programs", the National Research Council noted that "there are virtually no data on the relative merits of one model over another" (2001, 171). Therefore, IFSP teams in NEIS design individual intervention plans for each child based on appropriateness for the particular child and family, not necessarily its adherence to a specific method or model.

NEIS funded providers will be expected to demonstrate that they use a comprehensive approach to intervention and incorporate these nationally-identified components for successful intervention within their programs for children with ASD. (Hurth, Shaw, Izeman, Whaley & Rogers, 1999, National Research Council, 2001)

- **Intensity of engagement**: Engagement refers to the amount of time a child is attending to and participating in social and non-social settings and includes sustained attention to a person or developmentally appropriate activity. Engagement may be facilitated by a variety of techniques, materials and activities throughout the day. Engagement includes both incidental teaching and direct instruction.

- **Individualization of services for children and families**: The structure of services, defined outcomes and goals, measurement procedures and instructional settings should be developed according to individual child needs. Additionally, the provision of services is to be based on the child and family's individual strengths and needs.

- **Family involvement**: Early intervention providers will have plans that include support, instruction and feedback to families on carrying over goals and techniques into everyday situations.

- **Systematic, planned teaching**: Intervention and instruction will be well planned, logical and consistent with a theoretical basis, as well as developmentally appropriate and useful.

- **Specialized curriculum**: Curriculum for children with ASD should plan for and address skills in communication (verbal and non-verbal), cognition, play, social interactions and the replacement of inappropriate behavior.

- **Objective measurements of progress**: Providers will have defined standard methods for tracking progress that allow themselves and parents to determine if an intervention is effective for that child. These standards will include objective, observable and anecdotal measurements for use in planning instruction and assessing whether a child is benefiting from a particular intervention.

- **Opportunities for inclusion with typically developing peers in natural environments.** Children should have opportunities for fully inclusive toddler or preschool settings, with appropriate supports, including community childcare and recreational settings. This increases in priority as the child ages, attains skills, and prepares for transition to preschool services.

Coordination of Services

The services provided to children by interventionists must be coordinated in order to meet the criteria of "systematic planned teaching". In addition, supervision of interventionists and therapists should occur at regularly scheduled intervals to ensure excellent clinical skills and program quality. IFSPs should be reviewed at a minimum of every three months. To facilitate these requirements, NEIS supervisors will monitor all IFSPs for children with ASD.

In many cases, the IFSP team for a child presenting on the Autism spectrum can be quite large, and include members with varying degrees of experience. In order to maintain consistency across all aspects of the program including data collection, intervention, generalization and documentation of progress, a team meeting should be written into the IFSP. This should be included as a strategy for specific outcomes although the frequency and intensity may be not be the same for each outcome. For example, a child learning to use a picture system may need bi-monthly team meetings if the child is making rapid progress and should have new pictures introduced. The same child who is working on eye contact, and is progressing toward the outcome, may need only a monthly team meeting for that outcome. Team meetings should be included on the IFSP support page as Family Training and Counseling.

 Further considerations for service coordinators include:

- When new strategies or programs are implemented, the team meetings should be used for training purposes for all team members. At the initial IFSP, a discussion with the team should be held about the amount of training a new service provider will need. A new member to the team or to NEIS may need additional training. This should be written into the IFSP. For example the IFSP could state that the Instructional Aide would shadow other team members for two weeks, and then will begin their own hours after that defined time period.

- Some team members may need further training on specific strategies or programs to be able to implement the IFSP, however, significant program changes (including more involved strategies) should occur within a team meeting. For example, for a child who is learning sign language currently, but who is not making progress, the team may consider introducing a picture system. This will be a significant change to the child and family and should take place within a team meeting, rather than being added to the IFSP without full discussion with the family.

- For the program to be effective, it is critical that the family be involved. Team meetings, given all considerations, should occur as often as needed or necessary. It may need to begin as a monthly meeting, but can decrease as the team becomes familiar with the program and with each other.

- IFSP meetings must be held to determine the number of hours of support the child will need. If a team agrees to a number of hours, but finds the hours are too much for the child to handle, the IFSP must be reconvened. The implementation of the hours can be written into the IFSP support page in increments if the team is uncertain how the child and family will do. The team may consider a start date for a few hours, and write in a second date to increase the hours if the team finds that the child is handling them well. In addition, if a number of hours are on the IFSP but cannot be met due to family cancellations, consider reconvening the IFSP to discuss how services might better work for the family.

- Nevada Regional Centers (Desert, Sierra and Rural), have funding to offer to

eligible families whose children are aged 2 to 8 years and have been diagnosed with Autism. The program provides self-directed services to families who will use monthly allotments of funds to help pay for supports the child may need which could include behavioral intervention. Should this occur, the IFSP team should work in conjunction with the team that is also working with the child to ensure that there is consistency for the child and family. The service coordinator should also remember, that only one person can be a service coordinator at a time for a child. If a child has a service coordinator with a regional center, the team must decide who will be able to bill for services.

Choosing Service Providers

NEIS has in place program and professional requirements for all early intervention personnel. These requirements guarantee, not only compliance with federal regulations and maintenance of personnel standards, but also accountability and quality assurance monitoring.

Once the outcomes for a child and family have been determined, service provider(s) will be identified based on the following procedures:

1. When families express a choice of providers, to the extent possible NEIS will honor that choice.

2. When only one NEIS provider is available for services, and the program is considered appropriate to meet the needs of the child, the implementation of the IFSP will begin using the available NEIS provider.

3. When options are presented that include an appropriate NEIS provider and an appropriate non-NEIS provider, the NEIS provider will be assigned. For example, a non-NEIS ABA provider will not be considered when an NEIS ABA provider is available just because a different preferred curriculum is used by the non-NEIS provider.

4. Families may choose to access services that are not adopted by NEIS, however NEIS will not provide financial support for those services.

Use of Paraprofessionals

Many programs use paraprofessionals as part of their intervention team. Paraprofessionals are a necessary part of intervention programs, especially when the direct contact hours exceed 5 hours per week. The NEIS title "paraprofessional" should not be interpreted to mean poor quality or lack of clinical skill. On the contrary, NEIS paraprofessional personnel have good experience and clinical skill but do not meet the other personnel standards set by NEIS . Families can be assured that all paraprofessionals are trained and supervised when working with families through the early intervention system.

IFSP Review

Review Timelines

The IFSP team evaluates and revises IFSP services on a regular basis. A child's progress should be reviewed at least every three months. Frequent ongoing reviews of the IFSP and of service delivery method are crucial to ensure progress and the appropriateness of services for all children. An IFSP review should include the family, service coordinator, primary intervention-ist, and other persons requested by the family.

A team may need to convene more regularly if:
- The child is not progressing after a period of approximately three months;
- New concerns arise (e.g. new behaviors, new information, new diagnosis); and/or
- The parents express concern managing the services or incorporating activities into their daily lives.

Modifying Intensity/Frequency of Services
When deciding if an increase or decrease in services is needed, outcome data will be reviewed by the team.

- Consistent progress toward defined outcomes indicates to an IFSP team that current services are effective and the intensity and frequency are appropriate.

- Regression or lack of progress indicates a need to consider different approaches or intensity of service. Changes in service due to lack of progress may include lowering child/interventionist ratios, increasing program time, introducing a new curriculum, or providing additional training or consultation.

- There may be times when it is appropriate to decrease the frequency/ intensity of services. Families may have difficulty managing the level of service within their daily routines. During review, the IFSP team may recognize that the child is regressing or showing difficult behaviors. One solution may be to decrease services for a short period of time to determine whether they are too intense for the child and are resulting in diminishing progress.

- Services may also be decreased or changed when the child is meeting goals and developing age-appropriate skills in a particular area.

Disagreements
The research on intervention for children with autism emphasizes "intensity" of services however; there are contradictory opinions and varying definitions of this concept. Should an IFSP team be unable to reach consensus as to the intensity needed for a child to meet the identified outcomes, teams can utilize local and regional technical assistance resources to build consensus of the team.

When a team disagrees the following steps to resolution should take place:
1. The IFSP must be written within 45-days of referral to NEIS.
2. Services that are agreed upon by the IFSP team should begin or continue in accordance with the IFSP.
3. The service coordinator will provide a Written Prior Notice to the family regarding the services in dispute, if the program is refusing the parent's request for a service.
4. Families must be informed of their procedural safeguard rights and options throughout this process.
5. The team will offer to reconvene the IFSP meeting, with support from the Autism specialists within their region, within two weeks of the IFSP meeting where consensus could not be reached.

Changing Services
The IFSP team is responsible for identifying and correcting problems, should it be determined that methods and strategies of an intervention plan are not working. The team should amend the IFSP to reflect the steps taken and changes made that address the barriers.

Changes to the IFSP may include but are not limited to:
- Redefining the outcomes;
- Identification and remediation of medical issues;
- Increasing or decreasing frequency and intensity of services; or
- Modifying/changing the intervention strategies.

Planning for peer interaction
One of the eight components of effective practice is "opportunities for inclusion with typically developing peers in natural environments". In order to meet this program goal, teams will need to assess the needs and capabilities of the child for peer interaction at each periodic review.

Principle 4
Children with ASD require intensive engagement

By the very nature of the disorder, we know that children with ASD spend little of their own time engaged in purposeful, appropriate, goal directed behavior. Their tendency is to be either disconnected from their surroundings or fixated on specific aspects of objects or people. This restricts children with ASD from discovering and learning. Most children learn from interacting with their environment through observation and imitation. These opportunities may be lost to children with ASD. Engagement refers to the amount of time a child is attending to and actively interacting with others. This may happen during the time that the early intervention staff is working with a child, and also during interactions with family members and other caretakers. The early intervention staff works with the family to develop ways to keep a child with ASD engaged. The goal of intervention for the child with ASD is to increase the amount of time he or she is engaged throughout the day in order to achieve the outcomes identified on the IFSP. The most intensive intervention program is of limited benefit if it does not result in active engagement in the times when the child is not receiving services.

1. Depending on the needs of the child, he or she may receive a program of up to 20 hours per week. The individualized level of services and precise number of hours, specified in the IFSP, will vary depending on the child and family, the age of the child, the significance of the symptoms of ASD, the child's rate of progress, the child's health, response to, and the family's participation.

2. Nevada Early Intervention Services recommends that children with ASD have multiple opportunities for active *engagement* including any and all time child is engaged with adults and other children, including family members and interventionists. Engagement is defined by the National Research Council (2001) as "sustained attention to an activity or person" (p.160). In early intervention, engagement is planned and purposeful activities by the family and interventionists with the child. It is important to realize and remember that children with ASD can and do learn in everyday activities when those activities are structured around the child's abilities, goals and tolerances. For example, in the grocery store, one child may be able to retrieve the bread and other small items and put them in the cart with adult guidance. Another child may need to sit in the cart and practice going in the grocery store for brief periods of time without buying anything, in order to adjust to the stimulation of the store. Both situations are considered engagement, as the grocery store trip had a purpose and a plan for each child. Engagement can also happen in child care settings, community recreation places and at home with the family during natural routines. Service coordinators and the IFSP team will help families identify opportunities for providing engaging activities.

   Although exposure to natural environments is critical for young children with ASD, simply placing a young child with autism in a natural environment is unlikely to lead to intervention gains (reference). Naturalistic interventions, including those that involve child-directed learning opportunities, and parent, sibling, or peer interactions, must be well-planned, systematic, and involve a high rate of active engagement (references). Moreover, parents, siblings, and peers will need explicit training for such interventions to be effective. Depending on the individual child's needs, a combination of direct instruction and naturalistic approaches may be necessary.

3. The decision regarding specific number of hours for direct service should be made by considering the following factors:

- The outcomes identified by the IFSP team;

- The child's age;

- Total hours of engagement the family currently implements;

- The developmental profile of the child;

- Learning characteristics of the child;

- The child's previous involvement in intervention;

- The family's availability for level of service including daily routines of the child and family; and

- Quality and quantity of concerning behaviors (behaviors that are injurious to self or others may indicate a need for more intensive services).

Decisions about the intensity and frequency are determined by the members of the IFSP team. Members of the team include families, service coordinators, early intervention providers and evaluation/assessment team members, other professionals within the NEIS and persons requested by the family. Information, assessments and recommendations from physicians, neurologists and other professionals outside of the NEIS are considered with all other information and clinical opinions. Ultimately, the intensity and frequency of services must be what a child needs to meet the outcomes set forth in the IFSP. Therefore, it will be crucial that teams identify and write appropriate and relevant outcomes and objectively monitor progress for each.

IFSP team meetings are an important component of Early Intervention services. Time spent in team meetings, including team meetings with families, is outside of the recommended number of direct service hours. An hour of service that involves more than one interventionist is still regarded as one hour of service. In addition, families need to continue to use the same strategies throughout the child's day to increase the amount of time the child is engaged with others. Intervention should occur on a predictable and routine schedule with attention to the number of hours per day and week, number of weeks per year and the number of environments where intervention occurs. Services should take place 12 months a year. Vacations, holidays, inclement weather, staff illness, or other variations in the service calendar should be discussed with a family well in advance and there should be written documentation that the family understands and agrees with any scheduling changes that are made. Intensive intervention takes place across many different natural learning environments. This includes the home as well as community settings where the child spends his or her time. Families, as part of the IFSP team, work to identify ways to expand learning opportunities in a variety of settings and activities.

Principle 5
Family involvement and participation is critical

The mission of the Nevada Early Intervention Services is to help families meet the developmental needs of their infants and toddlers. Families are the most important teachers for their child. They are the constant in a child's life. Service systems and personnel will change over time, but families maintain the continuity from day to day and year to year. Families become lifelong advocates for their child. NEIS assists families with identifying how they want to be involved now and in the future. Nevada Early Intervention Services will provide families with education, support, and guidance to help them develop the skills necessary to help their child with ASD reach his or her potential.

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

1. Planning and participating in decisions about what services their child will receive through the IFSP process.
2. Evaluating child progress.
3. Training and assisting with activities of daily living and developing strategies for addressing the IFSP during daily routines.
4. Developing competence and confidence in order to support their child's needs through coaching from the early intervention providers (Hanft, Rush & Sheldon, 2004).

Family may choose to also be involved in:

1. Identifying services that may affect family resources such as obtaining housing, medical insurance, counseling or medical referrals.
2. Networking with other parents such as parent-to-parent support or support groups.
3. Taking part in program evaluation or advisory and policy committees for Nevada Early Intervention Services.

(See listing of Parent Resources, Appendix A Local Early Intervention Programs also have more specific resources for families.)

FAMILY SUPPORT

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

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

Without a doubt, having a child with ASD has a significant impact on the entire family, both nuclear and extended. Raising a child with ASD presents unique challenges and stressors, which become even greater if there are multiple births or a sibling with autism or another disability. Characteristics of ASD increase difficulties in daily care giving which in turn can impact marital and family relationships. Feelings of loss and grief, coping with the responses of extended family and friends, reactions to the child in public, financial strains, accessibility of services and concerns for the child's future care can put parents on an emotional rollercoaster. Adequate intervention and supportive services are critical to the well being of families and prevent isolation from relatives, friends, and the community.

Family support goals on the IFSP are as important as child developmental goals and reflect the needs of the individual child and family. These goals provide the support network required by the family to meet the extensive needs of their child with ASD. The family should be made aware of supports available and be offered them without delay. This information should be provided both verbally and written since the need for specific resources can vary over time in type, frequency and amount. Parents should be aware of public and private resources available to them. Informed and knowledgeable parents will be better able to help their child with ASD. The IFSP should reflect a wide range of family support outcomes that include:

Information about ASD
 It is crucial the family receives prompt and accurate information about ASD, if it is suspected or diagnosed. The information should be current, from nationally known ASD resources, and readily available. Parent(s) may not recognize the characteristics of ASD and therefore must be shown what to look for. They should have access to a resource library and training on ASD that provides practical information. This information should be provided to the family in a sensitive and respectful manner as the parents may be coming to terms with news of their child's ASD. Each family responds differently and the need for information may vary over time.

ASD Intervention and Training
The single most important support to parents is comprehensive early intervention for their child using current best practices and the hands-on training to utilize those practices in working with their child with ASD. Families need to be made aware of the benefits of early intervention and the positive impact on the child. Parents must be an integral part of the intervention planning

process and must be informed of the intervention options available to them. Parents need training on how to teach the child new skills or strategies to integrate the child's intervention into daily routines. Training opportunities should be ongoing so parent can build on the knowledge and experience in working with their child. It is critical that the interventions are consistent across people and environments. Parents may choose to provide additional intervention and/ or supplemental treatments to meet their child's unique needs and to enhance intervention outcomes. Intervention services and supports must fit into the context of family life and assist to meet the child and family outcomes. <u>Intervention services should begin as soon as possible because of the life-long impact on the family and cost to society.</u>

Support Groups for Families

Providing support to parents, grandparents, siblings and children is extremely helpful in coping with the impact of ASD on the family. Group meetings can help families cope with the isolation that can occur because of the challenges inherent to ASD and by the lack of understanding of the people around them. Because of the demands of caring for their child who may have eating, sleeping, and communicating difficulties along with behavioral excesses, parents may no longer be able to participate in preferred activities. The opportunity to meet with other families of children with ASD and benefit from their knowledge and experience is important. Parents can more comfortably ask questions of people who understand living with ASD. Meeting other families gives parents a glimpse of future possibilities and challenges they may come to experience. Families can find out how other parents have built support networks for themselves and their children. Support groups specific to ASD can provide guidance on intervention strategies, organizational tools, and resources available in their community and nationally. Attending group support meetings, hearing guest speakers, participating in special activities and social events, and networking provide families with invaluable information and opportunities to meet and recreate in a supportive atmosphere.

Grandparents and extended family members need to be included in support meetings or have access to their own. Grandparents may be at a loss on how to respond to their grandchild and not know how to support their son or daughter. Grandparenting a child with ASD may be confusing so grandparents need information on ASD and learn how they can enhance opportunities for bonding. Other family members need the same information, especially when in a supportive role. Understanding and helpful relatives contribute to the well being of the parents who have a child with ASD.

Siblings need help to cope with the demands placed upon their parents caring for a family member with ASD. The intense focus of time and attention for the child with ASD may limit the interaction and attention provided to "typical" siblings in the home. Siblings need to learn about ASD and receive help and instructions in interacting with their brother or sister with ASD. Parents need opportunities to spend quality time with their "typical" child. Support group activities can provide opportunities to meet peers who have siblings with ASD and participate in special events that are comfortable for the whole family.

Professional Counseling

It is important to recognize that parents need to help themselves before they can meet the often overwhelming demands placed upon them by their child with ASD. Individual counseling along with support groups can help parents deal with their feelings over the loss of their "typical" child and/or feelings of guilt of having somehow contributed to their child's ASD. Counseling can be provided in many ways by different professionals from psychologists to religious counselors and may even be the same person who is treating the child with ASD. Parents need someone to

speak to who is compassionate and understands their challenges, will provide emotional support, and provide constructive suggestions to cope with their situation. The birth of a child with ASD can challenge already fragile relationships. Reducing marital or non-marital stress experienced by parents will go a long way in providing the stable and supportive environment needed by a child with ASD. It is critical that all professional involved in the lives of families with ASD be understanding and not add to the stress of parenting. The successful provision of early intervention services for the child with ASD and the coping skills of parents are directly linked. If families are hopeful about the future then children with ASD will benefit from their positive feelings in the home.

Advocacy

Parents know their child best and are a wealth of knowledge about how their child with ASD responds. When knowledgeable about ASD, interventions, and service systems, parents make incredible advocates for their child. Other family members may take on the role of advocate as well. It is important to understand that this advocacy will involve life-long learning and the challenges presented by ASD will ebb and flow over time. Parents and family members need to learn as much as they can and as early as possible. They must have access to the resources in the community and elsewhere that will provide them with the tools to become an effective advocate. Good advocacy on behalf of the child with ASD will most certainly enhance intervention outcomes.

Transition

A hallmark of autism is difficulty with change. It is important that the child's transition from NEIS services to public school services are seamless and uninterrupted. Interruptions of services for extended periods of time are unacceptable and detrimental to the child's progress. If a child with ASD regresses due to an interruption of services, it may take considerable time and effort to bring the child's skills back to the level prior to the cessation of services. A significant amount of preparation by NEIS, public school and the parents should occur prior to the transition. All entities will meet and cooperatively develop a transition plan prior to the move and in enough time to be effective. The transition will take place as agreed upon and with all the necessary supports in place prior to the transition. Advance planning by all parties will help the child's adjustment to new settings and minimize adjustment difficulties.

Principle 6

Intervention is based on an individualized program designed to address the specialized needs of the child with ASD

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

1. **Attending to and staying engaged in the environment, especially to other people and learning opportunities**. Children with ASD are many times thought of as "being in their own world". The more attention and engagement with the environment the child has, the more opportunities for intervention are presented. Engagement does not only mean during planned activities. Engagement also means how to include the child when laundry needs to be done and the child is wandering around the house. Families and interventionists need to look at arousal levels before, during and after planned activities and help families to understand the level of arousal their child needs to participate in daily routines and play behavior.

2. **Imitating others, including both verbal and motor imitation. Imitation is seen as a fundamental tool for learning**. Imitation is a broad concept in child development and can be encouraged across most environments, activities and people.

3. **Using verbal and non-verbal communication such as gestures, vocalizations and words.** A child with ASD must develop some type of communication system in order to be successful socially, and to communicate in a way others will understand. An alternative or augmentative system may be necessary. The type of communication system will vary depending on the child and their activities and environments they participate in.

4. **Understanding and using language to communicate**. An alternative or augmentative system does not mean that the child will not develop verbal language skills or speech. The communication system is used as an aid to improve communication and speech, increase social interactions, and provide structure to daily activities and routines. The use of these systems can decrease a family's feelings of frustration at not being able to communicate with their child, and also reinforce families as they see the child become successful in their use of language.

5. **Playing appropriately with toys.** Before focusing on social interaction in play, a child needs to have some skills for using toys in a playful way. Usually children begin interacting with toys by playing by themselves. Planned play sessions can help teach a child to play. The environment needs to be organized. The physical space should be defined in a way that is clear to the child such as sitting at a table or on a rug. As a child becomes more sophisticated in their use of toys, play will develop into symbolic use of toys, then social or parallel play, followed by more cooperative play. However, many children with ASD will need to be taught these play skills using a variety of methods.

6. **Playful interaction with others.** Playful interaction with others generally starts with the immediate family. Children with ASD can be affectionate, playful and enjoy physical attention as well as enjoy interaction with peers/siblings. Spontaneous moments of play

should be encouraged and sought by families. Each child will need to be considered individually for many characteristics such as their sensory needs which could impact play and affection and their ability to tolerate touch; their ability to join small groups, which may mean planning and slow exposure to child-adult interactions and child-child interactions; and disruption of routine, which may not be easily tolerated by a child with ASD.

7. **Reciprocal interactions.** A key area of concern for a child with ASD is participating in reciprocal interactions such as turn taking, showing, and joint attention. Helping a child participate in turn taking for example, focuses not only on engagement, but also social interaction and language.

8. **Spontaneous interactions.** Young children engage in spontaneous interactions on a daily basis. A book open on the floor is brought to the parent to read, or a child hears a plane and points up. A child with ASD usually does not demonstrate spontaneous interactions with any regularity. Careful planning and set up of situations can help develop this skill in children with ASD, as well as working with families and caregivers to recognize and reinforce any spontaneous interaction on the part of their child.

9. **Making choices.** Choice making is a huge part of developing independence, communication and social skills. Choice making should be encouraged across all daily routines and all environments whenever possible. Alternative communication systems can aid in choice making.

10. **Following daily routines and variations in routines**. Children with ASD often have difficulty following routines, or tolerating variations in set routines. Intervention should focus on helping a child participate with the family and with peers. Intervention should also focus on slowly helping the child learn to adapt to small changes in routines.

11. **Regulating Sensory Challenges.** Understanding each child's unique regulatory-sensory processing differences is important to daily activities and routines. Patterns of over or under responsivity, as well as sensory discrimination and sensory-based motor challenges should be considered.

Principle 7
Intervention is carefully planned and systematic

Systematic intervention or instruction is carefully planned and consistent. It involves assessing, planning, teaching and measuring progress with each intervention step. Each step is coordinated toward a meaningful set of outcomes or goals. The only reliable way to determine if our intervention is effective is to be systematic and to measure progress on a regular basis. Systematic instruction relies on intervention decisions that are driven by data collection. Data is used to measure the change in a behavior over time. Data may be taken on the frequency (how often) a behavior does or does not occur, the duration (how long) a behavior does or does not occur, and the range of a behavior (how much support or prompting a child needs). In order to use data in reviewing the effectiveness of intervention the following must happen:

1. An assessment is completed prior to intervention including formal developmental assessment, observation and parental interview;

2. Outcomes and objectives are written to be functional and in measurable terms. There must be a specific description of the desired behavior;

3. Data on outcomes and objectives are taken prior to intervention and used as a baseline for intervention. Videotape is an excellent way to determine a baseline;

4. Steps or tasks towards outcomes are analyzed and defined. The team needs to determine how the child will reach the outcome and identify any pre-skills that need to be developed;

5. Instructional strategies and supports are identified (e.g. where, when, with whom, level of support); The team should begin where the child is at and always remember to move from least to most prompting when necessary;

6. Methods for motivating or reinforcing the desired behaviors are identified. Reinforcer surveys and functional behavior analysis, as well as observation from team members who may have a unique perspective or experience can be helpful to determine ways to decrease or increase the specified behavior;

7. Methods and timelines for measuring progress are determined. Team meetings should be included on the IFSP;

8. Data is taken and analyzed on a routine basis, but does not need to be taken on each of the child's actions. The service coordinator maintains the data;

9. Adjustments in intervention plans including outcomes, strategies and methods and frequency and intensity are made based on analyzing progress on the IFSP as supported by the data.

Ongoing collaboration between the family and service providers in the analysis of data and flexibility in adjusting strategies is a key to successful teaching and learning. Continuation of ineffective strategies or relying on techniques merely because they have been shown to be effective with other children may be harmful. Many intervention teams find that a regularly scheduled meeting of all team members (including the family) is important to review data, maintain consistency in intervention, and make timely changes in the intervention. The frequency of this meeting and the participants should be included as an outcome on the IFSP. (Please refer to Principle 3 in this document).

Although programs will be allowed some flexibility, good practice indicates that you should consider the following ways to collect and maintain the data; which should always support the outcomes identified on the IFSP.

- **Formal Data Collection Sheets** – Data sheets capture data in an easy to read format, tracking progress over time towards a particular outcome. Each data collection sheet should include the target response or outcome, the type of prompt needed (e.g. Verbal, gesture, physical), and the percentage of correct independent responses. These forms can be printed on NCR paper, which would make the duplication of data very easy for the team.

- **Notebooks** -- Two notebooks should be created to maintain the data sheets; one for the family and a duplicate for the service coordinator. Anyone working with the child and family would be able to access the information to know at a glance what the child is working on, how they are progressing and if any changes are needed. The service coordinator's notebook should be kept with the child's confidential record.

- **Cover Sheet** -- The notebook should include a cover sheet that identifies the programs the child is working on. The program would be specified as would the response, the date introduced and the date it was mastered.

- **Maintenance Sheet** -- Another type of data sheet that could be included in the notebook is a maintenance data sheet which tracks programs that have been considered mastered and are included in expanded trials. Any program that the child appeared to no longer have mastered could be put back into rotation of new programs. It is very important for the service coordinator to remember to keep their notebook updated on a weekly basis.

- **Shared Files** -- Consistent communication among team members is essential. Teams may consider using shared files to access one another's progress notes or other important information. Each program would determine procedures to set up and maintain the files (e.g. with codes for write or read only). The service coordinator would be responsible for maintaining the shared files.

- **IFSP outcomes** – Formal data sheets can also be adapted to collect data on progress toward IFSP outcomes that are not based in Discrete Trial. For example, if a child is working on responding to their name, the team member might document how many times during a session they called the child's name, and how many times the child was able to turn independently. This generally would not be a discrete trial program, but data should be maintained to determine progress. Additional outcomes that might be documented in this manner are drinking from a cup, using a spoon, pulling off / on clothes, etc.

- **Videotape** -- Videotape is an excellent way to capture data. Initial video can document a baseline of the child's skills. Additional videotaping on a consistent basis can demonstrate change over time and can be a concrete way to view progress and the nuances of a child or parent's behavior that might be missed otherwise. Monthly videotaping of each staff member working with the child is recommended. The tapes must be kept in a secured location by the service coordinator to protect confidentiality. In addition, the tapes, with the parent's permission, can be used as training materials for new staff.

- **Progress notes** – All progress notes should be comprehensive. See the Effective Practice Guidelines Service Coordination Module for information on thorough documentation in DAP or SOAP format. All team members must complete their documentation.

- **IFSP** -- IFSP updates must happen at a minimum of every six months. However, more frequent IFSP reviews can be conducted if the data is showing that the child achieved an outcome or is not progressing towards an outcome. The IFSP should always reflect the

current concerns of the parent as well as appropriate, not ineffective, outcomes for the child and family.

- **Transition** – The most current data should be made available to statewide Early Childhood Special Education Programs (Part B of IDEA) for consideration during the development and implementation of an appropriate IEP.

Principle 8
Challenging behaviors are addressed using positive behavioral support

Positive behavioral support is a set of principles that frame the way we think about and respond to children and their behavior. The principles are grounded in the appreciation of each child's strengths and challenges. To practice positive behavioral support means getting to know the whole child and assuming his or her behavior has meaning and that the behavior is a form of communication. It requires recognizing that children develop and respond best when they are respected and supported to enjoy relationships and make choices. The Individualized Support Project or ISP model developed by Glenn Dunlap and Lise Fox (1996) provides a framework for working with families who have children with challenging behaviors. (9) Challenging behaviors displayed by children with ASD are complex and may create frustration and confusion for those who interact with the child. Behavior may range from aggression, tantrums, or self-injury to withdrawal or repetitive, stereotypical actions. Some of these behaviors occur in children who are typically developing. For children with ASD we see behaviors that are extreme, occur more frequently, or are more disruptive to development. Although some behaviors occur for medical or other reasons the majority of challenging behaviors occur because of:

1. Social misunderstanding
2. Communication frustration
3. Discomfort with the physical environment
4. Anxiety
5. Intense preoccupations or interests

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

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

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

The plan may also include strategies to address sensory problems. Many individuals with ASD display different or atypical reactions to common sensory experiences. There may be an over-

reaction or under-reaction to sights, sounds, touch, movement, body position/awareness and the pull of gravity. Due to this, the individual may become over-aroused, display discomfort, complain, withdraw or engage in some sensory related behavior. This results in problem behavior. Intervention to address sensory related behaviors is called Sensory Integration (SI) Therapy. Individuals who have difficulty processing and regulating sensory information are challenged by difficulties with attention, learning, and social interaction. There is no research that indicates that sensory integration therapy has any direct impact on ASD. However, sensory issues may be particularly overwhelming to children with ASD, so treatment that addresses them may prove to be helpful. Sensory Integration therapy strives to reduce the child's preoccupation with his/her sensory needs by satisfying the sensory craving, reducing the stimuli in the environment and increasing the tolerance for sensory stimulation. Once able to regulate the sensory input, the child is more available for engagement and learning opportunities.

What is Positive Behavior Support

Positive behavior support (PBS) is an approach to intervention with children with ASD derived broadly from social, behavioral, educational, and biomedical science to achieve reduction in problem behavior and improved quality of life. The research based principles and strategies of applied behavior analysis and the values of person centered planning provided the foundation for positive behavior support. PBS is applicable across contexts and with diverse populations. As an approach for addressing concerns of behavioral adaptation, PBS has expanded rapidly from its beginnings in developmental disabilities to include many additional populations, disciplines, and units of analysis. PBS has become the approach of choice for individuals with diverse characteristics and for a great range of circumstances and challenges in school and community settings.

The critical features of PBS include comprehensive lifestyle change and quality of life, life-span perspective, ecological validity (contextual fit), ongoing stakeholder participation, and social validity. PBS is unique in its focus on systems change and use of multi-component intervention guided by functional behavior assessment. Emphasis is placed on prevention, environmental redesign and instruction.
In the positive behavior support approach, the following components will be present:

- A team assembled that has agreed to support the child. The team includes individuals who know the child, who know the relevant settings, and who have expertise in behavior.
- Person-centered planning regarding lifestyle ambitions of the family.
- A description of goals for improved lifestyle for the focus child and the family.
- Functional assessment identifying all of the major environments in which the problem behavior occurs.
- Functional assessment identifying possibly relevant antecedent stimuli and maintaining stimuli.
- Direct observation relevant to the confirmation of the hypothesis.
- A multi-component behavior support plan using research validated strategies that is implemented in all relevant environments by multiple intervention agents with a high level of integrity for as long as needed.

In serving children with ASD, positive behavior support provides a comprehensive framework for behavioral assessment, intervention and evaluation. A behavior support plan may incorporate a variety of strategies or programs (e.g., PECS, DTI) as relevant and appropriate to the comprehensive approach created for the child. The PBS approach assumes that behavior support may be needed for a long time, that sustainable behavior support will be a dynamic process, and that functional systems change may be necessary.

Principle 9

The transition from Nevada Early Intervention Services to preschool special education and related services should be well planned

Children with ASD often have difficulty with change, including change experienced when starting something new and different. During the transition to a school based program there will be changes in adults, children, settings, and routines. The child with ASD may be so sensitive to change that they may notice differences that we do not. There are significant differences between the service delivery model used in the Birth to Three System and an educationally based program developed by a local school district.

Planning and flexibility on the part of Early Intervention providers and preschool programs are necessary to assist families and children with adjusting to this change. When planning the transition from a Birth to Three program to a school program, the following is helpful:

1. By 27 months or earlier, notification to the school system that the child is receiving Early Intervention Services. This should occur even before discussions regarding transition take place. Early notification allows the school district to plan for the child with ASD. This may include identification of the appropriate staff and resources needed as well as completion of any training staff may need;
2. Details of the program that is in place and strategies that have been successful;
3. A focus on the family as well as on the child throughout the transition process.

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

Unfortunately, many children with ASD do not present their complex needs until very shortly before their third birthday. If that is the case, Early Intervention providers must work diligently to help parents understand the need to share information with the school district as soon as possible. Transition and transition activities should be a major focus of IFSPs for all children with ASD but especially for those nearing the age of three. School districts may wish to participate in joint evaluations or observations of the child. It is important for Birth to Three programs to participate in early information-sharing with school districts for all children with complex or challenging behaviors whether or not they have an ASD diagnosis. (See Module 5 Transition). Service coordinators are encouraged to attend the IEP meeting with parental consent and share the IFSP.

Types of Alternative or Complementary Treatments for ASD

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

These interventions will not be financially supported by NEIS.

Hormone Therapies
Several health problems in children and adults are associated with deficiencies of particular hormones. Some hormone replacement therapies have been proposed as possible treatments for autism. In particular, adrencorticotropin hormone (ACTH) and secretin (a hormone that helps regulate digestion) have been suggested. These have not been found to be effective in scientific studies for young children and the potential side effects from treatment with secretin are unknown.

Secretin
The information below is extracted from the Autism Society of America website: www.autism-society.org

Secretin is a hormone produced by the small intestines that helps in digestion. It is currently used as a single dose to diagnose gastrointestinal problems. In 1996, a young boy with autism was given secretin for an endoscopy and showed improvements in some of his symptoms of autism. Other parents and professionals who tried secretin on children with autism reported similar results, including improvements in sleep patterns, eye contact, language skills, and alertness. However, several studies funded by the National Institute of Child Health and Human Development (NICHD) in the past three years have found no statistically significant improvements in the core symptoms when compared to patients who received a placebo. It is also important to remember that secretin is approved by the FDA for a single dose; there are no data on the safety of repeated doses over time.

Chelation Therapy Described by Proponents
Excerpted from Adelle Jameson Tilton, Part 1: A new hope for Autism?
http://autism.about.com (accessed on 8/2/2005)

Chelation therapy was first developed by the United States Navy as a way of removing toxic metals from the bodies of military personnel exposed to high concentrations of lead during the 1940's. Since that time, it has been used in the treatment of people exposed to lead paint particles and other environmental exposures, and is a recommended treatment by the American Academy of Family Practice and the American Academy of Pediatrics for this purpose. Now, however its use is being expanded to the treatment of other medical conditions such as Autism.

The chemical process that takes place in chelation is complicated, but put in simple terms, the heavy metals, such as mercury, bind to the chelating agent and then are eliminated from the body. In theory, once they are removed, their toxic effects are eliminated and the individual begins to show improvement in the areas which were exposed to these metals. There are

several products which are in use as chelators and are prescribed for use by some physicians.

One of the best and safest chelators is DMSA. While not approved by the FDA for use in Autism, it is approved for removal of lead from children who have been diagnosed with lead poisoning. Due to the nature of DMSA, however, it does not simply bind to lead, but to any heavy metal.

Another common chelator is DMPS. This substance, however, has never been tested in children and has not been found to be safe and effective. It also is very expensive and can only be purchased through a compounding pharmacist. For these reasons, it is usually not covered by health insurance policies. Because of these factors, it is not recommended for use with children and is a poor alternative to DMSA according to many specialists.

Another product in use is lipoic acid. This is an excellent chelator, since it is lipid soluble, and is therefore able to cross cell membranes better than the water soluble product DMSA. In theory, this makes it more effective, since most of the mercury is stored within the cells and is harder to reach and create bonds with.

There are two steps to chelation therapy that are essential if it is to work. First, the loosely-bound body mercury must be eliminated. This can be done with DMSA. It is given in a one week on, one off pattern with dosages being administered every four hours. Once the urine mercury levels have stabilized, the next step is chelating the mercury that is tightly bound within the cells. This is done using lipoic acid.

It is important to provide nutritional support designed to counteract mercury's known effects and to use monitoring tests to check on blood counts, kidney and liver function, and mineral levels, and to gauge how much mercury is being eliminated from the body. These tests must be done under supervision of a physician, and as in any medical treatment should be closely supervised and the recommendations of the physician should be followed by the patient.

The Opposing View of Chelation Therapy
Excerpted from Adelle Jameson Tilton, Part 1: A new hope for Autism?
http://autism.about.com (accessed on 8/2/2005)

While much publicity has been given to chelation therapy within the Autism community, the overwhelming opinion of the traditional medical community is that it is an unproven therapy that should be avoided. According to Saul Green, PhD, the American College for Advancement in Medicine (ACAM), the primary proponents of chelation, and its Board Certification program are not recognized by the scientific community.

Green also points out that the typical treatment program costs between $75 and $125 per treatment, takes between 20 and 100 treatments to show results, and is not covered by insurance. Other physicians point out that some chelation therapists attempt to secure insurance coverage by misrepresenting the patient's treatment to the insurance companies, therefore practicing insurance fraud rather than medicine.

It is interesting that none of the material discussed above is related to chelation therapy in the treatment of Autism or other developmental disorders. It relates to claims that chelation is an effective treatment for heart disease. The implication, however is that if it is a fraudulent treatment for heart disease, then all treatments using this procedure are suspect and should be avoided.

It is obvious that more research needs to be done into this treatment. In November 2000, Cure Autism Now (CAN), a leading Autism research organization called for research proposals to finally investigate the effectiveness of chelation therapy in Autism treatment. Since there has been no research studies done to validate the claims of those who tout chelation in the treatment of Autism, this treatment should be considered unproven and the safety and effectiveness of it are still undetermined.

This viewpoint is supported by the Autism Biomedical Information Network, which lists chelation as an unproven treatment. They point out that no reliable research studies have been made on many treatments being offered as alternatives to traditional Autism treatments, and that most of the information available on their effectiveness is anecdotal rather than based on valid scientific research techniques.

While it is not illegal for a physician to prescribe chelation therapy for the treatment of Autism, without valid research studies, any treatment that has not been properly researched should be undertaken with a degree of skepticism. Until chelation is approved for use with individuals with autism spectrum disorders and until valid research is conducted, the traditional medical community recommends that it be avoided.

Immune Therapies

Immune therapies include treatment with intravenous immune globulin has been suggested as a possible treatment for children with autism. Proponents of these therapies suggest that a subset of children with ASD have abnormalities in their immune systems. The only treatment described in the scientific literature is intravenous immune globulin (IVIG) therapy.

Diets (e.g. gluten-free, casein free)

The information below is extracted from the Autism Society of America website:
www.autism-society.org (accessed on 4/7/2005)

Individuals with autism may exhibit low tolerance of or allergies to certain foods or chemicals. While not a specific cause of autism, these food intolerances or allergies may contribute to behavioral issues. Many parents and professionals have reported significant changes when specific substances are eliminated from the child's diet.

Individuals with autism may have trouble digesting proteins such as gluten. Research in the U.S. and England has found elevated levels of certain peptides in the urine of children with autism, suggesting the incomplete breakdown of peptides from foods that contain gluten and casein. Gluten is found in wheat, oats and rye; casein in dairy products. The incomplete breakdown and the excessive absorption of peptides may cause disruption in biochemical and neuroregulatory processes in the brain, affecting brain functions. Until there is more information as to why these proteins are not broken down, the removal of the proteins from the diet is the only way to prevent further neurological and gastrointestinal damage.

It is important not to withdraw gluten/casein food products at once from a child's diet as there can be withdrawal symptoms. Parents wishing to pursue a gluten/casein free diet should consult a gastroenterologist, nutritionist, etc., who can help ensure proper nutrition.

Some hypothesize that children with autism have what is referred to as a "leaky gut" -- tiny holes in their intestinal tract that may be caused by an overgrowth of yeast. Some believe that this overgrowth may contribute to behavioral and medical problems in individuals with autism, such

as confusion, hyperactivity, stomach problems, and fatigue. The use of nutritional supplements, anti-fungal drugs and/or a yeast-free diet may reduce the behavioral problems. However, caution should be paid to the fact that just as antibiotics can lead to bacterial resistance, antifungals can lead to fungal resistance.

Dietary supplements/Vitamins

The information below is extracted from the Autism Society of America website: www.autism-society.org (accessed on 4/7/2005)

Over the past 10 years or more, claims have been made that vitamin and mineral supplements may improve the symptoms of autism, in a natural way. While not all researchers agree about whether these therapies are scientifically proven, many parents and an increasing number of physicians report improvement in people with autism with the use of individual or combined nutritional supplements.

Malabsorption problems and nutritional deficiencies have been addressed in several as-yet unreplicated studies. A few studies conducted in 2000 suggest that intestinal disorders and chronic gastrointestinal inflammation may reduce the absorption of essential nutrients and cause disruptions in immune and general metabolic functions that are dependent upon these essential vitamins. Other studies have shown that some children with autism may have low levels of vitamins A, B1, B3, B5, as well as biotin, selenium, zinc, and magnesium, while others may have an elevated serum copper to plasma zinc ratio, suggesting that people with autism should avoid copper and take extra zinc to boost their immune system. Other studies have indicated a need for more calcium

Perhaps the most common vitamin supplement used in autism is vitamin B, which plays an important role in creating enzymes needed by the brain. In 18 studies on the use of vitamin B and magnesium (which is needed to make vitamin B effective), almost half of the individuals with autism showed improvement. The benefits include decreased behavioral problems, improved eye contact, better attention, and improvements in learning. Other research studies have shown that other supplements may help symptoms as well. Cod liver oil supplements (rich in vitamins A and D) have resulted in improved eye contact and behavior of children with autism. Vitamin C helps in brain function and deficiency symptoms that include depression and confusion. Increasing vitamin C has been shown in a clinical trial to improve symptom severity in children with autism. And in a small pilot study in Arizona using a multivitamin/mineral complex on 16 children with autism, improvements were observed in sleep and gastrointestinal problems as well as in language, eye contact, and behavior.

Using Vitamins and Minerals

If you are considering the addition of vitamins or minerals to your child's diet, a laboratory and clinical assessment of nutritional status is highly recommended. The most accurate method for measuring vitamin and mineral levels is through a blood test. It is also important to work with someone knowledgeable in nutritional therapy. While large doses of some vitamins and minerals may not be harmful, others can be toxic. Once supplements are chosen, they should be phased in slowly - over several weeks - and then the effects observed for one to two months.

The increase in the use of medications to treat autism has highlighted the need for more studies of these drugs in children. The National Institute of Mental Health has established a network of Research Units on Pediatric Psychopharmacology (RUPPs) that combine expertise in psychopharmacology and psychiatry. Located at several research centers, they are intended to become a national resource that will expedite clinical trials in children. Five groups are

specifically funded to evaluate treatments for autism, studying dose range and regimen of medications as well as their mechanisms of action, safety, efficacy, and effects on cognition, behavior, and development. For example, the RUPP at Kennedy Krieger Institute is conducting a study on the efficacy of methylphenidate (Ritalin) in children and adolescents with Pervasive Developmental Disorders (PDD).

If you are considering the use of medications, contact a medical professional experienced in treating autism to learn of possible side effects. People with autism may have very sensitive nervous systems and normally recommended dosages may need to be adjusted. Even the use of large doses of vitamins should be done under the supervision of a medical doctor.

Sound Therapy Programs
There are a host of sound therapies available that have been utilized in the treatment of ASD. The Polyvagal Theory suggests that sound therapies improve facial expression, looking, vocalizing and listening. Research to validate claims has been limited and not well supported. Programs vary significantly with regards to cost, intensity and the training of practitioners.

Tomatis
Alfred Tomatis is credited with original theories regarding listening and the impact of the ear as an "integrator" connected to receptive and expressive language, learning, motor control and motivation. Technique designed to start at 3-4 years of age.

Auditory Integration Training AIT (Berard)
This work is based on the work of Tomatis, which believes that distortions in "hearing" are the cause of auditory processing problems. This technique was designed to start at 3-4 years of age and participants are to "never listen to headphones again."

Listening Fitness (Madule)
Paul Madule based concepts on the work of Tomatis with the emphasis on program on relating listening to learning, academics and vocal expression. This intensive program follows detailed assessment with 60 hours of listening over 10 weeks, two hours per day 6/7 days per week.

EASe (Mueller)
This program is based on the work of Tomatis and Verard with the intent of making programs more affordable, available and less intensive.

Therapeutic Listening
Modified music is utilized to train sensory systems to improve sensory processing used within a comprehensive sensory integration approach. This technique is intended for children age two and above.

The Listening Program
This one-size fits all approach utilizes a progression of CDs in an eight week program. The goal is to improve listening state and remediate auditory processing issues.

Craniosacral Therapy

One alternative therapy for children with autism is Craniosacral therapy. Prescribed by some osteopathic physicians, Craniosacral therapy is described as "a gentle hands-on approach which helps improve central nervous system function and dissolve the effects of stress. It also helps boost the immune system and can be used for a number of infantile disorders in addition to autism." Dr. John Upledger, the creator of this approach, believes that children who have ASD show symptoms of restricted fluid movement through head banging, wrist biting, teeth grinding and hyperactivity.

Using a soft touch generally no greater than 5 grams, or about the weight of a nickel, practitioners release restrictions in the craniosacral system to improve the functioning of the central nervous system.

Some parents of children with autism who have had their children treated with Craniosacral Therapy have reported that the child is more relaxed, able to make better eye contact and is more verbal. All claimed benefits for Craniosacral Therapy come in the form of anecdotal evidence. To date there are no research studies indicating Craniosacral Therapy is a viable treatment for autism spectrum disorders.

Music Therapy

http://www.musictherapy.org/ (Accessed on 8/24/05)
Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program. *(American Music Therapy Association definition, 2005)*

What do music therapists do?

Music therapists assess emotional well-being, physical health, social functioning, communication abilities, and cognitive skills through musical responses; design music sessions for individuals and groups based on client needs using music improvisation, receptive music listening, song writing, lyric discussion, music and imagery, music performance, and learning through music; participate in interdisciplinary treatment planning, ongoing evaluation, and follow up.

Holding Therapy

(Richard, 2000)
Holding therapy gained wide-spread attention when Dr Martha Welch, a child psychiatrist from New York, began using it as a means of working with children with autism. Her work is written in the book, *Holding Time*.

During holding therapy the parent attempts to make contact with the child in various ways. This may mean simply comforting a distressed child, but often the parent may hold the child for periods of time, even if the child is fighting against the embrace. The child sits or lies face to face with the parent, who tries to establish eye contact, as well as to share feelings verbally throughout the holding session. The parent remains calm and in control and offers comfort when the child stops resisting.

There is no empirically validated research that supports the use of Holding Therapy as a viable treatment for autism spectrum disorders.

Vision Management Therapy
(Richard, 2000)
Visual Management Therapy is based on the proposition that many individuals with autism have problems with visual perception. This does not mean that individuals with autism have any greater problems with visual acuity than the population as a whole. Visual perception, however, involves far more than visual acuity; it is a process for receiving, integrating and interpreting visual stimuli. A lack of integration between the visual and vestibular systems, or an inability to orient oneself in space and adapt to changes in the visual environment are examples of visual perception dysfunction. Proponents of Visual Management Therapy suggest that visual perception dysfunction can produce symptoms of mental and physical disorders, as well as autism.

Treatment involves the use of special lenses, which transform light, in combination with visual exercises designed to enable the patient to process visual stimuli in an organized, integrated fashion. Such therapy is presumed to allow the patient to achieve harmony with his environment and reduce the panic responses to visual information, which are symptomatic of autism.

There is no empirically validated research that supports the use of Visual Management Therapy as a viable treatment for autism spectrum disorders.

Facilitated Communication
The information below is extracted from the Autism Society of America website:
www.autism-society.org (accessed on 4/7/2005)

Facilitated communication (FC) was developed in the 1970s in Australia by an aide who was trying to help a patient with cerebral palsy to communicate. It is based on the idea that the person is unable to communicate because of a movement disorder, not because of a lack of communication skills. FC involves a facilitator who, by supporting an individual's hand or arm, helps the person communicate through the use of a computer or typewriter. It has not been scientifically validated; critics claim it is actually the ideas or thoughts of the facilitator that are being communicated. FC is very controversial and organizations such as the American Association of Mental Retardation, and the American Academy of Child & Adolescent Psychiatry have adopted formal positions opposing the acceptance of FC.

Medications (should be noted on IFSP under health/medical information)
The information below is extracted from the Autism Society of America website:
www.autism-society.org (accessed on 4/7/2005)

There are a number of medications, developed for other conditions that have been found effective in treating some of the symptoms and behaviors frequently found in individuals with autism, such as hyperactivity, impulsivity, attention difficulties, and anxiety. The goal of medications is to reduce these behaviors to allow the individual with autism to take advantage of educational and behavioral treatments.

When medication is being discussed or prescribed, ask about the safety of its use in children with autism. What is the appropriate dosage? How is it administered (pills, liquid)? What are the long-term consequences? Are there possible side effects? How will my child be monitored and by whom? What laboratory tests are required before starting the drug and during treatment? Are there possible interactions with other drugs, vitamins or foods?
Given the complexity of medications, drug interactions, and the unpredictability of how each patient may react to a particular drug, parents should seek out and work with a medical doctor

with an expertise in the area of medication management.

What Medications are Available?

There are a number of medications that are frequently used for individuals with autism to address certain behaviors or symptoms. Some have studies to support their use, while others do not.

The Autism Society of America does not endorse any specific medication. The information provided here is meant as an overview of the types of medications sometimes prescribed. Be sure to consult a medical professional for more information.

Serotonin re-uptake inhibitors have been effective in treating depression, obsessive-compulsive behaviors, and anxiety that are sometimes present in autism. Because researchers have consistently found elevated levels of serotonin in the bloodstream of one-third of individuals with autism, these drugs could potentially reverse some of the symptoms of serotonin disregulation in autism. Three drugs that have been studied are clomipramine (Anafranil), fluvoxamine (Luvox) and fluoxetine (Prozac). Studies have shown that they may reduce the frequency and intensity of repetitive behaviors, and may decrease irritability, tantrums and aggressive behavior. Some children have shown improvements in eye contact and responsiveness.

Other drugs, such as Elavil, Wellbutrin, Valium, Ativan and Xanax have not been studied as much but may have a role in treating the behavioral symptoms. Most of these drugs have not been tested on children under the age of three. However, all these drugs have potential side-effects, which should be discussed before treatment is started. Medication should only be an adjunct to good intervention.

Anti-psychotic medications have been the most widely studied of the psychopharmacologic agents in autism over the past 35 years. Originally developed for treating schizophrenia, these drugs have been found to decrease hyperactivity, stereotypic behaviors, withdrawal and aggression in individuals with autism. Four that have been approved by the FDA are clozapine (Clozaril), risperidone (Risperdal), olanzapine (Zyprexa) and quetiapine (Seroquel). Only risperidone has been investigated in a controlled study of adults with autism. Like the antidepressants, these drugs all have potential side effects, including sedation.

Stimulants, such as Ritalin, Adderall, and Dexedine, used to treat hyperactivity in children with ADHD have also been prescribed for children with autism. Although few studies have been done, they may increase focus, and decrease impulsivity and hyperactivity in autism, particularly in higher-functioning children. Dosages need to be carefully monitored, however, because behavioral side effects are often dose-related.

Resources on Alternative or Complementary Treatments

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

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

American Music Therapy Association
8455 Colesville Road, Suite 1000
Silver Spring, MD 20910
301-589-3300
www.musictherapy.org (Music Therapy) (accessed one 8/5/2005)

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

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

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

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

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

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

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www.healthstatenyus/nysdoh/eip/indexhtm (Multiple)

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

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

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Neuropharmocoloical therapy in autism. In P. Accardo, C. Magnusen & A. Capute (Eds.), Autism Clinical and Research Issues. Baltimore, York Press. (Medication)

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

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Brochure: Autism Information Written for Kids Only Available from: Autism Society of America 7910 Woodmart Avenue, Suite 650 Bethesda, MD 208114-3015 1-800-3-AUTISM www.autism-society.org

Videos

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

Discrete Trial Teaching (1999)
Family Education Series NY Families for Autistic Children, Inc.
718-641-6711

An Introduction to PECS:
The Picture Exchange System (1998)
Pyramid Ed Consultants, Inc.
226 W. Park Place, Suite 226
Newark, DE, 1974

Autism: Being Friends (a video for children)
Indiana Resource Center for Autism
3853 East 10th Street
Bloomington, IN 47408
812-855-6508
www.iidc.indiana.edu (publications catalog screen)

Appendix A

Resources for parents of children with Autism

The opinions or information expressed by these agencies are not necessarily those of NEIS or its staff

Organizations and Agencies

PEP (Parents Encouraging Parents)
Statewide: 1-800-216-5188
Las Vegas: (702) 388-8899
Reno: (775) 448-9950
www.nvpep.org (*accessed on June 22, 2005*)

Nevada Disability Advocacy & Law Center
North: (775) 333-7878
North Toll Free: 1-(800)992-5715
Las Vegas: (702) 257-8150
South Toll Free: 1 (800)349-3843
www.ndalc.org (*accessed on June 22, 2005*)

Northern Nevada Center for Independent Living
Reno- (775)355-3599
Fallon- (775)423-4900
Elko- (775) 753-4300

Sierra Regional Center
(775) 688-1930
www.mhds.state.nv.us/src/ (*accessed on June 22, 2005*)

Rural Regional Center
(775) 687-5162
www.mhds.state.nv.us/rrc/ (*accessed on June 22, 2005*)

Desert Regional Center
(702) 486-6200
www.mhds.state.nv.us/drc/ (*accessed on June 22, 2005*)

Southern Nevada FEAT (Families for Early Autism Treatment)
(702) 595-2067
www.featonv.org (*accessed on June 22, 2005*)

FEAT of Carson Valley
(775) 782.4138
www.featofcarsonvalley.org (*accessed on June 22, 2005*)

Easter Seals of Southern Nevada (can provide respite vouchers for Northern and Rural Nevada as well)
(702) 870-7050
www.sn.easterseals.com (*accessed on June 22, 2005*)

Appendix A

Consumer Leadership Fund- Governor's Council on Developmental Disabilities
(775) 687-4452

Project ASSIST
(775)688-2819
Statewide: 1-800-522-0066
www.health2k.state.nv.us/BEIS/ (*accessed on June 22, 2005*)

Family Ties
Statewide: 1-866-326-8467
www.familytiesnv.org (*accessed on June 22, 2005*)

Center for Family Enrichment
(775) 355-7722

Nevada Autism Summit
University of Nevada- Reno
Research and Education Planning Center
(775) 784-4921 ext. 2354 or 2399

R.A.I.N. (Reno Autism Information Network)
(775) 240-3997

Websites on Autism

Autism Society of America (ASA)
www.autism-society.org (*accessed on June 22, 2005*)

Autism Research Institute (ARI)
www.autism.com/ari/ (*accessed on June 22, 2005*)

Parents' resource for autism
www.autismweb.org/ (*accessed on June 22, 2005*)

Autism guide
http://www.patientcenters.com/autism/ (*accessed on June 22, 2005*)

Autism Today
http://www.autismtoday.com/ (*accessed on June 22, 2005*)

Autism Society of North Carolina (online bookstore)
www.autismsociety-nc.org (*accessed on June 22, 2005*)

Cure Autism Now
www.cureautismnow.org (*accessed on June 22, 2005*)

Positive Behavior Supports
http://repc.unr.edu/UCED/pbsNevada/ (*accessed on June 22, 2005*)

Appendix A

Indiana Resource Center on Autism
www.iidc.indiana.edu/irca/ (*accessed on June 22, 2005*)

Organization for Autism Research
www.researchautism.org (*accessed on June 22, 2005*)

Defeat Autism Now (DAN)
www.danconference.com (*accessed on June 22, 2005*)

Center for the study of Autism
www.autism.org (*accessed on June 22, 2005*)

National Alliance for Autism Research
http://www.naar.org/ (*accessed on June 22, 2005*)

The SCERTS Model
http://www.barryprizant.com/barryprizant/ *(accessed on December 16, 2005)*

State of Nevada, Division of Health
Bureau of Early Intervention Services DRAFT 1/6/06

3427 Goni Road, Suite 108
Carson City, NV 89706

Phone: 775-684-3460
Fax: 775-684-3486
Toll Free 1-800-522-0066

Visit us on the web at:
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