



NEBRASKA AUTISM PARENT BOOKLET

(2003)

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CHAPTER 1

WHAT IS AUTISM?

Disclaimer

The following is an introduction to autism, some of the many treatment approaches, and local and national resources available for individuals with autism. This is not an exhaustive list; its purpose is to provide information on some of the more common aspects of autism and does not reflect an endorsement of any one particular treatment or resource.

There is no 'one treatment fits all' therapy just as there is no cure for autism. There are treatment and education approaches that may reduce some of the challenges associated with the disability. Treatment approaches will vary with each child as their individual strengths and needs are taken into consideration. It is important to research treatments and resources/providers thoroughly before implementation.

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

WHAT IS AUTISM?

Autism is a life-long developmental disability that typically (see Aspergers) appears during the first three years of life. The result of a neurological disorder that affects the brain, it is four times more prevalent in boys than in girls and knows no racial, ethnic, or social boundaries. Autism affects communication, social skills, pattern and range of interests, and sensory responsiveness. Autism is a *spectrum* disorder meaning the symptoms and characteristics of autism can be present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults with autism can exhibit any combination of the behaviors in any degree of severity.

Autism (or Autism Spectrum Disorders - ASD) falls under the category of Pervasive Developmental Disorder and includes the following:

- * *Autistic Disorder*
impairments in social interaction, communication, and imaginative play prior to age 3 years. Stereotyped behaviors, interests and activities.
- * *Asperger's Disorder*
characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, and testing in the range of average to above average intelligence.
- * *Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)*
(commonly referred to as atypical autism) a diagnosis of PDD-NOS may be made when a child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors.
- * *Rett's Disorder*
a progressive disorder. Period of normal development and then loss of previously acquired skills, loss of purposeful use of the hands replaced with repetitive hand movements beginning at the age of 1-4 years.
- * *Childhood Disintegrative Disorder*
characterized by normal development for at least the first two years, significant loss of previously acquired skills.

Prevalence of Autism

Autism is the third most common developmental disability, more common than Down Syndrome. According to the Autism Society of America (www.autism-society.org, 2003), it is estimated that between 1 per 500 to 1 per 250 individuals are affected by autism; around 1.5 million in America that are believed to have some form of autism.

The Centers for Disease Control and Prevention (www.cdc.gov) indicates studies internationally show as many as 6 in every 1,000 children are on the autism spectrum. Studies conducted by the CDC in Atlanta, Georgia and Brick Township, New Jersey show a prevalence of 3.4 in 1,000 and 6.7 in 1,000 respectively. A larger study is currently underway with several states and the report findings should be available in late 2003.

Characteristics

As indicated above, autism is a spectrum disorder and no two children with autism will have the exact same symptoms. Below is a partial list of the characteristics of autism.

1. Social Skills

- * may have difficulty with nonverbal behavior (eye contact, facial expression)
- * may have problems making friends
- * may have difficulty understanding another person's point of view
- * may have difficulty understanding other people's emotions or their own
- * may not interact with others in a typical manner or may not be interested in people at all
- * may prefer to be alone
- * may be interested in people but not know how to relate to them.

2. Communication

- * may be non-verbal or have a delay in talking
- * may repeat (echo) words and phrases over and over (echolalia, instant and delayed)
- * may have difficulties with 'you' and 'I'
- * may have a large vocabulary, formal speech and speak like a 'little professor'
- * may have problems with conversations
- * may have difficulty in turn taking
- * may speak too loudly or have a flat or unusual tone of voice
- * may have difficulty with metaphors and take everything literally
- * may have difficulty understanding abstract ideas

3. Play/Interests/Activities

- * may have lack of spontaneous or imaginative play
- * may not imitate others' actions
- * may not initiate pretend games
- * may have limited interests or activities
- * may do the same things repeatedly
- * may have problems breaking with routines
- * may have an unusual fascination in a subject or activity

4. Sensory

- * may have unusual responses to sound
- * may have unusual responses to smells
- * may have unusual responses to pain (may exhibit no reaction to pain)
- * may have unusual responses to touch
- * may not like to be held or cuddled or might cuddle only when they want to.
- * may engage in self-injury, such as head-banging or biting

5. Other

- * may have no sense of danger
- * may have problems generalizing information from one setting to another
- * may have poor sleeping patterns
- * may have poor eating habits
- * may have poor coordination (may have difficulty in understanding where own body is located in space in relation to surroundings)
- * may have problems with sequencing and/or organization
- * may have difficulty determining important information from irrelevant information
- * may have uneven skill development
- * may focus on details rather than the big picture or the reverse

Co-Existing Conditions

Autism can co-exist with any number of other conditions such as (but not limited to) Epilepsy, Mental Retardation, Down Syndrome, Fragile X Syndrome, Landau-Kleffner Syndrome, William's Syndrome, Tourette's Syndrome, or Oppositional Defiant Disorder.

Causes

Although much research has been devoted to finding the answer to this question, no specific cause is known. The ASA states that current research links autism to biological and neurological differences in the brain. There does appear to be a genetic basis to the disorder because of the pattern of autism and related disabilities in families. However, no gene has been directly linked to autism.

What is known is that autism is not a mental illness, children with autism do not choose to behave in the manner that they do, and it is not caused by poor parenting.

Is There a Cure?

The understanding of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943. Some of the earlier searches for "cures" now seem unrealistic in terms of today's understanding of brain-based disorders. To cure means "to restore to health, soundness, or normality." In the medical sense, there is no cure for the differences in the brain which result in autism. However, better understanding of the disorder has led to the development of better coping mechanisms and strategies for the various manifestations of the disability. Some of these symptoms may lessen as the child ages; others may disappear altogether. With appropriate intervention, many of the associated behaviors can be positively changed, even to the point in some cases, that the child or adult may appear to the untrained person to no longer have autism. The majority of children and adults will, however, continue to exhibit some manifestations of autism to some degree throughout their entire lives.

Selected Resources:

Autism Society of America: www.autism-society.org (autism info, what is autism?)
<http://www.autism-society.org/site/PageServer?pagename=whatisautism>

Mayo Clinic: www.mayoclinic.com (autism, signs & symptoms)
<http://www.mayoclinic.com/invoke.cfm?objectid=3710611C-2A4D-4E6B-B91023AC481ECA12§ion=2>

FEAT - Chattanooga, Welcome Packet:
www.untangleautism.org/feat_welcome_packet.htm

MYTHS ABOUT AUTISM

Many myths about autism exist. Some are out-dated theories or ideas which current research has proven false. Others are broad generalizations about autism characteristics, which may apply to some individuals with autism, but do not apply to all. Autism is a spectrum disorder, with symptoms ranging from mild to severe. Individuals vary greatly; each person with autism is unique and a person first and foremost.

THE FOLLOWING STATEMENTS ARE NOT TRUE:

- 1) Individuals with autism never make eye contact; they do not look at you.
- 2) Autism is a mental illness.
- 3) Progress means that a person doesn't have autism.
- 4) Individuals with autism don't speak.
- 5) Autism can be outgrown.
- 6) Individuals with autism cannot learn.
- 7) Underneath all of the difficult behaviors is a normal person.
- 8) Individuals with autism cannot show affection and do not respond to physical affection.
- 9) Individuals with autism do not want friends.
- 10) Individuals with autism do not relate to peers/adults.
- 11) Individuals with autism are very manipulative.
- 12) Individuals with autism could talk if they wanted to.
- 13) Individuals with autism can't smile.
- 14) Individuals with autism don't notice others and don't pick up cues from peers/adults.
- 15) When a person with autism does not respond to a question/direction to which he has shown a previous correct response, he is being stubborn, non-compliant, and/or obnoxious.

From the Autism Society of America

Autism Fact Sheet

Other Names:

- * Autistic Disorder
- * Asperger's Disorder
- * Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)
- * Rett's Disorder
- * Childhood Degenerative Disorder (CDD)

Defining Characteristics:

Autism is a neurological disorder that typically appears during the first three years of life and can cause discrepancies or differences in the way information is processed. It is a spectrum disorder and can range from mild to severe. Typical characteristics are:

- * **Communication** - children with autism may be verbal or non-verbal. There is difficulty in the understanding and use of language. For those that do speak, many are often echolalic (will parrot or repeat what they have heard).
- * **Socialization** - children with autism may have difficulty in understanding and relating to people, events, and objects in the environment. Unable to understand and process social cues.
- * **Stimulation** - may experience over/under sensitivities in the five senses, exhibit repeated body movements (hand flapping, rocking), and aggressive and/or self-injurious behaviors may be present.
- * **Routines** - many children with autism are resistant to changes in routines and may have a great deal of difficulty with transitions

Incidence/Prevalence:

- * Research indicates current rates are 1 in 500
- * Autism is four times more prevalent in boys than girls
- * There are no racial, ethnic or social boundaries
- * Family income, lifestyle, and educational levels do not affect the chance of occurrence.
- * There is a 3-8% risk of recurrence in families with an affected child

Genetics:

Genetic causes are being researched at this time but no gene(s) has/have been directly linked to autism.

Etiology:

There is no known cause for autism though there are several theories. Genetic or a combination of genetic and environmental factors may contribute to autism.

Physical/Motor Characteristics and Development:

Physical and motor development may be delayed, normal or advanced.

Cognitive Characteristics and Development:

There is a wide range of cognitive ability from gifted to profoundly mentally retarded. Up to 75% of children with autism may have some form of mental retardation.

Behavioral/Social/Emotional Characteristics and Development:

For infants and young children with autism problems may occur in the following areas:

- * do not use normal eye gaze
- * do not become involved in mutual sharing of feelings
- * do not engage in imitative, turn-taking games
- * do not signal to continue an enjoyable activity or initiate joint attention
- * do not understand they can gain assistance from others

Older children may have difficulty with the following:

- * Social rules are learned rigidly without realizing there is a range of acceptable behavior
- * Public behavior tends to be private behavior.
- * Behavior will seem incongruent or startling due to different social perspective or viewpoint
- * Unable to manage themselves in loosely structured situations.
- * Have difficulty initiating, entering or negotiating conversations.
- * Friendly social overtures, humor and jokes are misunderstood.

Speech/Language Characteristics and Development:

- * Phonology - difficulty with expressive prosody (e.g., fluctuations in the vocal intensity, monotonous pitch, tonal contrasts inconsistent with the meanings expressed)
- * Morphology/Syntax - Confusions of pronominal forms (e.g., gender confusion [he for she or it], case substitution [him for he], first- and second-person singular forms [you for I or me]). Use of less complex sentences than peers.
- * Semantics - Word-finding problems. Inappropriate answers to questions.
- * Pragmatics - Limited range of communicative functions. Difficulty initiating and maintaining a conversation. Few gestures. Failure to make eye contact prior to or during communicative interactions. Preference to follow rather than lead in a conversation. Engaging of potential communication partners at a level that requires little actual sharing.

Hearing Characteristics and Development:

Hearing development is typically normal though hearing sensitivities may exist.

Implications for Educational Need:

Intensive and early education is recommended for children with autism. Appropriate communication and social interactions need to be modeled and generalized to different settings and different people. Settings need to be structured, routine and allow for quiet areas when overwhelmed with stimulation. Effective intervention plans are based on cognitive/behavioral strategies and are based on three strategies:

- * Evaluate problem situations and refine the structure of environments and elements of the teaching/support plan to clarify the situation, solve problems quickly, and prevent reoccurrence.
- * Organize and structure space, time, and events (including instruction) to compensate for the deficits of autism.
- * Teach new skills to develop and expand competence and independence.

Selected References:

Autism Society of America (2000): [On-line]. available: www.autism-society.org

Centers for Disease Control and Prevention Vaccine Safety (2000): [On-line].
<http://www.cdc.gov/nip/vacsafe/vaccinesafety/sideeffects/autism.htm>

Janzen, J. (1996) Understanding the nature of autism: A practical guide. Texas: Therapy Skill Builders

Mayo Clinic - Autism (2000): [On-line]. available:
<http://www.mayohealth.org/mayo/9905/htm/autism.htm#one>

McCormick, L., Loeb, D., & Schiefelbusch, R. (1997). Supporting children with communication difficulties in inclusive settings. Boston: Allyn and Bacon.

CHAT - Checklist for Autism in Toddlers

This information was supplied by Sally Wheelwright, University of Cambridge

The CHAT (Checklist for Autism in Toddlers) is a screening instrument which identifies children aged 18 months who are at risk for social-communication disorders.

Questions and answers about the CHAT

What is the CHAT?

The CHAT is a short questionnaire which is filled out by the parents and a primary health care worker at the 18 month developmental check up. It aims to identify children who are at risk for social-communication disorders.

How is the CHAT administered?

The CHAT can be found in the following pages. It consists of two sections: the first nine items are questions asked to the parents, and the last five items are observations made by the primary health care worker. The key items look at behaviors which, if absent at 18 months, put a child at risk for a social-communication disorder. These behaviors are (a) joint attention, including pointing to show and gaze-monitoring (e.g. looking to where a parent is pointing), and (b) pretend play (e.g. pretending to pour tea from a toy teapot).

How is the CHAT scored?

The CHAT is very easy to score. There are 5 key items: A5 (pretend play), A7 (protodeclarative pointing), Bii (following a point), Biii (pretending) and Biv (producing a point). If a child fails all 5 key items, they have a high risk of developing autism. Children who fail items A7 and Biv have a medium risk of developing autism.

What happens if a child fails the CHAT?

Any child who fails the CHAT should be re-screened approximately one month later. As with any screening instrument, a second CHAT is advisable so that those children who are just slightly delayed are given time to catch up and also to focus efforts on children who are failing consistently. Any child who fails the CHAT for a second time should be referred to a specialist clinic for diagnosis since the CHAT is not a diagnostic tool.

What happens if a child passes the CHAT?

If a child passes the CHAT during the first administration, no further action needs to be taken. However, passing the CHAT does not guarantee that a child will not go on to develop a social-communication problem of some form and if parents are worried they should seek referral.

What are the advantages of the CHAT?

Because there is no single known medical cause of social-communication disorders, it is very unlikely that there will be a medical test available in the near future. Whatever the cause of these problems, the behavioral characteristics have been identified and this is what the CHAT is based on. In addition, the CHAT is cheap, quick and easy to administer. Currently, autism is rarely detected before the age of three and for the other social-communication disorders, age of detection can be even later. The CHAT, however, is administered when the child is 18 months old. The earlier a diagnosis can be made, the earlier intervention methods can be implemented and family stress reduced.

How can further information be obtained?

If you have any questions about the CHAT, please contact:

Sally Wheelwright
Department of Experimental Psychology
Downing Street
Cambridge, CB2 3EB, UK
Tel: 01223 333550
Fax: 01223 333564
Email: sjw18@hermes.cam.ac.uk

The CHAT

To be used by GPs or Health Visitors during the 18 month developmental check-up.

SECTION A: ASK PARENT:

1. Does your child enjoy being swung, bounced on your knee, etc.?

YES/NO

2. Does your child take an interest in other children?

YES/NO

3. Does your child like climbing on things, such as up stairs?

YES/NO

4. Does your child enjoy playing peek-a-boo/hide-and-seek?

YES/NO

5. Does your child ever PRETEND, for example, to make a cup of tea using a toy cup and teapot, or pretend other things?

YES/NO

6. Does your child ever use his/her index finger to point, to ASK for something?

YES/NO

7. Does your child ever use his/her index finger to point, to indicate INTEREST in something?

YES/NO

8. Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling or dropping them?

YES/NO

9. Does your child ever bring objects over to you (parent) to SHOW you something?

YES/NO

SECTION B: GP OR HV OBSERVATION:

i. During the appointment, has the child made eye contact with you?

YES/NO

ii. Get child's attention, then point across the room at an interesting object and say 'Oh look! There's a (name of toy!)' Watch child's face. Does the child look across to see what you are pointing at?

YES/NO*

iii. Get the child's attention, then give child a miniature toy cup and teapot and say 'Can you make a cup of tea? ' Does the child pretend to pour out tea, drink it, etc.?

YES/NO**

iv. Say to the child 'Where's the light?', or 'Show me the light'. Does the child POINT with his/her index finger at the light?

YES/NO***

v. Can the child build a tower of bricks? (If so how many?)
(Number of bricks:.....)

YES/NO

* (To record YES on this item, ensure the child has not simply looked at your hand, but has actually looked at the object you are pointing at.)

** (If you can elicit an example of pretending in some other game, score a YES on this item.)

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

INDICATIONS OF SENSORY PROCESSING PROBLEMS

Abnormalities in sensory registration and sensory processing can be associated features of autism. It is likely that most people with autism or a related disorder have sensory processing disorders. Not all people with sensory processing disorders have autism, however.

These irregularities often take the form of a hyper-responsiveness to non-noxious stimuli. Alternatively, some individuals demonstrate an underreactivity to sensation, a hypo-responsiveness.

Over-responsiveness/Defensiveness

Under-responsiveness

Touch

Avoids touching certain textures
Stiffens body when picked up
Struggles against being held
Avoids using hands, especially palm contact w/surfaces
Dislikes cuddling, being held or hugged
Overly sensitive to bath temperatures
Prefers to touch rather than be touched
Momentary grasp of toys then quick release
Approach-avoidance movements of hands and body
Decreased environmental exploration with hands and feet
Irritable to weight bearing on bare feet
Toe walking
Lack of hand to mouth play
Irritable with finger feeding
Excessively ticklish, irritable when touched
Fearful, irritated when approached
Strongly dislikes shoes or socks on or off
Irritated by underwear, tags in clothes

Does not react to pushing or hitting
Lacks awareness of being touched
Unaware of cuts, bumps, bruises, pain
Head banging, self biting
Receptive behavior
Excessive mouthing of objects

Taste and Smell

Overly sensitive to environmental smells
Reacts defensively to odors
Over-focus on house odors, restaurant odors
Restricted food preferences - usually bland
Acts as though all foods taste similarly

Loves hot and spicy foods
Attracted to sour foods - pickles, lemons
Likes noxious odors - smoke, exhaust
Explores by smelling or tasting

Movement/Vestibular

Fearful of imposed movement
Dislikes playground equipment
Avoids changing head position in relation to gravity
Trouble learning to climb stairs or negotiate hills
Avoids leaving contact with ground
Becomes easily motion sick
Complains of nausea, headache with movement

Spins for long periods without dizziness
Jumps a lot
Lack of judgment when negotiating space
Likes fast movement, being tossed in the air
Rocked in crib as an infant
Seeks movement experiences
Likes fast, spinning carnival rides

Prismatic Conference, Saturday, February 1, 1997
Presented by Speech & Language Development Center, Buena Park, CA. (714) 821-821-3620

**Muscles and Joints/
Proprioception**

Irritated by having arms and legs pushed or pulled
 Crept on tummy rather than hands and knees
 Went from sitting to standing with little crawling
 Avoids certain weight-bearing positions
 Dislikes jumping
 Delayed self-care

Holds hands or body in strange positions
 Over-focus on arms/legs pushed/pulled
 Toe walking

Visual

Excessive blinking
 Likes to be in the dark
 Intolerant of sunlight, brightness
 Excited by visual stimuli
 Gaze aversion
 Fleeting eye contact
 Hyervigilance

Lacks visual focus
 Difficulty following objects, people
 Lacks conscious awareness of environment
 Dull eyes, no 'sparkle'
 Difficulty discriminating shapes, colors

Auditory

Responds defensively to unexpected noise
 Distracted by noise
 Irritated by loud noises
 Constant noise-making, e.g. humming, talking
 Distracted by white noise, e.g., lights, fans

Does not orient to sound
 Misses some sounds
 Enjoys strange noises
 Delayed response to sounds

Related Behaviors

Intense, easily
 Hyper-reactive
 Distractible
 Sleep problems
 Strong need for routine
 Fright, flight, fight behaviors
 Arrhythmic suck, swallow, breathing pattern
 High pitched vocal tone
 Highly aroused, easily frustrated during feeding
 Increased extension (avoidance), decreased flexion (approach)

CHAPTER 2

DIAGNOSING AUTISM

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

Diagnosing Autism

There are no medical tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual's communication, behavior, and developmental levels. However, because many of the behaviors associated with autism are shared by other disorders, various medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited.

A brief observation in a single setting cannot present a true picture of an individual's abilities and behaviors. Parental (and other caregivers') input and developmental history are very important components of making an accurate diagnosis. At first glance, some persons with autism may appear to have mental retardation, a behavior disorder, problems with hearing, or even odd and eccentric behavior. To complicate matters further, these conditions can co-occur with autism. However, it is important to distinguish autism from other conditions, since an accurate diagnosis and early identification can provide the basis for building an appropriate and effective educational and treatment program.

Early Diagnosis

Research indicates that early diagnosis is associated with dramatically better outcomes for individuals with autism. The earlier a child is diagnosed, the earlier the child can begin benefiting from one of the many specialized intervention approaches.

Diagnostic Tools

The characteristic behaviors of Autism Spectrum Disorders may or may not be apparent in infancy (18 to 24 months), but usually become obvious during early childhood (24 months to 6 years).

As part of a well-baby/well-child visit, your child's doctor should do a "developmental screening" asking specific questions about your baby's progress. The National Institute of Child Health and Human Development (NICHD) lists these five behaviors that signal further evaluation is warranted:

- * Does not babble or coo by 12 months
- * Does not gesture (point, wave, grasp) by 12 months
- * Does not say single words by 16 months
- * Does not say two-word phrases on his or her own by 24 months
- * Has any loss of any language or social skill at any age.

Having any of these five "red flags" does not mean your child has autism, but because the characteristics of the disorder vary so much, a child should have further evaluations by a multidisciplinary team that may include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant, or other professionals knowledgeable about autism.

While there is no one behavioral or communications test that can detect autism, several screening instruments have been developed that are now used in diagnosing autism.

1. CARS rating system (Childhood Autism Rating Scale), developed by Eric Schopler in the early 1970s, is based on observed behavior. Using a 15-point scale, professionals evaluate a child's relationship to people, body use, adaptation to change, listening response, and verbal communication.
2. The Checklist for Autism in Toddlers (CHAT) is used to screen for autism at 18 months of age. It was developed by Simon Baron-Cohen in the early 1990s to see if autism could be detected in children as young as 18 months. The screening tool uses a short questionnaire with two sections, one prepared by the parents, the other by the child's family doctor or pediatrician.
3. The Autism Screening Questionnaire is a 40 item screening scale that has been used with children four and older to help evaluate communication skills and social functioning.
4. The Screening Test for Autism in Two-Year Olds, being developed by Wendy Stone at Vanderbilt, uses direct observations to study behavioral features in children under two. She has identified three skills areas - play, motor imitation, and joint attention - that seem to indicate autism.

From the Autism Society of America

Educational Vs. Medical Diagnosis

When receiving a diagnosis you should be aware that there are two types your child can receive, either an educational or medical diagnosis of autism.

What is the difference?

- Educational

An educational diagnosis is given through the local school district and is concerned only with how the condition affects the child's education. Federal law concerning special education is called the Individuals with Disabilities Education Act (IDEA) and spells out the states responsibilities in the education of children with special needs. Your local school district will use the laws set out in Rule 51 (Nebraska Department of Education, Regulations and Standards for Special Education Programs, Title 92, Nebraska Administrative Code, Chapter 51.) This is the state law covering special education in Nebraska and will provide detailed information on qualifications for autism.

It is important to remember that State law must meet the minimum standards set forth in the Federal law. Services provided through the school district are free of charge to parents.

- Medical

The medical diagnosis is based off of the Diagnostic and Statistical Manual of Mental Disorders (DSMV-IV) put out by the American Medical Association (AMA). A medical diagnosis is simply that, a medical determination of an existing condition. A medical diagnosis would be required for medications and may be required for private services.

Nebraska currently does not offer a Medicaid waiver for autism and SSI (Supplemental Security Income) through Social Security is dependent on income. If your child does qualify for SSI, he/she is also eligible for Medicaid. (See Medicaid Chapter for further information).

Are both diagnoses required?

No, though depending on the type of therapies and programs your child requires and is enrolled in, he/she may receive both. A diagnosis in one area will not necessarily transfer over to the other area.

Is an autism diagnosis required?

No, however obtaining services may require an evaluation to be performed. It is not uncommon for a child with autism to be given other labels, either prior to receiving the autism diagnosis or in conjunction with the autism diagnosis. Developmentally delayed, speech language impairment, behavior disorder, oppositional defiance disorder, and mentally handicapped as well as many other labels may be given to a child with autism.

Why so many labels?

A child may have co-existing conditions in addition to autism. The person giving the diagnosis may not have enough experience in identifying autism or in diagnosing autism in very young children. The symptoms may not be as obvious at a young age. Onset can occur between birth and three years of age (with the exception of Asperger's). There may also be a hesitation in labeling a very young child with a diagnosis of autism.

Why is this important?

It is important to understand how autism is diagnosed because not all professionals, either in the medical or educational fields, have had the training or experience in diagnosing a child with autism. Parents need to understand what autism is, how it's diagnosed, and understand the special education laws to be an effective advocate for their child.

Educational Label for Autism from Rule 51

006.04 Eligibility for Special Education

006.04A School districts or approved cooperatives shall provide special education services only to children with verified disabilities.

006.04B Autism

006.04B1 The MDT shall include at least:

006.04B1a A school psychologist or licensed psychologist;

006.04B1b The child's teacher(s) or a teacher qualified to teach a child that age;

006.04B1c A speech language pathologist;

006.04B1d A school district administrator or a designated representative.

006.04B1e The child's parent(s).

006.04B2 In order for a child to be verified as having autism, the evaluation shall include the analysis and documentation of the manifestation of severe developmental and educational problems exhibited in varying degrees of atypical behavior in each of the following areas:

006.04B2a Disturbance of developmental rates and sequence. The child's developmental profile reflects varied developmental age levels for skills. The child exhibits delays, arrests, or regressions in physical, social, sensory processing, or learning skills. Areas of precocious or advanced skill development may also be present, while other skills may develop at normal or extremely depressed rates. The order of skill acquisition frequently does not follow normal developmental patterns.

006.04B2b Disturbance of responses to sensory stimuli. The child exhibits unusual, repetitive or nonmeaningful responses to auditory, visual, olfactory, gustatory, tactile, and/or kinesthetic stimuli. The child's behavior may vary from high levels of activity and responsiveness to low levels.

006.04B2c Disturbance of cognitive processes. The child exhibits abnormalities in the thinking process and in generalization. Delayed intellectual functioning may or may not be present. In addition, one or more of the following occurs:

006.04B2c(1) Difficulties in abstract thinking, awareness, or judgment;

006.04B2c(2) Perseverative thinking; or

006.04B2c(3) Impaired ability to process symbolic information.

006.04B2d Disturbance of communication. The child exhibits a qualitative impairment in verbal and/or nonverbal communication. The impairment includes problems that extend beyond speech and language to many aspects of the communicative process. Speech and/or language are either absent, delayed, or disordered.

006.04B2e Disturbance in relating to people, events and objects. The child displays difficulties in relating to people, events and/or objects. Often the child is unable to establish and maintain reciprocal relationships with people. Their capacity to use objects in an age appropriate or functional manner may be absent, arrested, or delayed. The child responds positively to consistency in environmental events to the point of exhibiting rigidity in routines. The child displays marked distress over changes, insistence on following routines and/or a persistent occupation with or attachment to objects. The child may display a markedly restricted range of interest and/or stereotyped body movements. There may be a lack of interest or an inability to engage in imaginative activities.

DSM-IV Criteria, Pervasive Developmental Disorders

299.00 Autistic Disorder

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

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication, as manifested by at least one of the following:
 - (a) 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 or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
 - (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

299.80 Pervasive Developmental Disorder, Not Otherwise Specified

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" --presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

299.80 Asperger's Disorder

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

- (1) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- (2) failure to develop peer relationships appropriate to developmental level
- (3) 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 to other people)
- (4) lack of social or emotional reciprocity

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

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

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

299.80 Rett's Disorder

A. All of the following:

- (1) apparently normal prenatal and perinatal development
- (2) apparently normal psychomotor development through the first 5 months after birth
- (3) normal head circumference at birth

B. Onset of all of the following after the period of normal development:

- (1) deceleration of head growth between ages 5 and 48 months
- (2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (i.e., hand-wringing or hand washing)
- (3) loss of social engagement early in the course (although often social interaction develops later)
- (4) appearance of poorly coordinated gait or trunk movements
- (5) severely impaired expressive and receptive language development with severe psychomotor retardation

299.10 Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

- (1) expressive or receptive language
- (2) social skills or adaptive behavior
- (3) bowel or bladder control
- (4) play
- (5) motor skills

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

- (1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
- (2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
- (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms

D. The disturbance is not better accounted for by another specific pervasive developmental disorder or by schizophrenia.

CHAPTER 3

EDUCATIONAL THERAPIES

- I. How to Determine if a Treatment Really Helped
- II. Research on Autism Therapies
- III. Educational Therapies
 - a. Applied Behavior Analysis/ABA
 - b. Verbal Behavior/AVB
 - c. Floortime/DIR/Greenspan
 - d. TEACCH
 - e. Option Institute/Son-Rise Program
 - f. Pivotal Response Training
 - g. Relationship Development Intervention/RDI
 - h. Social Stories
 - i. Power Cards

Selected Resources:

- * Facing Autism by Lynn Hamilton
- * Straight Talk about Psychiatric Medications for Kids by Timothy E. Wilens, M.D.
- * Power Cards: Using Special Interests to Motivate Children and Youth with Asperger Syndrome and Autism by Elisa Gagnon
- * What Your Doctor May Not Tell You About Childhood Vaccinations by Stephanie Cave, M.D.
- * websites: autism.about.com; www.autismuk.com; www.connectionscenter.com

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

How to Determine If a Treatment Really Helped

by Stephen M. Edelson, Ph.D.

Center for the Study of Autism, Salem, Oregon

There are many types of interventions available today for autistic individuals, including nutritional, biomedical, educational, sensory, and behavioral. When beginning a new intervention, it is important to be as objective as possible to determine whether the treatment truly helped the person. If the treatment is not helping, then it does not make sense to continue it, especially if it has negative side effects or involves a great deal of time, money or effort.

When deciding to try a new treatment, whether “proven” or not, here are a few tips to help determine whether the person may have improved from the specific treatment:

1. One treatment at a time.

When a parent begins to learn about all of the various treatments given to autistic children, she/she sometimes tries many at once in order to see improvement as soon as possible. However, if the child improves after receiving several treatments, it will be impossible to determine which one(s) really made a difference. A general rule is to try one treatment for about two months before beginning a new one, to determine whether or not the treatment was helpful. However, if it is quite clear that the child improved from a treatment, even after a week or two, then another treatment can be started.

2. Keep your own data.

Parents should consider keeping a daily log and completing the monthly ATEC form for a few months prior to the intervention and then monthly following the intervention. The ATEC was designed specially to evaluate treatment effectiveness. If the improvement occurs due to maturation, then one typically sees gradual improvement over time. However, if there is a sharp improvement after the intervention is started, then the treatment may be helping. There is no charge for use of the ATEC. You can complete the checklist on the web at: www.autism.com/atec or you can order a hardcopy of the checklist by writing to the Autism Research Institute, 4182 Adams Ave., San Diego, CA 92116.

3. Seek objective information.

If at all possible, tell no one when a child starts a new treatment. This includes teachers, friends, neighbors, and relatives. If there is a noteworthy change in the child, positive or negative, it is likely that the people who come in contact with the child will say something about the change. It is also a good idea not to ask “Have you noticed any changes in my child?” In this way, any spontaneous statements regarding the child’s improvement will be credible.

4. Collect data from those involved in treatment implementation.

People who do know that the child received a specific treatment can, independently, compile a list of what changes they have noticed in the child. After a month or two, you can compare their observations. If similar changes are observed by different people, then there is a reasonable chance that these changes are real. It is important that these observations be written down; otherwise, when appropriate behaviors replace inappropriate ones, you may not remember what the child's behavior was like before the treatment.

5. Note unexpected or unanticipated changes.

Parents and others should note in writing when the child's behavior 'surprises' them. Basically, parents usually know how their child will respond in various situations; and once in a while, their child may do something unexpected. Be aware of unexpected side effects, positive or negative, of any new treatment.

6. Educate yourself about the treatment.

Before trying a new treatment, learn as much as possible about the treatment. Rather than focusing only on the positive reports, seek out criticisms as well. When evaluating conflicting claims, look to the nature of the studies and their methodologies - poorly conducted studies should not be given the same credence as methodologically sound research.

Some people suggest that parents should give their children only treatments for which there is ample research to support their effectiveness. However, when a relatively new treatment is introduced, there will likely be a limited amount of research, if any, on its effectiveness. It takes, on average, 5 to 10 years to complete enough research to support or refute an intervention's efficacy. Be leery of any treatment if it has been around for ten or more years and there are no research studies to support its effectiveness. For example, Ritalin is one of the most frequently prescribed treatments for Autism, but there are no published studies supporting its effectiveness with this population.

It is important to keep in mind that no treatment will help everyone with Autism. Although one child may have improved dramatically from a certain treatment, another child, may not benefit to the same degree or at all. Careful observation along with a critical perspective will allow parents and others to decide whether or not a treatment is truly beneficial.

Research on Autism Therapies

As you read about various autism therapies, one thing to keep in mind is the research that's been conducted on whatever therapy you intend to implement. There are many books and research journals that can aid you in your search (refer to the book chapter in this booklet). One report listed below was put together by the New York Department of Health Early Intervention Program in 1999 by an independent panel of professionals and parents. The independent panel reviewed research articles on each therapy and provides the pros and cons of each one.

You can view the entire document in full at the following website:

http://www.health.state.ny.us/nysdoh/eip/autism/index.htm#Table_of_Contents

Clinical Practice Guideline: Report of the Guideline Recommendations
Autism / Pervasive Developmental Disorders
Assessment and Intervention for Young Children (Age 0-3 Years)
Sponsored by
New York State Department of Health
Early Intervention Program

Some of the therapies that were considered in the document are as follows:

Intervention Methods

- * **Intensive Behavioral and Educational Intervention Programs**
- * **Basic Principles of Specific Behavioral Intervention Techniques**
- * **Behavioral and Educational Intervention Techniques for Maladaptive Behaviors**
- * **Behavioral and Educational Intervention Techniques to Improve Communication**
- * **Behavioral and Educational Intervention Techniques to Improve Social Interactions**
- * **Parent Training as Part of Behavioral and Educational Programs**
- * **Interventions Based on the Developmental, Individual Difference, Relationship (DIR) Model**
- * **Sensory Integration Therapy**
- * **Touch Therapy**
- * **Music Therapy**
- * **Auditory Integration Training (AIT)**
- * **Facilitated Communication**

Medication and Diet Therapies

- * **Psychoactive Medications**
- * **Hormone Therapies**
- *

Immunologic Therapies

- * **Anti-Yeast Therapies**
- * **Vitamin Therapies**
- * **Diet Therapies**

EDUCATIONAL THERAPIES

Applied Behavior Analysis

In simple terms, Applied Behavior Analysis (ABA) teaches complex tasks by breaking them down into bite-size pieces that can be learned more easily, with each piece building upon the previous one. Rewards, called “reinforcers,” are given for correct responses or behaviors while inappropriate responses are corrected, ignored, or redirected. Precise data on each learning trial is recorded, and adjustments in the educational program are made accordingly.

ABA targets development in many areas of skills, including, but not limited to, attending, imitation, language, social, play, self-help and academics.

Other terms, such as discrete trial training and Lovaas therapy, have been used in reference to ABA. Discrete trial training, which breaks down a task and teaches it systematically, is a subset of the ABA program that is often used. The term “Lovaas therapy” comes from Dr. O. Ivar Lovaas, whose landmark research led to the application of ABA techniques for teaching children with Autism. Dr. Lovaas is not the only professional who uses ABA to address Autism, but his name is probably the most recognized.

ABA is a form of behavioral therapy, which has been used to treat many disorders for years with notable success. B.F. Skinner in 1938 called this concept of changing behavior by the response of the teacher “operant conditioning.” If a reinforcer immediately followed a desired behavior, the chances of the behavior being repeated increased. If the reinforcer was taken away, the desired behavior would eventually decrease. The same applies to negative behavior; it will increase if it is reinforced and decrease if it is ignored.

The Lovaas Institute for Early Intervention <<http://www.lovaas.com/>> (Los Angeles, Ca)

Wisconsin Early Autism Project <<http://www.wiautism.com/>>

Association for Behavior Analysis Homepage <<http://www.wmich.edu/aba/index.html>> - The Association for Behavior Analysis is dedicated to promoting the experimental, theoretical, and applied analysis of behavior. It encompasses contemporary scientific and social issues, theoretical advances, and the dissemination of professional and public information.

Right from the Start: Behavioral Intervention for Young Children With Autism: A Guide for Parents and Professionals (Topics in Autism) - By Sandra L. Harris, Mary Jane Weiss

Good beginner book for ABA

Verbal Behavior/AVB

Verbal Behavior Analysis views language as the key feature of intervention with an autism or developmental delay. Language training is incorporated into all activities and there are a large number of daily trials that include discrete trials and natural environment trials. What are discrete trials? They can be defined as teaching activities to a child at a table setting. What are natural environment trials? They can be defined as teaching a child in a natural setting such as: at the grocery store, while working in the kitchen, dressing for school and etc.

It incorporates the use of reinforcement as a means to use when teaching or using intervention with a child. You will use the reinforcer (candy, toys, whatever your child likes and wants) to begin teaching them language. This will also involve fading the reinforcer once the skill is mastered.

With Verbal Behavior Analysis, it is imperative that you establish instructional control, in other words, the likelihood that your instructions will provide a correct response from your child. If you do not have instructional control, then your child will be noncompliant or unresponsive. In order to ensure that you will have instructional control while you teach, you will need to “pair” or bond with your child. Pairing is the process where you establish yourself as the reinforcer, in order to build a positive relationship and rapport with your child. It involves the association of a “neutral stimulus” (you or an instructor) with an existing reinforcer and results in the neutral stimulus being reinforcing. You need to present yourself and your words in association with the delivery of reinforcers (candy, toy) and also reinforcing interaction and engagement at whatever the child’s level.

Whenever you pair, you need to make sure the reinforcers are controllable, delivered at many times, and are associated with you.

VBA also involves the use of a correction procedure. It is a systematic method of prompting and fading. It can be used in either a discrete trial or natural environment training. Rather than punishing the student for incorrectly responding, you can help them be successful by using the Correction Procedure.

VBA consists of teaching language beginning with mands (commands, demands, what do you want to elicit language), moving on to echoic, receptive, tacting (labeling objects), receptive by function, feature, and class, and finally intraverbals (both simple and complicated). VBA tries to incorporate all aspects of language not just the labeling capacity, but all aspects, intraverbals, labeling, receptive and etc. By teaching all aspects of language this will enhance the success for intraverbal and expressive language to emerge.

It does utilize many of the same elements of ABA only with the emphasis being more on a more naturalistic acquisition of language and development of language versus merely labeling items. VBA is a behavior model that tries to teach the child to expand their language and try and teach them to describe things, people, events, and etc. It is utilizing the elements of ABA with the emphasis having a very language-oriented environment for the child.

B.F. Skinner Foundation <<http://www.bfskinner.org/>>

Dr. Vincent J. Carbone <<http://www.dr-carbone.net/>>

Teaching Language to Children with Autism and Other Developmental Delays - by
by Drs. Mark Sundberg and James Partington
A guide to teach an autistic child using Verbal Behavior Analysis.

Floortime/D.I.R./Greenspan Method

Dr. Stanley Greenspan is well-known for his approach to treating children with Autism and other developmental disorders. His method centers on relationships and interaction while taking into account underlying sensory issues.

In his book "The Child with Special Needs," Dr. Greenspan specifies six functional milestones of development in this order: self-regulation and interest in the world, intimacy, two-way communication, complex communication, emotional ideas and emotional thinking. He believes these lay a foundation for more advanced learning since they are based upon emotional interactions usually developed early in life.

Dr. Greenspan encourages the D.I.R. (Developmental, Individual-Difference, Relationship-Based) model. The primary goal of the D.I.R.-based intervention is to enable children to form a sense of themselves as intentional, interactive individuals and develop cognitive language and social capabilities from this basic sense of intentionality.

Part of this method uses "floor time" which is an intensive, one to one experience during a 20-30 minute period when you get down on the floor with your child and interact. The focus is on relationships, since he believes that the more intellectual functions of the brain don't develop without a constant source of relating. During floor time, the adult follows the child's interest, even if the interest is a self-stim behavior, in order to encourage interaction. For example, if the child spins wheels on a car, the adult may help him or spin a different wheel. The adult may limit the number of toys available so that the child has to interact to get more toys. The goal is not just to follow the lead of the child but to help the child expand his interactions. According to Dr. Greenspan, the four goals of floor time are two-way communication, logical thought, attention and intimacy, and the expression and use of feelings and ideas.

Floortime/DIR Model <http://www.play-to-learn.com/dir_floortime.htm>

Autism and Developmental Disorders: A Developmental Approach
<<http://www.mindspring.com/~dgn/>> - The approach discussed here is what Stanley Greenspan calls a developmental, individual-difference, relationship-based approach (D.I.R.) to intervention--also known as "floor-time."

TEACCH

TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) was started in the early 1970's by Dr. Eric Schopler. This program uses "structured teaching" in a variety of settings. TEACCH doesn't have a specific technique of therapy. Proponents claim their structured teaching considers the needs of each child and develops a treatment plan using a variety of techniques. Their goal is increasing the child's skills and functioning ability, not recovery from autism.

TEACCH uses an evaluation tool called the Psycho Educational Profile (PEP) in order to begin therapy at the appropriate level. TEACCH adapts the learning environment and schedule to be effective and stress free for the child; the child is provided with an environment designed to accommodate the characteristics of autistic children.

One drawback of TEACCH is the lack of objective data to support it's effectiveness with autistic children. Whether it is better to adapt the environment or help the child adapt to the world around him may depend on the abilities and level of functioning of the child.

Division TEACCH Home page <<http://www.unc.edu/depts/teacch>>.

Paul Trehin. "Some Basic Information about TEACCH" <<papers/TEACCHN.htm>>.

Option Institute/Son-Rise Program

The Son-Rise method was developed by Barry and Samahria (Suzi) Kaufman, whose son Raun was diagnosed as autistic and mentally handicapped with an IQ level under thirty. In this program, the parents and therapists follow the lead of the child and join what he's doing, including self-stimulatory behavior, in order to show the child love and acceptance. When they receive any response from the child, they try to expand the activity and encourage more responses. The Son-Rise program believes that the best teacher is the child.

The intention is to enter and understand the child's world, to create a bonding so special, so loving that the child will want to know more and learn more from us. The Son-Rise program does not record data on changes in the individual.

Option Institute Web Site <<http://www.option.org/>> (Organization in Sheffield MA, for autistic and other special-needs children formed by Barry Neil Kaufman, author of "Son-Rise").

Pivotal Response Training (PRT)

Pivotal Response Training, like ABA, is based on discrete trials. Unlike most traditional ABA programs, these trials take place in a more natural play setting. In this way it has similarities to Dr. Greenspan's floor-time program; one might say that it has elements of both of these approaches. PRT identifies pivotal behaviors that affect a wide range of behaviors in children with autism and concentrates on those areas to help increase generalization of new skills and motivation.

PRT was developed by Robert L. Koegel and Laura Schreibman. The efficacy of PRT is still under investigation. Research is being conducted to compare this approach with that of ABA-style discrete trials method.

PIVOTAL RESPONSE TRAINING <<http://psy.ucsd.edu/~vcestone/PRT2.html>> - PRT is a naturalistic treatment approach developed by: Robert L. Koegel & Laura Schreibman. Pivotal Response Training (PRT) is a behavioral treatment intervention based on the principles of applied behavior analysis (ABA).

Pivotal Response Training <<http://www.spectrumcenter.org/autismplanning.html>>

Relationship Development Intervention/RDI

Relationship Development Intervention, created by Steven Gutstein, is modeled upon the means by which typical children become competent in the world of emotional relationships. It is an intervention approach quite different from the typical social skills programs currently available.

RDI uses information from the Relationship Development Assessment to develop clear, specific, developmentally appropriate treatment objectives and customized activities. The RDI curriculum is composed of six levels. Each of the six levels represents a dramatic developmental shift in the central focus of relationships. The six levels are: Novice, Apprentice, Challenger; Voyager, Explorer, and Partner.

RDI provides a path for people on the Autism Spectrum to learn friendship, empathy and a love of sharing their world with others. Language comes alive when integrated with real emotion. People with Autism and Asperger's learn not only to tolerate but to enjoy change, transition and going with the flow. The path begins at the edge of each person's current capability and carefully, systematically teaches the skills needed for competence and fulfillment in a complex world

Connections Center: <http://www.connectionscenter.com/>

Relationship Development Center <http://www.autismrelationship.com/aboutRDI.htm>

.Social Stories

Social stories, also known as Social Scripts, were developed by Carol Gray in 1991 to help a student with autism understand the rules of a game. It was further developed to address understanding subtle social rules of "typical" culture. They are also used to help explain new situations to a child to take some of the anxiety out of the unexpected. An example would be of writing a social story about going to the dentist and reading it with the child prior to the first visit. Social stories can also be used to help teach "theory of mind", or the ability to take the perspective of another person.

The goals of social stories are to clarify social expectations for students with ASD, address issues from the student's perspective, redefine social misinterpretations, provide a guide for conduct or self-management in specific social situations.

Social stories are specific to the individual, addressing situations which are problematic for the person. Social stories can be read to or by the person with ASD. To be most beneficial, they should be introduced far enough in advance of the situation to allow multiple readings, but especially just before the situation is to occur.

Social Stories: Stephen Edelson <<http://www.autism.org/social.html>>

My Social Stories Book - by Carol Gray and Abbie Leigh White

Short narratives to teach social skills and to facilitate understanding of common situations

Power Cards

Power cards, and power card stories, are similar to social stories in that they help those with ASD learn appropriate behaviors in social situations. This strategy was created by Elisa Gagnon. She incorporates a child's special interest or favorite character (or "obsession" as some may call it) into a story that helps the child understand appropriate behaviors. Power card stories are meant to be fun for the child since his or her favorite character explains the importance of using the appropriate behavior and explains how to display this behavior by following the listed steps. The child can relate to their "obsession" while learning social rules.

Older children can also use a "power card", which is a short version of the story. A brief, motivational text related to a special interest or a highly admired person is combined with an illustration and made into a bookmark or business card-sized "power card" that the child can refer to whenever needed.

Power Cards - Using Special Interests to Motivate Children and Younger with Asperger Syndrome and Autism - by Elisa Gagnon

Visual aid that incorporates the child's special interest and teaching appropriately.

CHAPTER 4

MEDICAL THERAPIES

- I. Medical Therapies
 - a. Nutritional Therapies
 1. B6 and Magnesium
 2. DMG/TMG
 3. Vitamin A
 4. Vitamin C
 5. Zinc
 6. Folic Acid
 7. Calcium
 8. Essential Fatty Acids/EFA
 9. Melatonin
 10. Digestive Enzymes
 - b. Anti-yeast Therapy
 - c. Secretin
 - d. Chelation
 - e. Neuro-Immune Dysfunction Syndromes/NIDS
 - f. Defeat Autism Now (DAN) Protocol
 - g. Medications
 1. SSRIs
 2. Stimulants
 3. Anticonvulsants
 4. Antihypertensives
 5. Antipsychotics
 6. New Medications
 - h. IVIG Therapy
 - i. Transfer Factor
 - j. Sulfate Deficiency/Epsom Salt Baths
 - k. Vaccinations
 - l. EEG Biofeedback
 - m. Hyperbaric Oxygen Therapy

Selected Resources:

- * Facing Autism by Lynn Hamilton
- * Straight Talk about Psychiatric Medications for Kids by Timothy E. Wilens, M.D.
- * Power Cards: Using Special Interests to Motivate Children and Youth with Asperger Syndrome and Autism by Elisa Gagnon
- * What Your Doctor May Not Tell You About Childhood Vaccinations by Stephanie Cave, M.D.
- * websites: autism.about.com; www.autismuk.com; www.connectionscenter.com

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

MEDICAL THERAPIES

Nutritional Therapies

Nutritional supplements can be used for a variety of reasons. Most of our children have limited diets or are on special diets, so supplements can provide them with necessary vitamins, minerals and fatty acids they may lack. Supplements can also address specific imbalances in the body to promote healing.

B6 and Magnesium

Vitamin B6 has a long history as a treatment for autism. Since the first studies in the 1960's, more than 17 studies have been published supporting its benefits. B6, often combined with magnesium, may help improve language, eye contact, brain electrical activity, behaviors, and immune system function. Magnesium is needed with high doses of B6 because when taken alone, B6 may cause a deficiency in magnesium and other B vitamins. Also, magnesium may decrease some possible side effects, such as irritability, bed-wetting, and sensitivity to sound. Companies such as Kirkman Laboratories have designed specific multivitamins with high doses of B6, magnesium and other nutrients.

Vitamin B12 - Methylcobalamin <<http://www.ephca.com/autism.htm>> - Stephen B. Edelson, M.D., F.A.A.F.P., F.A.A.E.M.

DMG/TMG

DMG (dimethylglycine) is classified as a food substance rather than a vitamin. The potential benefits from DMG range from behavior changes, reduction of seizures, decreased obsessive-compulsive behaviors to improved language. TMG is similar, but with one more methyl group. This third methyl group may assist with mood stabilization, and acts similar to the nutritional supplement SAME. Additional folic acid may be needed as some children may become more hyperactive when taking DMG.

Dimethylglycine (DMG) <<http://www.autism.org/dmg.html>>

Dimethylglycine (DMG) <<http://www.autism.com/ari/editorials/dmg1.html>>

Vitamin A

For years, high doses of this vitamin have been used successfully to treat the measles virus. But because vitamin A is found naturally in foods we don't often eat, like liver or cod liver oil, most people are not getting enough of this important vitamin.

Using cod liver oil, Dr. Mary Megson began vitamin A therapy with some of her patients and found some positive results. Some patients spoke more frequently and clearly; others made gains in eye contact. Some other benefits of the natural form of vitamin A include cell growth, repair of epithelial cells found in the gut wall, immune system function, and gene expression and transcription.

Discuss this treatment method with your doctor first if you would like to consider trying this. Too much vitamin A or D, which is also found in cod liver oil, can be toxic.

Vitamin A <<http://www.autism.com/ari/megson.html>>

Vitamin A <<http://www.newsnet5.com/yourhealth/yourhealth-990812-191714.html>>

Vitamin C

The benefits of vitamin C are widely known in the general public and it may be of help with children with autism as well. Vitamin C is an antioxidant that helps the brain utilize oxygen. Without this vitamin, confusion and depression can develop. Vitamin C can also help support the immune system, aid in detoxification, and fight viruses and bacteria. Vitamin C is nontoxic, even in very high doses. If you take too much, you may have diarrhea, but generally no other side effects occur.

Vitamin C in the Prevention and Treatment of Autism

<<http://www.autism.com/ari/editorials/vitaminc.html>> - Bernard Rimland, Ph.D.

Zinc

Zinc promotes brain development, improved immune function, and overall health and can help reduce other out-of balance minerals. Your body can even tell you if you need it by taste. If you put some liquid zinc in a glass of distilled water, drink it, and you cannot taste it, your body needs it. If you can taste it, and it doesn't taste good, you do not need it.

Folic Acid

Folic acid is a nontoxic B vitamin, which has been reported as helpful in treating autism. It is widely recommended that pregnant women take extra folic acid during their pregnancy to help prevent some birth defects. It is most effective when taken with vitamins B12 and C.

Calcium

As most people know, calcium is very important in bone development and maintenance. Most people get their calcium from dairy sources. However, if your child is on a dairy or casein-free diet, it is very important that a calcium supplement is given.

Essential Fatty Acids/EFA

Fatty acids are essential to proper brain development and most of us do not get enough of them. Infant formulas are now being made that include more of these fatty acids, in particular DHA and AA. We usually need more of certain fatty acids: ALA (alpha linolenic acid), GLA (gamma linolenic acid), EPA (eicosapentaenoic acid), DHA (docosahexaenoic acid), and AA (arachidonic acid).

According to Dr. James Braly, of Immuno Laboratories, the following are reasons for fatty acid supplementation: they are a source of energy and they are an important ingredient of the membranes in all body tissues; a deficiency in EFA's may contribute to an increase in the permeability of the membrane of the digestive tract, leading to a leaky gut (refer to the section on the GF/CF diet for more information on "leaky gut" and autism).

Essential fatty acids and autism

<<http://server37.hypermart.net/autismunravelled/Fatty%20acids%20autism.htm>>

Elementary Introduction to Essential Fatty Acids (EFAs) <http://www.shop-in-service.com/efa,_what's_that!.htm>

Melatonin

Many children with autism have problems sleeping. Melatonin, which is actually a hormone, not a vitamin, can be bought at most health food stores and helps regulate sleep. Our bodies produce melatonin in response to the diminished light at the end of the day until sunlight triggers it to stop. It should be taken within two hours of bedtime so it can work in conjunction with the body's natural melatonin. A word of caution: melatonin is a hormone, its long-term effects on puberty are not clearly known.

Melatonin, The Sleep Master - An emerging role for this over-the-counter supplement in the treatment of autism. Jaak Panksepp, Ph.D. <<http://www.autism.org/melatonin.html>>

Melatonin - Autism and melatonin: The connection
<<http://www.udaan.org/drugs/autrx2.html>>

Digestive enzymes

Digestive enzymes do just what they say they do, help the body digest foods. Some parents report that they have seen positive effects by adding these supplements to their child's diet. A few have even reported that they have been able to take their children off of the GF/CF diet by using these supplements (see GF/CF diet section for more information). Digestive enzymes, particularly made for persons with dietary intolerances and allergies, can be found through Kirkman Laboratories and Houston Nutraceuticals Inc.

Enzyme Potentiated Desensitization

<http://www.dma.org/~rohrers/allergy/epd_faq.htm> - a method of allergy or immunotherapy treatment using extremely small doses of allergens to desensitize people from their allergies

Autism & Enzymes <<http://groups.yahoo.com/group/enzymesandautism/>>

Why Use Enzyme Based Dietary Supplements?

<http://www.houstonni.com/pages/why_enzymes.html>

Anti-Yeast Therapy

Candida albicans is the medical name for one type of yeast. Many people have heard of thrush and vaginal yeast infections that women often get after taking antibiotics. However, a person can have a yeast overgrowth in the intestinal tract as well. In a healthy gut, bacteria, yeast and other fungi exist together and aid in digestion. When a person takes an antibiotic to fight infection, the balance is disrupted. Good and bad bacteria are killed off but not the yeast. With the good bacteria gone, yeast becomes more abundant and in turn releases more toxins in the body that can damage the nervous and immune systems.

Dr. William Crook, author of *The Yeast Connection*, believes that yeast overgrowth produces a vicious cycle in children. First antibiotics are taken for ear and other infections, which in turn weakens the immune system. A weakened immune system sets up the child for more infections and on it goes. This cycle of antibiotics allows for extensive yeast overgrowth. Dr. William Shaw, author of *Biological Treatments for Autism and PDD*, describes the yeast problem in great detail. He points out that the yeast in the gut produces enzymes that actually break down the lining of the intestinal wall, which can lead to a leaky gut.

To test for a yeast overgrowth, contact your doctor or one of the laboratories that does this testing, such as Great Plains Laboratory or the Great Smokies Diagnostic Laboratory. Usually a urine and/or stool sample is needed for this testing.

One way to help get rid of yeast is to replenish the good bacteria. These “good bacteria” products, or Probiotics, can be found at most health-food stores. Two common ones are *Lactobacillus acidophilus* and *Bifidobacterium bifidum*. Culturelle, a product which can be found at some main drug stores like Target, is one of these types of Probiotics.

Another line of treatment is using antifungals, such as Nystatin or Diflucan. These are prescription medications, so discuss this with your doctor.

Non-prescription products can also be used. Garlic, cranberry, black walnut, caprylic acid, oregano oil, MCT oil, grapefruit seed extract, goldenseal, lactoferrin and Tanalbit have been used to help kill off yeast.

The Candida Yeast-Autism Connection <<http://www.autism.org/candida.html>>

Candida-caused autism? <<http://www.autism.com/ari/editorials/candida.html>> - Bernard Rimland, Ph.D.

Secretin

Secretin is a hormone produced by the small intestine that stimulates the pancreas to release sodium bicarbonate, as well as enzymes that help with digestion. The bicarbonate neutralizes the stomach acids, which allows the enzymes to break down food properly.

Secretin became a possible treatment option for Autism in 1996 when Victoria Beck's son received an endoscopy where a Secretin challenge test was performed. Within days of this test, Parker, her son, began to change dramatically. However, the doctors refused to believe that Secretin had anything to do with the improvements. After months of searching, his parents found a doctor who would help them explore the possibility of Secretin helping their son. Victoria wrote about her experience in the book “Unlocking the Potential of Secretin.”

Secretin is currently under investigation in research studies as a potential treatment option. Consult with current research and your medical professional about the pros and cons of this course of treatment.

Secretin <<http://www.autism-society.org/news/secretin.html>> .

"The Use of Secretin To Treat Autism" <<http://www.nih.gov/nichd/html/secretin.htm>> from the NIH.

Chelation Therapy

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 (Di-mercaptosuccinic acid). 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, and therefore will bind to mercury, such as has accumulated due to vaccinations containing thimerosal. It has been tested in children and found to be safe and effective when properly used.

Another common chelator is DMPS (2,3 dimercaptopropane sulfonate). 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.

For more information on physicians who practice Chelation Therapy, contact the American College for Advancement in Medicine (ACAM). Their database includes over 600 physicians and clinics that are certified in this treatment method.

Chelation of Mercury for the Treatment of Autism <<http://www.healing-arts.org/children/holmes.htm>> - By Amy S. Holmes, M.D.

Chelation Therapy <<http://www.autism-treatment.com/metals.htm>> ,

Neuro-Immune Dysfunction Syndromes/NIDS

The NIDS hypothesis, originating with Dr. Michael Goldberg, M.D., F.A.A.P. of Tarzana, California is based on the understanding that Autism and related disorders, as we know them today, are actually immune mediated disorders.

By treating these and other diseases (Autism, PDD, Asperger's Syndrome, CFS, etc.) as Neuro-Immune Dysfunction Syndromes (NIDS) and looking upon them as medical rather than developmental disorders, Dr. Goldberg and his colleagues at the Neuro-Immune Dysfunction Syndromes Research Institute (NIDS-RI) have seen dramatic improvement and normalization in children previously deemed medically untreatable. During more than 20 years of evaluation and research, Dr. Goldberg has reduced or eliminated symptoms in numerous children throughout the United States and helped return cognitive function to normal and near normal states in many.

According to Dr. Goldberg, NIDS patients are genetically predisposed to having a dysregulated immune system. The immune system malfunction can be triggered by a virus, intrauterine, prenatal or neonatal stress, combination of other stresses, illnesses or trauma and accounts for the cognitive processing and other deficits seen in many of these children. However, while there is likely to be a genetic pre-disposition in many of these children, this is not a genetic disorder as thought of in the past. Recent research supports the likelihood of an autoimmune connection in many of these families.

Diagnosis for NIDS is simple: an immune panel run through blood testing and, in some cases, a NeuroSPECT scan which measures blood flow to the brain. In many instances, testing reveals high titers for a number of herpes-like viruses, fungal or Candida overgrowth and multiple food sensitivities or allergies, which are usually secondary to a very activated immune system. A child's blood work frequently shows lowered counts of natural killer (NK) cells, an imbalance in certain immune cell ratios, as well as low ferritin and elevated lymphocyte counts, with no apparent physical illness.

NeuroSPECT scans of children with NIDS show reduced blood flow to portions of the brain, including areas of the temporal lobes, which affect social skills, auditory processing and language. Other "autistic" symptoms correspond to areas of dysfunction seen in the frontal lobes and the cerebellar area.

By regulating and cooling down the immune system and the targeted use of FDA approved drugs, Dr. Goldberg and other specialists working with these children have seen dramatic improvements. Many children have returned to fully normal functioning, often near or at the top of their classes academically. In the future, Dr. Goldberg hopes to see more advanced medications approved by the FDA that would act as "immune modulators", which he believes would dramatically increase the number of fully normalized patients. These medications to date are not currently available.

Extensive clinical work over the past five years supports the NIDS-RI hypothesis that many developmental disorders are actually immune-mediated diseases affecting the central nervous system.

Immunology - Dr. Michael J. Goldberg MD. F.A.A.P.
<<http://www.neuroimmunedr.com/>>- ADHD/ADD - Learning Disabilities, Immune Dysfunction - CFS/CFIDS - Autism/PDD

Neuro Immune Dysfunction Syndromes Medical Advisory Board and Research Institute
NIDS <<http://mat.org/>> - The NIDS Research Institute, which consists of the NIDS

Defeat Autism Now (DAN) Protocol

In 1995, one of the leading researchers into the field of Autism, Dr. Bernard Rimland, brought together a group of experts to brainstorm the nutritional, genetic and chemical factors that might be involved in Autism and PDD conditions. Their sessions, refined over the years, brought about what has been popularly called the DAN Protocol.

DAN (Defeat Autism Now) is an organization which is a leading research group, centered at the Autism Research Institute. Two members of the original group, Dr. Sidney Baker and Dr. Jon Pangborn were selected to write the actual protocol, using the information that had been developed. Then the full group reviewed the protocol and suggested changes before it was finally published.

One of the key tenants of the DAN Protocol is returning to a diet that is healthy. To quote Dr. Baker, "The American diet is not fit for human consumption." Elimination of refined sugars, junk foods, artificial additives, and the other things that are common in the diet of most children in the United States does nothing to promote good health. Instead it loads their system with unnecessary substances some of which have been shown to be harmful.

A Gluten Free/Casein Free diet is also an important step toward implementing the DAN Protocol. This diet has been shown to have beneficial affects in Autistic children and is a key component of the Protocol. These substances often are found in laboratory blood tests that are done on Autistic children, as well as in urinary peptide tests. The DAN Protocol suggests specific lab testing that should be done, and provides a list of recommended laboratories to do these tests. These labs have been found to provide the best quality information about the test results and help the treating physician determine the priorities that must be addressed in each individual case. It is important to note that each child should be looked at on an individual basis, and there is no "cookie cutter" approach that can be taken for everyone.

Dietary supplementation is also a key ingredient of this treatment method. Many Autistic/PDD children have been found to have deficiencies in various vitamins and minerals. The combination of all of the above factors have been shown to have sometimes dramatic effects on Autistic children, but the people at DAN are the first to admit that it is not a "cure all" and that all improvements may not be solely the result of the protocols. Autism is a complex illness, and there are multiple factors that may influence it's course.

As with any treatment, the Dan Protocol should be undertaken with medical supervision. The Protocol involves a combination of changes to the diet and implementation of vitamin supplement therapy as a means of producing changes in Autistic behaviors. These changes include the following steps, according to published information.

1. Eliminate dairy products.
2. Eliminate cereal grain products.
3. Eliminate junk foods and other food products that contain refined sugars.
4. Supplement the diet with the vitamin and mineral therapy.

If your child is currently taking any medications especially those such as Prozac or Ritalin, it is recommended that you discontinue use before beginning Secretin infusions.

Defeat Autism Now! (DAN!) <<http://www.autism.com/ari/danlist.html>> Biomedical Assessment Options for Children With Autism and Related Problems, (or DAN! Clinical Manual)

Medications

At this time, there is not a specific standard medication regimen to treat autism, so prepare yourself to be patient through the trial-and-error process that this kind of treatment often demands. The problem with medications in treating autism is that they blunt only some of the core symptoms and therefore cannot entirely resolve the impairment. Also, as with any medication, side effects from mild to severe are possible. Be sure to discuss medications as a treatment option with a knowledgeable professional and go slow. The following are some of the classes of medications which have been used to help treat some of the characteristics of autism.

SSRIs

Selective Serotonin Reuptake Inhibitors, or SSRIs for short, may be helpful in reducing the obsessive and compulsive activity, rigidity, anxiety, and irritability that are often a part of autism. Common SSRIs are: Zoloft, Prozac, Paxil, Celexa, and Luvox. Anafranil, which is a tricyclic antidepressant, has also been shown to be helpful in these areas. These medications, however, are not useful in treating the social interaction or communication problems. These medications may also cause agitation in addition to their typical side effects of stomach upset, headaches, nausea or sleep problems, so be sure the doctor starts your child on them slowly.

Stimulants

Since many children with autism have attentional and/or hyperactivity problems, stimulants may be a medication option to treat these problems. The way in which these medications work is that they appear to normalize biochemistry in the parts of the brain involved in ADHD. Specifically, they enhance nerve-to-nerve communication by making more neurotransmitters available to boost the “signal” between neurons. The neurotransmitters that are released more effectively, when a child takes stimulants, are dopamine, and to a lesser extent, norepinephrine.

The most widely-known stimulant for ADHD and ADHD-type symptoms is Ritalin. Other medications in this class that are commonly used include: Cylert, Concerta, Dexedrine, and Adderall.

Some of the more common side effects of the stimulants are appetite suppression and sleep disturbances. Sadness or irritability as well as a worsening of the ADHD symptoms during wearoff (called a rebound effect) can also occur.

Anticonvulsants

These medications are most commonly used to treat seizures, which do occur in some children with autism. Anticonvulsants may also act as a mood stabilizer; these medications help control volatile emotional and behavioral swings, overactivity, and aggressiveness by reducing abnormal firing of nerve impulses in the limbic regions (the emotional center) of the brain. Tegretol, Depakote, Neurontin, and Topamax are some of the medications in this class.

Antihypertensives

While these medications are used to treat high blood pressure in adults, they can also be helpful in treating certain behaviors associated with autism. They are increasingly reported to be useful in treating aggression, self-injurious behaviors, tics, ADHD-type symptoms, and sleep problems. These medications work by dampening one of the major chemical transmitter systems in the brain, the adrenergic nervous system. A common side effect of these medications is sedation, which may be helpful if the child also struggles with sleep problems. Common antihypertensives include: Clonidine, Tenex, and Propranolol.

Antipsychotics

The older antipsychotics, also known as major tranquilizers or neuroleptics, are mainly used to treat severely disruptive, aggressive and psychotic behavior. They may also cause very significant side effects.

The newer medications in this class, called atypical antipsychotics, are increasingly being used as first-line drugs of choice of treatment since their side effects are much less common. Like the older antipsychotics, they affect the dopamine system but appear to influence different subsets of dopamine and serotonin receptors. These newer drugs are being used for marked mood swings, tics and aggression. Risperdal, Clozaril, Zyprexa, and Seroquel are the names of some of these newer atypical antipsychotics.

New medications

One such medication new to the treatment of ADHD and ADHD-type symptoms is Strattera. It is being marketed as the new “non-stimulant” medication for treating ADHD. It works by affecting the levels of norepinephrine in the brain. Side effects may include sedation and a lack of appetite.

Drug companies are always creating more medications, so there will always be something new that may help treat some of the symptoms of autism. As with any medication, proceed with caution and the guidance of a knowledgeable professional.

Medication and Autism PDD from eMedicine by James Robert Brasic, MD
<<http://www.emedicine.com/PED/topic180.htm>>

Medication - Pediatric Psychopharmacology Autism - general information about drugs used to treat autism. <<http://www.vh.org/Providers/Conferences/CPS/41.html>>.

IVIG Therapy

IVIG therapy is a blood product that is extensively tested for several viruses and purified by physical and chemical processing of the blood. It is used as a replacement therapy for immune deficiency syndromes and as an immunomodulatory therapy for autoimmune and immunoinflammatory disorders. This therapy may have an anti-inflammatory effect on the brain, or it may suppress the manufacture of antibodies that attack the CNS myelin.

Transfer Factor

One way to help enhance the immune system is through antigen-specific transfer factors. This therapy collects specific transfer factors from appropriate donors and gives them to the patient. For example, if a person needs to fight measles, then anti-measles transfer factors are collected and given to that person so his body will have help in “learning” to fight the measles virus.

To determine which viruses are causing problems, blood tests by a qualified professional is needed. Discuss this with your doctor or contact Kirkman Laboratories to find a qualified professional.

Transfer Factor <http://www.gansys.com/transfer_factor.htm>

Sulfate Deficiency/Epsom Salt Baths

Many children with autism have a deficiency of sulfates in their plasma. Low sulfates can lead to a leaky gut and increased colonization of viruses in tissues and a weakness in the phenosulfotransferase (PST) system. Some symptoms of a PST weakness may include, migraines, red face, red ears, dark circles under the eyes, bloated stomach, runny nose, eczema, and sweating at night.

Some people have tried to raise the levels of sulfates in the body through special creams or by adding magnesium sulfate, Epsom Salts, to the bathwater. Since magnesium sulfate can be absorbed through the skin, it may increase the amount of sulfates in the system.

Vaccinations

For a quite a while now, vaccinations have been accepted a part of childhood. Their benefits have been long documented, protecting many from serious diseases and death.

The other side of the issue is the potential of side effects and injury. Like medications, vaccines will never be 100% safe. Aware of the damages caused by vaccines, Congress passed the National Childhood Vaccine Injury Act of 1986 and directed the U.S. Department of Health and Human Services to administer the Vaccine Injury Compensation Program, which financially compensates vaccine-injured people after cases are heard in the U.S. Court of Claims in Washington D.C.

Each vaccine may cause a variety of reactions, but two immunizations have drawn the most attention for children with autism: MMR (measles, mumps, rubella) and DaPT (diphtheria, acellular pertussis, tetanus).

Controversy over the MMR shot escalated when in early 1998 Dr. Andrew Wakefield and associates published research in which autistic symptoms were linked with the MMR vaccine. Dr. Wakefield identified associated gastrointestinal disease and developmental regression in a group of previously normal children. In most cases, the onset of symptoms was after the measles, mumps, and rubella immunization was received.

A reaction to the DaPT immunization may be encephalitis (brain inflammation). This is thought to be related to the pertussis portion of the vaccine, in particular the older version. The version which is now being administered is its newer, acellular form, which is believed to be better tolerated.

The subject of vaccinations is one of concern and controversy. Discuss your concerns with your child's doctor, inform yourself as much as possible and be aware of the risks and benefits of your options.

ALLIED VACCINE GROUP <<http://www.vaccine.org/>>

Immunization Safety Review Committee
<<http://www.iom.edu/IOM/IOMHome.nsf/Pages/immunization+safety+review>>

EEG Biofeedback

EEG Biofeedback is a learning strategy that enables persons to alter their brain waves. When information about a person's own brain wave characteristics is made available to him, he can learn to change it. Consider this exercise for the brain.

EEG Biofeedback is used for many conditions and disabilities in which the brain is not working as well as it might. These include Attention Deficit Hyperactivity Disorder (ADHD), conduct problems, specific learning disabilities, sleep problems, teeth grinding, chronic pain such as headaches or stomach pain, or pediatric migraines. Training is also helpful with the control of mood disorders such as anxiety and depression, as well as for more severe conditions such as medically uncontrolled seizures, minor traumatic brain injury, or cerebral palsy.

Biofeedback <<http://www.eegspectrum.com/Applications/Autism/EEGandAutism/>>

Biofeedback <<http://www.biomental.com/>>

Hyperbaric Oxygen Therapy

Hyperbaric Oxygen Therapy, or HBOT, delivers pure oxygen at higher-than normal pressures to patients sitting or lying in a chamber. Although there is no proof, advocates believe that in brain damage cases the extra oxygen can prompt dormant or damaged neurons to become reinvigorated.

HBOT has been used in mainstream medicine to treat a dozen very specific problems, such as stubborn wounds, but its use on neurological conditions is controversial.

HYPERBARIC OXYGEN AND AUTISM <<http://mars.he.net/~strokedr/autism.htm>>

CHAPTER 5

ADDITIONAL THERAPIES

- I. Additional Therapies
 - a. Dietary Interventions
 - 1. GF/CF diet
 - 2. Feingold diet
 - 3. Ketogenic diet
 - 4. Anti-yeast diet
 - 5. Rotation diet
 - b. Occupational Therapy
 - c. Sensory Integration
 - d. Speech Therapy
 - 1. PECS
 - 2. Sign Language
 - 3. Facilitated Communication
 - e. Physical Therapy
 - f. Listening Therapies
 - 1. Tomatis Method
 - 2. Auditory Integration Therapy/AIT
 - 3. EASe
 - 4. Sonas
 - 5. Samonas
 - g. Fast ForWord
 - h. Earobics
 - i. Vision Therapies
 - 1. Irlen Lenses
 - 2. Ambient Lenses
 - 3. Vision Exercises
 - j. Animal Therapies
 - 1. Hippotherapy
 - 2. Dog Companion Therapy

Selected Resources:

- * Facing Autism by Lynn Hamilton
- * Straight Talk about Psychiatric Medications for Kids by Timothy E. Wilens, M.D.
- * Power Cards: Using Special Interests to Motivate Children and Youth with Asperger Syndrome and Autism by Elisa Gagnon
- * What Your Doctor May Not Tell You About Childhood Vaccinations by Stephanie Cave, M.D.
- * websites: autism.about.com; www.autismuk.com; www.connectionscenter.com

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ADDITIONAL THERAPIES

Dietary Interventions

Many children with autism have allergies, seizures, trouble digesting certain foods, and problems with yeast overgrowth in their systems. By removing the offending items from the diet, many children begin to feel and act better as their bodies begin to heal. The following diets may help a child with some of these problems.

GF/CF diet

In a healthy body, the digestive tract takes complex foods and breaks them down into substances the body can absorb and utilize. As the food travels through the gastrointestinal system, the enzymes in the digestive juices convert the food into a simpler form. Food starts out similar to a long chain of paper clips. Through digestion, they are unhooked and left as single paper clips, which is the form needed by the intestines to absorb and deliver nutrients to the body. During digestion, protein - which is made up of building blocks called amino acids - is broken down into the single amino acids.

Many children with autism have trouble digesting certain proteins called gluten, which is found in wheat, barley, oats, and rye, and casein, which is found in dairy and many baked products. Gluten and casein contain certain combinations of amino acids that are very difficult for the body's digestive system to break down into single amino acids. Structures remain in the form of a chain of several amino acids called peptides. These peptides may then seep out of the intestine and into the bloodstream. The term "leaky gut" is used to describe this condition where the intestinal wall can't keep the contents of the intestine separate from the bloodstream. In a healthy gut, a few peptides may escape, but they are recognized as foreign and the body's immune system deals with them. However, in a leaky gut many peptides enter the bloodstream and can cause harm.

The peptides left over after digestion of casein and gluten react at certain sites in the brain called opined receptors, sites where opiate drugs like morphine and heroin act. Therefore, if these peptides aren't breaking down into amino acids and they are getting out of the intestine, then when they reach the brain they act like these drugs.

Also, when there is a leaky gut, proteins from other foods may be absorbed through the intestinal wall as well. If this happens, the body's immune system may kick in. An allergic reaction may occur within a minute to hours after the offense. Symptoms may include vomiting, diarrhea, skin rashes, headaches or a runny nose. Food sensitivities may create a variety of other symptoms, from stomachaches, appearing "spaced out", excessive whining and crying, sleep problems, hyperactivity, aggression, sound sensitivity, fatigue, and intestinal problems .

Some children with autism may respond well to a gluten-free, casein-free diet. To avoid casein, no dairy products can be consumed. To avoid gluten, foods such as wheat, barley, barley malt, malt, rye, oats, oatmeal, bulgar, durum, spelt, tritical, semolina, and couscous must be avoided. Many other products, like baking powder, soy sauce, bouillon cubes, sauces and others may contain gluten and/or casein. Thus it is very important to know specific sources of gluten and casein and to read labels!

Lisa S. Lewis. "Understanding and Implementing a Gluten & Casein Free Diet"
<<http://www.princeton.edu/~serge/ll/gfpak.htm>>.

Feingold's diet

Dr. Ben Feingold's book "Why Your Child is Hyperactive" suggests that hyperactivity is caused by dyes, artificial colorings, preservatives, and other additives in food. He recommends removing salicylates from the diet since they are peptidase inhibitors. Salicylates are found naturally in some fruits and vegetables, including tomatoes, cucumbers, apples, apricots, berries, cherries, grapes, oranges, plums, tangerines and almonds.

The Feingold Association advocates a two-stage approach. In stage one, remove dyes, additives, preservatives and all items with salicylates. After four to six weeks reintroduce, one at a time, each food containing salicylates to determine if there is a reaction. If there is no reaction, bring that food back into your child's diet. The dyes, additives, and preservatives should not be brought back into the diet at all.

Ketogenic diet

The ketogenic diet is designed for those who suffer from seizures. This diet began many years ago when some doctors at Johns Hopkins Hospital gave patients high-fat, low-protein, and low-carbohydrate food in order to control the seizures. Fat is the focus of this diet because when the body burns fat, it creates ketone bodies, which are suspected to inhibit seizures. In 1996 Dr. John Freeman, Millicent Kelly and Jennifer Freeman published a book titled "The Epilepsy Diet Treatment: An Introduction to the Ketogenic Diet" that brought this diet into more public exposure.

This diet should be followed with the close supervision of a neurologist. The diet needs to be tailored for each child and carefully monitored.

Ketogenic Diet <[ketopgs.htm](#)>

Anti-yeast diet

Dr. Bruce Semon, a child psychiatrist, nutritionist and father of a son with autism, wrote a book entitled "Feast Without Yeast." Through treating his son and many others, he has come to believe that Candida yeast overgrowth can be effectively treated. Along with antifungal medication, Dr. Semon recommends a four-stage diet. Dr. Semon's book gives a detailed description and understanding of each stage, along with more than two hundred recipes.

Rotation diet

As the name suggests, foods that are not a problem for a child are rotated on a specific cycle, commonly every fourth day. Rotating the staples in a diet may help prevent the body from reacting to these products and developing antibodies to them.

Dietary Control of Autism - Diets, Allergies, Foods and Supplements, Food Additive Database <diet.htm>

Special Diets for Special Kids Books I and II - by Lisa Lewis

A guide to understanding and implementing special diets to aid in the treatment of Autism. There is also a second edition available now.

Occupational Therapy

Occupational therapy is a health service that is concerned with an individual's ability to participate in desired daily life tasks, or "occupations," which give one's life meaning. If a person's ability to perform these tasks which include caring for one's self and others, working, going to school, playing, and living independently is impacted by an illness, disease, and/or disability, occupational therapy can be important.

Following an evaluation of the child's functioning in various age-appropriate performance areas, or life tasks, occupational therapy intervention is targeted towards those areas that are interfering with the child's ability to function. Some tasks that may be targeted include: writing, improving hand-eye coordination, buttoning a shirt, tying one's shoes, getting dressed, feeding oneself, as well as other identified tasks. Intervention with children is often in the form of play activities specifically geared to facilitate and support the child's self-help, play and learning skills.

Occupational therapy intervention with persons with autism often includes a sensory-integrative approach, which focuses on providing controlled sensory input during specific activities (see next section on sensory integration). Other therapeutic approaches are also used as part of the intervention with the ultimate goal of assisting the individual to participate in important daily life tasks and activities as independently as possible.

Occupational Therapy and Autistic Children <<http://www.autism.ca/occther.htm>>

The American Occupational Therapy Association <<http://www.aota.org/index.asp>>

Sensory Integration

Sensory integration is a process used by the brain to locate, sort, and make sense out of incoming sensory information. This process is important in the successful accomplishment of life tasks. Children who have autism and other pervasive developmental disorders often have difficulty regulating their sensory systems.

For example, a child may scream when wearing certain clothing because their sensory system is hypersensitive to the sense of touch. This same child may crave bear hugs because his proprioceptive system (deep touch) is hyposensitive. These hypersensitive and hyposensitive sensations impact the child's independent functioning in many facets of life including peer interaction, attention at school, and activities of daily living at home.

Sensory integration therapy is child-centered. The therapy gym is often filled with large balls, swings, and ball pits. The child initiates play activities while the therapist guides the child in understanding what he or she is sensing. The therapist also empowers the child to organize his or her senses. The positive effects of sensory integration vary from child to child. Some positive effects include an increased willingness to try new activities, increased social participation, increased independence in self-care activities, increased attention and increased coordination during activities.

Professionals trained in the area of sensory integration include physicians, physical, speech and occupational therapists. However, most professionals trained in this area are occupational therapists. Using the sensory integration technique, occupational therapists promote functional independence through the purposeful activity of play.

Cohn, E. S. (2001). Parent perspectives of occupational therapy using a sensory integration approach. *American Journal of Occupational Therapy, 55*, 285-294.

Kranowitz, C. S. (1998). *The Out of Synch Child*. Perigee Book: New York.

Linderman, T. M. & Stewart, K. B. (1999). Sensory integrative-based occupational therapy and functional outcomes in young children with pervasive developmental disorders: A single subject study. *American Journal of Occupational Therapy, 53*, 207-213.

VandenBerg, N. L. (2001). The use of a weighted vest to increase on-task behavior in children with attention difficulties. *American Journal of Occupational Therapy, 55*, 621-628.

** The *American Journal of Occupational Therapy* is available at the Creighton University Library.

Speech Therapy

Most children who have been diagnosed with autism or other disorders on the spectrum have speech and/or language difficulties as well as poor social skills. One of the common identifying factors for the diagnosis of autism is the normal development of speech followed by the loss of speech skills or the lack of/late development of speech. The speech-language pathologist (SLP) is a skilled professional that can address the following areas of concern:

1. **Receptive language** - the ability to comprehend what is seen, heard, touched, tasted, smelled, etc. This includes identifying objects, actions, adjectives, prepositions, people, etc.
2. **Expressive Language** - the ability to label what is seen, heard, touched, tasted, smelled, etc. This also includes sentence structure, verb tenses, regular/irregular plurals, length of utterance, etc.
3. **Articulation** - includes developing sound production, correcting errors in production, increasing/decreasing rate, increasing/decreasing volume, and improving intonation.
4. **Oral-Motor Skills** - includes improving range, rate, complexity, strength, and coordination of motor movements. May also include massage of cheeks, lips, and gums, brushing teeth, and decreasing teeth grinding.
5. **Feeding and Swallowing** - includes ability to close lips, manipulate food with tongue, age-appropriate chewing pattern, and safe swallowing. Other areas that can be addressed include oral-desensitization to different tastes, textures, smells, temperatures, and consistencies of foods.
6. **Social skills/Play skills** - includes appropriate social language, ability to read facial expressions, ability to understand social cues/body language, and age-appropriate play skills such as sharing, turn taking, playing independently or with others.
7. **Cognition** - includes problems solving, reading comprehension, academic skills, and answering various “wh” questions.
8. **Augmentative Communication** - includes assessing ability to use high-tech and low-tech devices, and teaching the use of the system selected. The most common communication options are:
 - a. Sign-language- use of signs alone or paired with speech
 - b. PECS - the Picture Exchange Communication System involves using picture symbols to communicate wants/needs, label, etc. The child goes through a learning process that teaches initiation of communication, and then expands to the use of sentences. Many children who use PECS develop some verbal skills and may graduate to speech as the primary form of communication.
 - c. Facilitation - involves holding the child’s hand or having the child hold the facilitator’s hand to help the child write messages. This method has been proven to work in a few case studies, however, its validity has not been scientifically tested on a larger scale.
 - d. Communication board - can be made with pictures or objects that the child points to or removes from the board to communicate wants/needs.
 - e. Communication devices- there is a wide range of devices available that are capable of putting together longer messages and operating electronic devices in the environment such as the TV, lights, etc. The SLP can assess the child’s abilities to use high-tech devices and make recommendations about the type of device best suited for the child’s individual needs.

- f. Total communication - involves using any and all methods of communication a child is capable of. The child is encouraged to use the words/phrases that he/she is capable of producing and supplementing communication with signs, symbols, etc. for what he/she can't communicate verbally.

The speech-language pathologist is a valuable member of an autistic child's treatment team. Therapy done with the SLP and occupational therapist working together has proven to be highly beneficial since the calming/sensory input provided by the OT usually increases the child's ability to focus on a task.

Physical Therapy

Physical therapy helps to restore function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities of patients suffering from injuries, disease, or a disability. Physical therapy targets more gross motor skills, as opposed to occupational therapy that usually targets more fine motor skills.

An evaluation may consist of testing and measuring a person's strength, range of motion, balance and coordination, posture, muscle performance, respiration, and motor function. Treatment often includes specific exercises for flexibility, strength, endurance, balance and coordination. Treatment goals for children may include working on balance, climbing/descending stairs independently, catching a ball or learning to jump.

Physical therapy may also work closely with occupational therapy, sensory integration and/or speech therapy to help maximize the effects of each therapy.

Listening Therapies

Tomatis Method

Created by Dr. Alfred Tomatis in the 1960's, this method consists of treating patients with "filtered" sounds of music, Gregorian chants, and voices, through an electronic device, in hopes of retraining the ear. The Tomatis Method is somewhat lengthy, since it sometimes lasts 100-150 hours or more, extending over weeks, months or years.

Auditory Integration Therapy

Auditory Integration Training, AIT, was developed by Dr. Guy Berard. He trained under Dr. Tomatis and created his own electronic device where patients could listen to filtered music for a total of ten hours over a ten-day period.

AIT consists of twenty half-hour listening sessions, usually two sessions a day over ten days. Before treatment begins, the therapist tests and charts the child's hearing on an audiogram to determine if any frequencies are uncomfortable or painful for the child. If so those frequencies are filtered out through the AIT device. The AIT device not only filters out disturbing frequencies, it randomly modulates the music, dampening either high or low frequencies. During the listening sessions, the child is free to play, jump, or move about as he or she chooses.

EASe, Sonas, and Samonas

Though AIT may benefit some children with autism, the cost of treatment or lack of available practitioners can make it inaccessible. Several compact discs are now available to allow listening therapy to take place in the home or school with the use of high quality headphones and an ordinary CD player. Programs include EASe (Electronic Auditory Stimulation effect), Sonas and Samonas, which can be purchased with the headphones, through clinicians trained in listening therapy. It is recommended to have a therapist guide your program since your child may need a combination of CDs based on his or her issues.

Earobics <<http://www.earobics.com/>> - Earobics software is based on 20 years of literacy research that have shown phonemic awareness to be the best predictor of success in early reading.

Auditory Integration Training <[ait.htm](#)> - My page of AIT links, Berard, Thomatis, Fast ForWord etc

Fast ForWord

The Fast ForWord Family of Programs develops the critical thinking, listening, and reading skills that are necessary for success in the classroom, the workplace and in everyday life. Based on over twenty-five years of brain research, Scientific Learning's interactive, adaptive programs use patented technology to target the language and reading skills widely recognized as the keys to all learning.

The programs are CD-ROM and Internet-based. Children who have trouble understanding and using oral language or who have reading difficulties are most likely to benefit from these programs. Using game-like exercises, Fast ForWord uses four training principles - frequency, intensity, adaptivity, and motivation - to help children improve their language skills. These principles are applied in a cross-training format that allows children to work on multiple complementary language skills. In all, the exercises provide training on over forty different language structures to help the child gain higher-level language skills. Fast ForWord exercises use enhanced sounds and provide more time between certain sounds to help children improve oral language comprehension. As the child progresses in the program, the sounds adapt to the child's skill level by becoming increasingly like normal speech.

Fast Forward is an intense program. The seven interactive exercises in Fast ForWord are rotated so that five are played each day. Each game requires twenty minutes, for a total of one hundred minutes a day, five days per week. Most children complete the entire program in four to eight weeks, although some may take longer.

Earobics

The Earobics Auditory Development and Phonics Program is designed for children with a developmental age of four to seven years, and Earobics Step 2 is designed for children who are developmentally between seven and ten years of age.

The program consists of six listening games with up to 114 levels, which increase in difficulty as the child improves. This program includes skill development in auditory memory, phonemic synthesis, sound segmentation, auditory and phonemic identification, sound-symbol correspondence, rhyming and phonological awareness. Like Fast ForWord, this CD-ROM program uses computer-modified speech to help the child distinguish sounds that may be difficult at first. It is less intense, and less expensive, than the Fast ForWord programs.

Vision Therapies

Some children may have vision problems that may cause them to have a different perception of the world. Currently there are three main approaches to treating vision disorders: Irlen lenses, ambient or prism lenses, and visual training.

Irlen lenses

These lenses are named after Helen Irlen, who discovered a visual perception problem related to light sensitivity. This perception disorder is known as Scotopic Sensitivity Syndrome (SSS), or Irlen Syndrome. Some symptoms include light sensitivity, poor depth perception, attention problems, contrast and color sensitivity, problems seeing groups of objects, and distortions.

The theory behind this intervention is that certain light frequencies can be disturbing or overstimulating. Specially tinted lenses for glasses, which come in a thousand different colors, filter out some of the frequencies to protect the individual from unpleasant input. If the individual can't tolerate the overabundance of visual input, filtering out some frequencies may allow the brain to process the remaining visual information more easily.

Ambient or prism lenses

Besides Irlen lenses, some people have found ambient or prism lenses can help with visual distortions. Melvin Kaplan, O.D., from the Center for Visual Management, states that abnormalities of ambient vision are often found in children with autism. Ambient vision is involved in spatial organization, related to body posture, locomotion and the perception of self-motion. These types of lenses can enhance depth perception as well as assist in centering the vision.

Vision exercises

Dr. Kaplan also suggests specific vision exercises. Vision exercises may help retrain the visual system, helping the brain to understand and function with the altered visual input.

Irlen Syndrome/Scotopic Sensitivity Syndrome
<<http://www.planet.eon.net/~judypool/irlen.htm>>

Vision Therapy <http://www.latitudes.org/amb_lens.html> - Ambient Lenses

Animal Therapies

Hippotherapy

Hippotherapy, or the practice of using a horse as a therapy tool, was first applied to the Greeks to help rehabilitate war injuries. In recent history, Hippotherapy came to the attention of the world in 1952 at the Helsinki Olympics when Liz Hartel won a silver medal that told the world that horseback riding had helped her recover from polio. In the 1960's, horses were incorporated into physical therapy programs in Germany, Switzerland and Austria. In the 1970's a team of American speech, physical and occupational therapists went to Germany to learn about Hippotherapy. This was the beginning of the American Hippotherapy Association.

Hippotherapy can help people with physical and emotional disabilities. For those with physical handicaps, the motion of the horse simulated walking and increases balance and coordination. For those with emotional problems, grooming the horse brings an opportunity for self-evaluation. For children with autism, connecting with a horse is a way to help keep them involved in the world.

Therapy can also take place while riding on a trail; therapists can set up reading and phonics exercises along the way, as well as work on sequencing needs and fine-motor skills.

Hippotherapy (Horseback Riding)

<<http://members.aol.com/vincicarets/hippotherapy.htm>>

American Hippotherapy Association

<<http://www.americanequestrian.com/hippotherapy.htm>>

Dog companion therapy

Since 1995, National Service Dogs has been training Labrador and Golden Retrievers to assist the parents of children with Autism.

Many families feel that they are trapped in their own homes as their child has great difficulties in public places, getting overstimulated, overwhelmed and not listening to or staying with others. A National Service Dog can accompany the families into malls, restaurants, hotels and schools.

The dogs assist in the following manner: The children are attached to the dogs via a leash. The dog responds to commands by the parents to go forward, turn left, turn right or stop. If the child approaches a curb or tries to walk away, the parent can tell the dog to stop and stay. The dog will use all of its power to brace its footing or slow the child down and stop.

The children are taught that they are responsible for the care of their new dog and some children develop a strong connection with the dog. Anecdotal evidence suggests some children may use the dogs as a source of comfort when they are upset while others may be less aggressive after the introduction of the dog.

CHAPTER 6

IEPs, IFSPs, STATE & FEDERAL LAW

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

Special Education Law

1. Federal Law

IDEA is the Individuals with Disabilities Education Act.(Public Law 94-142). Previously called the Education for All Handicapped Children Act of 1975 (EAHCA), it was reauthorized in 1997. IDEA requires public schools to provide a free and appropriate public education to school-aged children ages 3-21 regardless of disability. USA Federal law provides funds to states that maintain certain standards in their education of handicapped children, i.e. providing a free and appropriate education in a least restrictive environment.

Currently (Summer/03) Congress is in the process of reauthorizing IDEA which may include several changes.

2. State Law

Title 92 -- Nebraska Department of Education Chapter 51 -- Regulations and Standards For Special Education Programs

Rule 51 is the Nebraska State Special Education law covering the state regulations and standards for special education programs in compliance with Federal Law. For a copy or information on Rule 51, contact:

Special Populations Office
Nebraska Department of Education
301 Centennial Mall South, Sixth Floor
P.O. Box 94987
Lincoln, NE 68509-4987
Phone: (402) 471-2471

Also helpful is a three-page index, A Parent's Guide to Nebraska's Rule 51, and the Special Education and the IEP in Nebraska (A Guide for Parents) included in this chapter and put out by:

Parent Training Information of Nebraska for Children with Special Needs (PTI)
3135 N. 93rd St.
Omaha, NE 68134
(402) 346-0525 (800) 284-8520
info@pti-nebraska.org
www.pti-nebraska.org

3. IEP/IFSP

IEP

Individual Education Plan (IEP) is the written statement for a child with verified disabilities that is developed and implemented in accordance with Rule 51. It is for children 3 - 21 years of age.

The Individual Education Plan (IEP) is a written statement for a child with a verified disability which specifies the special education and related services necessary to assure that child a free, appropriate public education. Parents shall receive a copy of the IEP. The IEP shall include:

- A statement of the child's present level(s) of development or educational performance.
- A statement of the annual goals describing anticipated behavior to be achieved, based on the child's present level of development or educational performance.
- A statement of the measurable short term instructional objectives.
- A statement of the specific special education and related services to be provided to the child.
- A description of the extent to which the child will participate in the regular education program.
- The projected date(s) for the initiation of services and anticipated duration of service(s).
- Appropriate objective criteria, evaluation procedures and schedules for determining, on at least an annual basis, the achievement of the instructional short term objectives.
- A list of individuals responsible for implementing the IEP.
- The amount of time per day, days per week, and the number of months of service to be delivered to children below age five.

IFSP

The Individual Family Service Plan (IFSP) is a written plan for providing early intervention services to a child with a disability age birth through age two and the child's family that is developed and implemented in accordance with Rule 51.

If a determination is made that an infant or toddler needs special education and related services, an Individualized Family Service Plan (IFSP) shall be developed for the child and the family. The IFSP shall include:

- A statement of the child's present levels of physical development (including vision, hearing, and health status), cognitive development, communication development, social or emotional development, and adaptive development which is based on professionally acceptable objective criteria;
 - With the concurrence of the family, include a statement of the family's resources, priorities, and concerns related to enhancing the development of the child;
 - A statement of the major outcomes expected to be achieved for the child and family, and the criteria, procedures, and timelines used to determine:
 - The degree to which progress toward achieving the outcomes is being made; and
 - Whether modifications or revisions of the outcomes or services are necessary.
-
- A statement of the specific early intervention services necessary to meet the unique needs of the child and the family including:
 - The frequency, intensity, and method of delivering the services;
 - The natural environments in which early intervention services will be provided;
 - The location of the services

Special Education and the IEP in Nebraska (A Guide for Parents)

PTI Nebraska

The vision of PTI Nebraska is that parents in Nebraska will have the capacity to improve the educational services for their own children and will be involved in policy making that will bring about systems change in the state of Nebraska to benefit the educational outcomes and improve the delivery of services to all children with disabilities.

The staff members at PTI Nebraska are Parent-Professionals who are available to talk to parents on the phone, at the office or at workshops across the state. They can answer parent's questions about their children's special education needs or provide information specifically related to the child's disability. The staff can also direct parents to resources in their own community or put them in touch with another parent in their area.

Workshops are presented throughout the state. There are no registration fees for the workshops and they are open to anyone who cares about children with disabilities and their families.

For Information On:
Special Education and Disability Related Topics,
Parent Workshops, or Parent-to-Parent Networking,
Call, email or write PTI Nebraska at:
3135 North 93rd Street
Omaha, Nebraska 68134
402-346-0525 or 1-800-284-8520
info@pti-nebraska.org
www.pti-nebraska.org

This document was originally developed by the Nebraska Parents Center under a grant from the U.S. Department of Education (H029M10010). The contents do not necessarily represent the policy of the Department of Education and you should not assume endorsement by the Federal Government. It was revised by a Stakeholders Committee sponsored by the Nebraska Department of Education and is being distributed by PTI Nebraska, formerly the Nebraska Parent Center.

1. What Are The Laws?

A. Federal Law

The Individuals with Disabilities Education Act (IDEA '97) says that all children, no matter what their disability, have the right to a free, appropriate, public education. (FAPE)

B. Nebraska Law

Rule 51, based on Nebraska law and in compliance with the Federal Law, explains how Special Education services are provided for children in Nebraska.

Additional information is available regarding federal and state special education laws.

2. Who Gets Special Education Services?

A. There are lists of disabilities in federal and state law. Children who have one or more of these disabilities are eligible to receive special education.

B. Nebraska's list of disabilities include:

- Autism
- Behavior Disorders
- Developmental Delay
- Deaf-Blindness
- Hearing Impairments (including deafness)
- Mental Handicaps
- Multiple Disabilities
- Orthopedic Impairments
- Other Health Impairments
- Specific Learning Disabilities
- Speech-Language Impairments
- Traumatic Brain Injury
- Visual Impairments (including blindness)

C. Nebraska special education law allows children who have disabilities to receive special education services from birth until the end of the school year in which their twenty-first birthday occurs.

This handbook is intended to be a helpful guide for parents whose children are between the ages of three and twenty-one.

3. What Should I Do If I Think My Child Needs Special Education Services?

A. You should speak to your child's doctor, social worker, classroom teacher and/or the principal about your child's problems and ask for a special education evaluation. Tell them:

1. What problems your child is having; and
2. That you think your child might need special education.

The school district will refer your child to a Student Assistance Team (SAT) for more information before a decision is made to evaluate your child.

1. If the decision is to evaluate your child, the school district will do an evaluation.
2. If the school decides your child does not need an evaluation, they must explain to you in **writing** why they do not think your child needs to be evaluated.

If you disagree with the school district's decision, you can request **mediation** at no cost to you. An impartial mediator will help both parties reach an agreement. You may want to file a **compliant** with the State Department of Education or you can ask for a **due process hearing** where a state appointed, impartial **hearing officer** will decide if your child should be evaluated. **Due process** may have some cost to you, as you may want to involve an attorney.

You or the school may ask for mediation or due process **any time** there is a **serious** difference of opinion regarding your child's education. Mediation, complaints, and due process are called **procedural safeguards**. Procedural safeguards are ways to ensure that your child is getting an appropriate education.

4. What Happens When The School Wants To Evaluate My Child?

- A. The school must notify you in **writing** that they want to do an evaluation of your child. The notice must tell you about:
 1. Your legal rights;
 2. Why the evaluation is needed
 3. The kind of tests that will be given;
 4. When the testing will be scheduled, how long it will take and how long it will take to get the results.
- B. Whenever the school evaluates or reevaluates your child, you **must be given written permission** for the evaluation. You may say:
 1. Yes, and the school will do the evaluation;
 2. No, and the school may not do the evaluation. If you say no, you should talk to the school about your reasons for not wanting your child to be evaluated. If you say no, the school may request **mediation or due process**.
- C. The school district must evaluate your child:
 1. Before they can provide special education services;
 2. When your child is receiving special education services, evaluations **must** be reviewed or redone every three years.

Testing can be done anytime **you** or the **school** thinks it is necessary. The decision to retest or review test information will be made by **you** and the other members of the **Multidisciplinary Team (MDT)**. **Multidisciplinary** means that each of the team members has different kinds of information about your child that will be shared with each other. Some members of the MDT have tested or will be the ones testing your child.

5. What Kind of Information Should You Share With the People Who Test Your Child?

- A. You know your child better than anyone. It is important that you share what you know about your child with the people who will do the testing. Share information about:
1. Problems with the pregnancy or birth;
 2. When your child walked, talked, etc;
 3. Your child's personality;
 4. How your child gets along at home;
 5. How you feel your child has done in school so far;
 6. Any medical condition your child has;
 7. Any medication your child is taking;
 8. Reports from outside check ups such as vision, hearing, or recent neurological or other medical exams;
 9. What you know about how your child learns;
 10. Things your child does well;
 11. things your child has trouble with;
 12. Anything else about your child that you feel is important.

6. What Should You Learn From The Multidisciplinary Team Report?

- A. Whether or not your child has a disability and why or why not special education services are needed;
- B. An explanation of the tests and the results;
- C. How your child is doing with schoolwork;
- D. Things your child can do compared to other children the same age;

- E. The things your child does well;
- F. The kind of assistance your child might need in school to help with learning.

7. What Happens After The Testing Has Been Done?

- A. The people who did the testing will go over the tests with **you** and the other members of the MDT and explain what the results mean.
- B. To be sure that you understand what the tests say, ask yourself these questions:
 1. Do I understand what my child's disability is and why my child needs special education services?
 2. Do I understand why my child is having problems?
 3. Was my child tested in all suspected, or identified, areas of disability?
 4. Does the information make sense?
 5. Does it sound like the things I know and understand about my child?
- C. As a member of the MDT you will be asked to indicate **in writing** whether or not you agree with the information you have received. If you disagree, you must state your reasons **in writing**.

If you disagree and you think there might have been a problem with the testing you can ask the school district to do a new test or ask to have someone else test your child. This is called an **independent educational evaluation**. When you ask for additional testing, your request should always be **in writing**.

8. What Is the Individual Education Program (IEP) Conference or Meeting?

- A. If your child has a disability and needs special education, there will be a meeting with the people who will work with your child. This is called an Individual Education Program meeting or conference. Sometimes it is called an Individual Education Plan rather than Program. The IEP meeting or conference is where **the plan for your child's special education program will be written for the whole year**.
- B. If your child has a disability, the IEP meeting **must** be held within 30 days after the evaluation. The school district will contact you to set up a meeting that is at a time that is **convenient** for **you** and for the **people from school**. **You, maybe your child** and **people from school** are the ones will meet. Some of the IEP team members may be the same as members of the MDT.
- C. Your child's special education teacher will probably be the one to schedule future IEP meetings and other meetings for your child. There must be **at least one** IEP meeting every school year. Any member of the IEP team can call a meeting at **any time** to discuss or review the IEP or to propose changes. All meetings **must** be scheduled at a time that is **convenient for everyone**.

- D. The IEP will say what kind of special education services your child will receive. The IEP is a written plan for teaching your child and is written **especially for your child** by a **team** of people who know your child well.

9. Who Must Come To The IEP Meeting?

- A. An **administrator** or someone else who is able to authorize the special education program your child needs.
- B. You child's teachers. The **special** education teacher and a **regular** education teacher who teaches your child, or who may teach your child in the future.
- C. You, the **parent (s)**
- D. **Your child**, if it is appropriate.
- E. If your child attends a nonpublic school, **someone from that school**.
- F. A **member of the team** that most recently evaluated your child, other than the team members mentioned above.
- G. You or the school can invite **others** who know about your child and your child's needs. This may be a professional or it may be a friend or family member.

10. How Should I Get Ready For the IEP Meeting?

- A. You will be contacted about a date and time for the meeting, usually in a letter. The **time** of the meeting **must work** for **you** and the **school**. If the times does not work for you, call the school and **ask** to have the conference time **changed**.
- B. **Planning** before the conference will help you remember all of the important things you have to talk about.
- C. Go over your child's last IEP and test results. Make a **list** of questions, things you are concerned about and things that seem to be working well. Take this list with you to the conference.
- D. Make sure you understand any new information you have before you go to the conference. This is especially important if your child has been tested recently.
- E. Ask who will be at the conference so you will be able to have your questions ready for those who will be there. If there is someone you need to talk to, ask that they come to the conference.
- F. It might be helpful for you to invite a friend or relative, someone who knows your child well, to go to the meeting with you.

11. What Should Be Written In An IEP?

A. The IEP **must** include:

1. **A statement of your child's present level of educational performance:**
 - a. Results of the most recent tests;
 - b. The things the child can do well;
 - c. The parent's concerns for the child's education;
 - d. The effect the disability has on how the child can learn in regular education classes;
 - e. For a child in preschool, the effect of the disability on the child's ability to do the things other children do.
2. Consideration of special factors: (All of the following factors must be discussed). If your child has trouble learning because of one or more of the factors, it must be written in the IEP as to how the school, in a positive way, will help your child overcome the problem(s) and how learning will be made easier for your child and teaching made easier for the teacher:
 - a. Behavior **problems** that keep your child from learning. **There is additional information on behavior, expulsion and suspension.**
 - b. A need for **Braille** if your child is blind or visually impaired;
 - c. Communication difficulties;
 - d. A need for special equipment sometimes call assistive technology.
 - e. A need to learn **English**.
3. **A statement of goals**, including benchmarks or short-term objectives must be included in the IEP.

Goals describe what a child will be able to do at a future date, such as "Shawna will learn to dress herself." This statement tells all the IEP team members what your child is trying to learn to do. All goals may not be completed in a year. Some goals will be carried over to the next IEP.

Goals should be positive. For example, "Juan will ask for help when he needs it", not "Juan will stop crying when he is frustrated."

The IEP should tell **how** you will **know** if your child has reached the goals that have been written.

Objectives are short-term steps made to reach a goal.

Objectives can be things your child needs to know, or skills they need in order to reach a goal. For example, “Shawna will button her blouse”, is a step toward helping Shawna learn to dress herself.

Progress toward the goals and objectives should be reported to you **at least as often** as all of the children in the school district receive report cards.

4. **A statement of services**, when will the services begin, how often will your child receive the service, for how much time and where will the service be provided for your child. The services your child might receive are:
 - a. Special education services;
 - b. Related Services;
 1. transportation
 2. speech-language pathology,
 3. audiology services,
 4. psychological services,
 5. physical & occupational therapy,
 6. recreation, including therapeutic recreation,
 7. early identification and disability assessment,
 8. counseling services, including rehabilitation counseling,
 9. medical services for diagnostic or evaluation purposes,
 10. school health services, social work services in schools, parent counseling and training, and orientation and mobility services.
 - c. Supplementary aids and services;
 - d. Program Modifications;
 - e. Supports for the teachers and others at schools.
 - f. Positive Behavior Intervention plan if necessary.
5. If your child is not participating in a regular classroom, is not being included in the general curriculum, or is not a part of the other school activities, **there must be a written explanation agreed upon by the IEP team**. This statement would include information as to how much time your student is spending with non-disabled students and if not, an explanation as to why your child is not being included with the other students in the school.

6. **Your child will be tested when all of the other students in the district are tested.** The IEP team will decide whether or not your child will be tested the same as the other students in the school, with modifications, or will be given a different test that will best measure your child's knowledge and progress. The different test is an **alternate assessment**. Why the team reached the decision it did as to who your child is tested, **must be written** in the IEP.
7. If your child is 14 **there must be a statement of transition service needs**, (moving from school to adult living). This statement can be developed at an age younger than 14. The statement will be a part of the IEP. It will talk about your child's abilities, needs and dreams as an adult.

At age 15 your child **must have a written statement of transition services needed**. The IEP will outline the school program that will prepare your child for meaningful and productive adulthood. The statement of transition services within the IEP will include:

- a. Instruction,
- b. Community Experiences outside of work,
- c. Work Experiences,
- d. Daily Living Skills, and a
- e. Vocational Assessment.

If your student is going to need services from agencies that service adults with disabilities, those agencies should be a part of the planning process.

The person who calls the team meetings should invite representatives from the agencies that might be providing services after graduation. **You can invite** someone who might be **helpful** or **is providing a service** for your son or daughter after high school

Depending on your student's needs and how old the student must be to be **eligible for adult services**, the IEP team should consider the appropriate age for graduation. Some special education students are ready for **work** or **higher education** at 18 or 19. Some will need to **stay in school** until they are 21.

12. What Should The IEP Tell You?

- A. **Who** will teach your child and what kind of teachers and therapists will be working with your child?
- B. **When** the school program will begin and how long it will last.
- C. **What** will be taught and what things your child will be working on during the year. These are the goals.

- D. **Why** these goals were chosen. Does the IEP have a section that explains what your child is doing now, (the present level of performance)? Was this information used to plan the goals?
- E. **How** your child will work toward the goals. What small steps your child will take to meet the goals. These are the objectives or may be called benchmarks.
- F. **Where** your child will be taught - in what school and in what kind of classroom.
- G. **How much time** your child is spending with children who do not have disabilities. If your child is not going to be in class with non disabled children, did the team agree and is there a written explanation telling you why your child is not being included with non disabled children?
- H. **How much** your child is being included in the general curriculum, what is being taught that other students are being taught, and what activities such as field trips, sports events, school assemblies, etc., are being provided.
- I. **How** your child is being tested in district or state assessments.
- J. The **suggestions** that were made by the team to help your child at school and at home.

All of this determines **placement**. Placement is a **decision** made by the **team**, based upon your child's **educational needs**. Placement may be decided at the **IEP meeting** or at **another meeting** of the **IEP team**. **Placement is the program and not a place.**

13. How To Judge The IEP.

- A. Is it written in clear, understandable words?
- B. Do you understand what your child will be working on during the school year?
- C. Do you understand the reasons why these things will be taught to your child?
- D. Do you understand how you will be able to tell if your child is doing better or reaching the goals?
- E. Is the IEP written especially for your child or does it look like everyone else's in your child's class?

A Parent's Guide to Nebraska's Rule 51
(Rule dated October 16, 2000)

* indicates information specific to Early Development Network, ages 0-3

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Ten Ways to Take Charge of Your Child's IEP Meeting or Family Support Plan

By Janet Holmes

(Reprinted by permission from Family News Digest)

Excerpt from Learning Disabilities 101

* **Be first** . . . make sure you talk first. Don't be afraid to lead the IEP meeting. Bring notes, take notes and make all introductions yourself. It's your school, your teachers, your child. Put your priorities on the table for discussion first.

* **Build a Strong Base of Information.** You know your child. Get to know his school behavior, attend his class for a substantial amount of time. Be sure to use the appropriate visiting procedures but don't be afraid to make a surprise visit. During the IEP meeting ask questions if you do not understand. You are the expert for your child, but you are not expected to understand all school terminology.

* **Know Your Rights** . . . Public Law has given all parents rights and schools legal responsibilities. How can you advocate for important issues if you're not sure you are right? Local family and state organizations hold workshops for parents. Find them!

* **Bring Notes** . . . make your own goals for your child. Start with making long-term goals for your child and family. Take your own notes to the meeting and write long- and short-term objectives in your words. It is appropriate to include your suggestions, you should expect nothing less.

* **Know How to Say No** . . . be gracefully firm. Take a firm stand on important issues and only important ones. Be willing to compromise and don't expect to get it all. Choose your fight carefully, and then use the phrase "that is unacceptable." Have your argument ready, but always speak carefully. Get areas of disagreement written on the plan or, better yet, go home and write a letter to attach to the IEP. Don't be rushed into accepting anything; IEP's can be continued at a later date. The IEP will go forward without your signature, but you need to document your disagreement in case you wish to take the issue to due process.

* **Make Friends** . . . at school. Always support your school and teacher. Be the room mother, volunteer to help whenever you can. If you are respected as a supporter of the school, you are more likely to be respected at the IEP. Let people know you appreciate them, make positive comments. A few kind words can only open doors for you and your child.

* **Keep Your Cool** . . . angry parents are sometimes written off. Although anger is sometimes needed to get your point across, remember, parents who lose their temper are quickly labeled as uncooperative and unreasonable which can make it easier for personnel to gather others against your ideas and concerns.

* **Keep Records** . . . put it on paper. Maintain records for your child. Put all your correspondence in the file. Make every IEP request in writing and ask for a written response. Check every so often to see if your correspondences are included.

* **End Your IEP** . . . with a good check up. At the end of the IEP, make sure all of your points have been included. Check up on the promises, goals, and objectives that were agreed upon at the meeting. It is your job to monitor the IEP plan.

Learning Disabilities OnLine
www.ldonline.org/ld_indepth/iep/holmes_tenways.html

The IEP: What do we do if it isn't working?

STEP ONE:

Why isn't the IEP working? There are really only TWO reasons. One, the plan is no longer appropriate for your child. Or, two, the IEP is appropriate but isn't being implemented.

If you think the plan is no longer appropriate, write down a "strengths/needs" list and then prioritize a list of the goals you feel the child should accomplish. Look at the current IEP. Have the goals been accomplished? Are they too easy? Too hard? Do they offer "educational benefit"? Are they specifically designed for your child? Are social, communication, pre-vocational and behavior needs being positively addressed? Write down your questions, and the things you feel are important to include in a new plan. Then, go to step two.

If you think the IEP isn't being implemented, review it and write down specific information like the amount of time the child should be receiving special education and related services, the modifications that should be made in general education classes, and the goals to be accomplished. Then, list your questions. Ask who is working on these, how are the skills being developed and reinforced. Specifically what modifications are working or not working, etc. Go to step two.

STEP TWO:

Talk to the special education teacher(s). Call ahead. Be positive. Schedule enough time for a comfortable discussion. If you're concerned about implementation, talk about what is being done at the school level to implement the various components of the IEP. Ask what still needs to be done. When will the changes be implemented and by whom? Take notes, and when you get home, follow up with a brief letter thanking the teacher for the meeting and summarizing what he/she said. Put a copy into your file.

STEP THREE:

If the teacher can't or won't help you find out what you need to know, talk to the principal or the next person in line administratively. Send a copy of the prior correspondence. In your letter, outline your concerns, review the answer provided by the school staff, and ask for a written response within an acceptable time frame. (If you were pleased with the response, thank the staff for their corporation.)

STEP FOUR:

Review and change the IEP as often as needed. It must be done at least once a year, but additional meetings can be held if you or your child's teacher feel that the IEP is no longer appropriate. The IEP can be amended or rewritten by the IEP team (of which you are a part) at any time.

STEP FIVE:

Make sure you understand and use the appeal process and use it to work your way “up the chain of command” for your particular district. After working with the teacher(s) and the principal to try to resolve your concerns, and after carefully creating a “paper trail” of documentation, if your concerns are not resolved, appeal the issues to the next level. Many schools have a district special education administrator, a district assistant superintendent or a district superintendent. It is often effective to appeal to these “higher-ups” after documenting all your efforts with others. At each step, if you feel your issues are still unresolved, write a letter summarizing what’s occurred so far, with whom you have already worked, and the reasons for your on-going concerns. Keep going “up” until you feel your concerns have been addressed. Technically up to this point, what you have been doing is called “informal dispute resolution”.

STEP SIX: Formal Resolution

Formal dispute resolution should be reserved for a “last resort”. In fact, to effectively claim some legal rights under IDEA, 504 and IDEA (such as those associated with attorney fees), you will want to have documentation that you have effectively “exhausted your administrative remedies” prior to pursuing formal resolution. In Nebraska, there are three main rights you have when it comes to formal resolution:

MEDIATION: Special Education Mediation is 1) voluntary, 2) confidential, 3) has no cost to either party and 4) can be a quick method to reach resolution of the dispute.

COMPLAINT PROCESS: This process is used when there is a suspected violation of special education law and/or regulations.

DUE PROCESS HEARING: The appeal or hearing process is necessary when there is a disagreement about the IEP that is not a violation of law.

Additional information on these processes is available from the Nebraska Parents Center. Call and ask for that information if the first five steps do not solve your situation.

To try and change things, you’ll need to go up the “chain of command”. And, you’ll want to document, in writing, what you’ve done to informally resolve the situation. It pays to be assertive but positive, keeping your rights and your child in mind while remaining collaborative. The “informal” dispute resolution will take time, but it is frequently an investment of time that “pays off” for your child.

(This information was adapted for Nebraska, from the Wisconsin Collaborator a publication of the Parent Education Project of Wisconsin.) July, 1999 - MDC

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CHAPTER 7

MEDICAID/ SSI / RESPITE

Resources:

Information contained in this chapter can be found at the Nebraska Health and Human Services website: <http://www.hhs.state.ne.us/>

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

Supplemental Security Income

Supplemental Security Income (SSI) is a federal cash benefit program designed to guarantee a minimum monthly income to persons who are either 65 or older, blind, or disabled and who have limited incomes.

Operated by the Social Security Administration, SSI benefits are based on need rather than the amount paid into the program or the number of quarters worked. SSI benefits are paid to eligible people only, not to family members or survivors.

To qualify, a person must be a U.S. citizen, living in the U.S., and over 65, blind, or disabled. In addition, income and resources tests must be passed. All of your income and that of your spouse is considered. You will also need to show that your resources or assets are limited.

Resources include possessions such as real estate, personal belongings, household goods, money, and stocks and bonds. However, not all resources are counted. For example, the house you live in and the land it sits on are exempt.

Papers needed when applying for benefits include: Social Security card; proof of birthdate; real estate tax notices; bank books; insurance policies and other papers which list resources; pay stubs; and medical records relating to disability.

Persons who know they will be eligible within 30 days (those age 64 and 11 months, for example) should apply immediately.

For more information contact your local Social Security Administration office, or call 1-800-772-1213 between 7 a.m. and 7 p.m.

Aged & Disabled Medicaid

Aged & Disabled Medicaid is a program financed by the state of Nebraska and the federal government to provide payment for some health care costs for people with limited incomes and resources. Medicaid generally pays the Medicare co-payments and deductible Medicaid. It also covers the costs of nursing facilities, prescription drugs, inpatient/outpatient hospital services, rural health clinic services, laboratory and X-ray services, and physicians' assistants. Nebraska rules relating to Medicaid eligibility vary depending upon several factors.

Generally, a single person is allowed to retain up to \$4,000 in resources and still be eligible for Medicaid. Certain resources are not taken into consideration.

- As long as the person remains in his or her home, the home is exempt. If the single person, however, later moves into a nursing home, he or she would need to sell the home and spend the proceeds on his or her care.
- Up to \$1,500 face value in life insurance policies is considered exempt. If the face value of the policies exceed \$1,500, the amount for which the policies could be cashed would be considered a resource.

- One car is exempt regardless of its value.
- You're also allowed to have up to \$3,000 in an irrevocable burial trust or in an irrevocable burial insurance plan. In addition, you're allowed to purchase a casket, vault, headstone, and burial space and you can prepay for the opening and closing of the grave.

The rules relating to a single person's income vary depending upon whether the person will be remaining in his or her home or going to a nursing home.

If the person will be remaining in his or her home and has less than \$687 in monthly income, his or her medical expenses will be paid by Medicaid without any cost to him or her.

The rules relating to a couple's resources also vary greatly depending upon their situation. Different rules are in effect depending upon whether one or both members of the couple will remain in their home.

As with a single person, certain resources are never considered in making a Medicaid determination.

- As long as one member of the couple remains in the home, the home is exempt.
- The couple is entitled to keep one car regardless of value.
- Each member of the couple is entitled to have an irrevocable burial trust with a value of up to \$3,000. Each can also pre-purchase his or her casket, vault, headstone, and lot and prepay for the opening and closing of his or her grave.
- Finally, each member of the couple can have a \$1,500 face value life insurance policy.
- In addition to the exempt resources, the couple can keep \$6,000.

If the couple is remaining in their home and their combined monthly income is less than \$922, their medical expenses will be paid by Medicaid without having to contribute anything.

If one member of the couple goes into a nursing home, the rules are different. The exempt resources remain the same as those described above. However, the spouses can divide in half up to \$168,240 in resources. The spouse remaining in the home can keep his or her half. The spouse in the nursing home must spend down his or her share of the resources to under \$4,000. Once those resources are spent down, the spouse in the nursing home is eligible for Medicaid. The spouse remaining at home gets to keep all of his or her income.

If his or her income, however, is less than \$1,383 per month, he or she will get to keep enough from the nursing home spouse's monthly income to bring him or her up to \$1,383. All of the nursing home spouse's remaining income must be spent on his or her care.

These amounts are current for 2000. Most of the income guidelines and some of the resource guidelines for Medicaid are adjusted every year. As a result, you should check with your local or the Health & Human Services System to find out the current income and resource guidelines.

To apply, an application must be completed and given to the Nebraska Department of Health & Human Services. For more information, contact your nearest Health & Human Services Office or go to <http://www.hhs.state.ne.us/fia/ssi.htm>.

What is Kids Connection?

Kids Connection is health care coverage for qualified children developed by the State of Nebraska. It includes both the Children's Health Insurance Program (CHIP) and the Nebraska Medical Assistance Program (also known as Medicaid).

What does Kids Connection cover?

Kids Connection provides well care for your child in helping to prevent diseases, finding and treating problems early, and maintaining good health and development.

Regular check-ups include:

baby checkups and immunizations
immunizations for school-age children
yearly checkups for school-age children, including school and sports physicals
dental check-ups and dental sealants
vision and hearing testing

Kids Connection also provides medical care for injuries and illnesses as early as possible. This is essential in treating or correcting health problems.

Treatment includes:

doctor's visits	medications
hospital care	lab tests/x-rays
dental treatment	eyeglasses
counseling	and more...

Specialty services for children with disabilities or chronic health conditions
mental health and substance abuse assessment and treatment services
counseling

How can Kids Connection be my child's health coverage?

Your child's eligibility to have health coverage through Kids connection is based primarily on your family's income.

Children may be eligible:

- * if they are under age 19
- * if they live in Nebraska
- * even if both parent live at home
- * even if one or both parents work full-time
- * even if their family already has some type of health insurance*

*When you apply for Kids Connection, your children will be evaluated for enrollment based on your income. Some programs under Kids Connection are not available to children who have health insurance.

Do your children qualify for Kids Connection?

First, take your gross income (before deductions are taken out), subtract \$100 per month for each employed adult and then subtract actual day care costs. Add in your unearned income such as child support, alimony, unemployment compensation, Workers' compensation, Social Security benefits, etc. Then, compare this number, along with your family size, with the adjusted income figures in this chart. If your adjusted income falls at or below the appropriate amount on this chart, your children may be eligible. If your adjusted income falls at or below the appropriate amount on the chart, your children may be eligible for Kids Connection.

Please note: these numbers are approximates. If your family income is slightly more than the amounts shown on the chart, your children may still qualify. The best way to find out if your children are eligible for Kids Connection is to apply in person. If you have questions, call toll-free at 1-877-NEB-KIDS (1-877-632-5437).

Go to <http://www.hhs.state.ne.us/med/kidsconxapp.htm> for further information on financial qualifications.

Disabled Children's Program (DCP)

The Disabled Children's Program (DCP) provides funding to help families care for their children with disabilities at home. A family focused assessment process determines the need for services.

Some of the funded services include:

- Respite care,
- Mileage, meals and lodging for long-distance medical trips,
- Special equipment, and
- Home modifications,
- Care of siblings while care is received by the child with a disability.

The Disabled Children's Program (DCP) was designed to serve children who:

- Have disabilities,
- Receive monthly Supplemental Service Income (SSI) checks,
- Are 15 years of age or younger, and
- Live at home with their families.

For more information, contact the Health and Human Services office nearest you or e-mail roger.hillman@hss.state.ne.us

Disabled Persons and Family Support (DPFS) Program

The Disabled Persons and Family Support (DPFS) Program coordinates and purchases services and items to assist employed adults with disabilities to maintain their independence. The Program also helps families keep family members with disabilities in their homes.

Services that may be provided by the Disabled Persons and Family Support (DPFS) Program are as follows:

- Home modifications,
- Attendant care,
- Home health care,
- Housekeeping,
- Payment for prescriptions/medical supplies,
- Respite care,
- Transportation services, and
- Mobility equipment.

For more information contact:

Phone: (402) 471-9310, 1-800-358-8802

E-mail: Rollie Snuttjer rollie.snuttjer@hhss.state.ne.us or Roger Hillman roger.hillman@hhss.state.ne.us

Early Intervention Medicaid Home and Community-Based Waiver

The Nebraska Medical Assistance Program (NMAP/Medicaid) offers -- under a waiver of statutory requirements -- home and community-based services to infants and toddlers who have care needs which meet a care level typically provided in a nursing facility. Waiver services are limited to infants and toddlers who are currently receiving services as defined under Nebraska's Early Intervention Act. Services coordination/case management is provided by the Early Intervention Services Coordinator.

Medically Handicapped Children's Program (MHCP)

Services for Families with Children with Disabilities or Chronic Health Care Needs
The Medically Handicapped Children's Program (MHCP) provides family-focused services coordination/case management, specialty medical team evaluations for children in local areas, access to specialty physicians, and payment of treatment services.

Program Benefits

A services coordinator/social services worker is assigned to help families access services to fit their needs and those of the child with a disability or chronic health care need. Help is provided to identify services that may be needed, referral and access to these services, and assistance in locating payment sources. The worker is also the family's link into the medical team evaluation and treatment planning process through specialty clinics for children and youth.

The Program provides access to specialty evaluations that provide a diagnosis and medical treatment plan prior to the family making a financial application. The evaluations may be provided with select specialty providers and/or one of the specialty clinics for children and youth.

Specialty clinics for children and youth are teams which consist of specialty physicians, nutritionists, nurses, occupational therapists, physical therapists, psychologist, dentists, speech and hearing pathologists, and the family. The teams meet all at one time and in one place. Team membership depends upon the particular medical conditions being reviewed. The most important member of the teams is the family. Teams provide diagnosis of the medical concerns and problems, a written plan of treatment, and access to all the team members at one time and place.

The family is able to carry a list of written recommendations home from the team clinic. Copies of the complete report and plan are provided to service providers and school systems as authorized.

Medical Teams

Medical teams review diagnosis and provide a treatment plan for the following conditions:

Craniofacial conditions including cleft lip/palate and other defects. These teams provide examinations to review progress, effectiveness of treatment and planning for future care and surgery.

Cystic Fibrosis. This team reviews children and adults with this condition.

Diabetes/Juvenile Diabetes. This team includes a specialist in childhood diabetes and personnel to provide education on how to minimize the effects of the condition through proper care and diet.

Heart conditions, which are severe and/or congenital. The joint children's heart team from the Nebraska Medical Center, Children's Hospital, and Creighton University travels to several sites in Western Nebraska.

Midline neurological defects including spina bifida and hydrocephalus. These teams provide examinations to review current medical condition and to provide a coordinated care plan.

Neuromuscular conditions including cerebral palsy and other conditions which may exhibit similar symptoms. These teams include members of the local community and are supplemented by specialists not usually available the community. This team is also referred to as the specialty clinic for children and youth team. All teams provide a written plan for care which is shared with treatment providers including the family's local school district as authorized.

Eligibility

This information can be found at the MHCP Program regulation site.

There are no financial eligibility requirements to have the Program provide a diagnosis and treatment plan.

Families are eligible for the Program if a child has a medical disability or special health care need that is congenital or chronic. A listing of some of these conditions are listed under the heading of Medical Conditions.

A financial application is not required until a diagnosis and treatment plan has been determined. The cost of care is factored into the financial application formula and a family may be eligible with the Program and the family sharing the cost. The Program can also assume medical insurance co-pays and deductibles.

Families with children eligible for Medicaid and/or Kids Connection are automatically eligible for attendance at the specialty clinics for children and youth, for services coordination, and for support services through the Supplemental Security Income-Disabled Children's Program.

Other Medical Conditions

In addition to the medical conditions listed under the medical teams heading, the Program can provide services for the following and other congenital and severe conditions:

The Program's medical director reviews the medical information and makes the eligibility decision.

- Asthma -- severe and persistent.

- Orthopedic conditions -- including scoliosis, rheumatoid arthritis, club foot, bow legs, leg length discrepancy and fractures that have not healed properly and have become chronic conditions.

- Eye conditions -- which may be corrected through surgery.

- Hearing loss which is severe.

- Hemophilia

- Major medical -- A 'catch all' term which includes many congenital and chronic conditions including: acute severe burns, neurological conditions, ill premature births, urology, Addison's disease, Turner's syndrome, sickle cell disease, hypothyroidism, esophageal strictures, imperforate anus, Hirschsprungs, disease growth hormone deficiency, and other conditions.

- Neoplasm -- cancers, tumors, lymphoma and leukemia.

- Other conditions which may be severe and chronic and/or congenital.

Services for Adults

Staff of the MHCP Program also administer the Genetically Handicapped Persons Program for adults. This program is a medical treatment payment program for adults with the medical diagnosis of hemophilia, cystic fibrosis, and sickle cell disease. The purpose of the Program is to provide a source of payment for medical care and services for persons with these conditions who are not disabled and/or could be working if they had a source of payment for the costs of care.

Please use these Lincoln telephone numbers for requesting information about this Program: (402)471-9327 or 1-800-358-8802.

Local Service Contacts

Broken Bow: (308) 872-6700

Grand Island: 1-800-892-7922, Local: (308) 385-6123
Gering: 1-800-477-6393, Local (308) 632-0380
Lincoln: 1-877-213-4754, Local (402) 471-5308 or 5379
Norfolk: 1-800-782-8844, Local (402) 370-3166 or 3131
North Platte: 1-800-782-8844, Local (308) 535-8238
Omaha: (402) 595-2120
Crete: 1-800-557-8511, Local (402) 826-2196
For more information, contact:
The Health and Human Services office nearest you
E-mail: Roger Hillman roger.hillman@hhss.state.ne.us
Phone: (402) 471-9283 in Lincoln, or 1-800-358-8802 in Nebraska.

Transportation for Children with Disabilities

Where can I find transportation for my child?

The programs listed under each setting can help arrange and finance the services described.

Medical appointments

Transporting an individual to and from health and other community services in non-emergency situations.

- * Social Services Block Grant (SSBG)
- * Aged and Disabled Medicaid Waiver
- * Disabled Children's Program (DCP)
- * Disabled Persons and Family Support (DPFS) Program

Therapies

Transporting an individual to and from community resources so that he/she can receive therapy. Examples of community resources include physical therapy, occupational therapy, speech therapy, and mental health therapy.

- * Social Services Block Grant (SSBG)
- * Aged and Disabled Medicaid Waiver
- * Disabled Children's Program (DCP)
- * Disabled Persons and Family Support (DPFS) Program

Visiting your hospitalized child

Transporting a parent to and from the hospital in order to visit his/her hospitalized child.

- * Social Services Block Grant (SSBG)
- * Disabled Children's Program (DCP)
- * Disabled Persons and Family Support (DPFS) Program

Assistance in obtaining mobility equipment

To assist an individual with a disability or his/her family in the purchase of equipment to further his/her independence. Equipment such as van lifts, wheel chair carriers, hand controls, motorized carts, and wheel chairs may be purchased.

- * Assistive Technology Project
- * Disabled Children's Program (DCP)
- * Disabled Persons and Family Support (DPFS) Program
- * Aid to the Aged, Blind and Disabled (AABD)
- * Medicaid
- * Vocational Rehabilitation

Support groups

Transporting an individual to and from community groups such as those for families and people with brain injuries, diabetes, and disabilities.

- * Social Services Block Grant (SSBG)
- * Aged and Disabled Medicaid Waiver

Accompanying individuals to appointments

Accompanying an individual who is unable to travel or wait alone for medical appointments, or to receive services from community programs.

- * Social Services Block Grant (SSBG)
- * Aged and Disabled Medicaid Waiver
- * Disabled Persons and Family Support (DPFS) Program

Pharmacy/drug store

Transporting an individual to and from a pharmacy/drug store in order to purchase and pick up prescriptions and medical supplies.

- * Social Services Block Grant (SSBG)
- * Aged and Disabled Medicaid Waiver
- * Medicaid

Seek reimbursement for travel costs during treatment

Daily living expenses incurred by families of dependent persons while away from the family's home/community when that individual is receiving medical care/treatment. Includes such things as food, lodging, and travel expenses.

- * Disabled Children's Program (DCP)
- * Disabled Persons and Family Support (DPFS) Program
- * Medicaid

For further information on the community services, go to <http://www.hhs.state.ne.us/chd/transchi.htm>

Nebraska Respite Network

The Nebraska Respite Network was created in 1999 with the passage of legislation and is currently being implemented by Nebraska Health & Human Services System (HHSS). The purpose of the Nebraska Respite Network is to establish a statewide system for the coordination of respite resources that serve the lifespan. Contracts are in place between HHS and six local entities (one in each Service Area) who are responsible for Information and Referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public's awareness of respite, coordinating training opportunities for providers and consumers, and quality assurance and program evaluation.

The following is a list of the respite coordinators in each area: CALL 1-866-RESPITE

<u>Service Area</u>	<u>Coordinator</u>
CENTRAL Loup City	Cheryl Albright Phone: (308) 745-0780 Ext. 146 or (800) 736-7491 FAX: (308) 745-0824 E-mail: calbright@cennecs.org
EASTERN Omaha	Chris Stewart Phone: (402) 996-8443 FAX: (402) 996-8445 E-mail: respitecenter@yahoo.com
NORTHERN O'Neill	Bev Nelson Phone: (402)336-4298 or (800) 279-3503 FAX: (402) 336-3420 E-mail: bnelson@cennecs.org
SOUTHEAST Lincoln	Danielle Schwab Phone: (402) 729-2278 Ext. 125 (866) 280-9712
SOUTHWEST McCook	Mary Bargaen Phone: (308) 345-2609 or (888) 576-6777 FAX: (308) 345-2107 E-mail: mbargaen@mccooknet.com
WESTERN Chadron	Sherri Blome Phone: (308) 432-8190 or (877) 932-8190 FAX: (308) 432-5092 E-mail: respitewest@bbc.net

For more information, contact:

Becky Veak

Health and Human Services System

P.O. Box 95044

Lincoln, NE 68509-5044

E-mail: becky.veak@hhss.state.ne.us

Phone: (402) 471-7780 in Lincoln, or 1-800-358-8802 in Nebraska.

Respite Subsidy Program Across the Lifespan
Nebraska Department of Health and Human Services
February 10, 2003

Respite Services provide short-term relief to primary caregivers from the demands of ongoing care for an individual with special needs.

The Lifespan Respite Subsidy Program offers money to help families with loved ones who have special needs (from birth through death) to pay for respite care. Families choose their own providers, decide how much to pay per hour or per day, and set their own schedules. This program can help only those families who do not receive services from any other governmental program.

Up to \$125 per month is allowed based on monthly adjusted family income*.

For a family of 1	\$2, 335	For a family of 5	\$5, 601
For a family of 2	\$3, 152	For a family of 6	\$6, 417
For a family of 3	\$3, 968	For a family of 7	\$7, 234
For a family of 4	\$4, 784	For a family of 8	\$8, 050

*Family income includes all money the family receives from any source. This includes gross (before tax) earnings. Disability-related expenses can be subtracted from this total. These expenses include, but are not limited to, payments on a past hospitalization; payments for home modifications like ramp building; purchase of adaptive equipment not covered by insurance; disability related medications.

Applications are mailed to and reviewed at the Aging and Disability Services Unit, Central Office in Lincoln. Each family who applies will receive a notice by mail when a decision has been made. For eligible families, the notice will include instructions for billing; payments will be made after care is provided.

Questions? Need an application?
Call 1-800-358-8802 or In Lincoln, call 471-9310.

Nebraska Respite Network
PO Box 509
Loup City, NE 68853
1-866-RESPITE (toll free)

Respite

Respite provides families who have a child who is dependent upon them for their basic needs with time away. Under this waiver service, a maximum of \$100 per month can be authorized for an eligible client's family.

For additional information, contact your local Early Development Network Services Coordination agency, or call (800) 358-8802.

RESPITE SUBSIDY

If you are the parent of a child from birth to age 18 with a mental health disorder, you may apply for grant respite subsidy money through Parent Assistance Network (support for families with a person with a disability through a grant from the Good Samaritan Hospital foundation- P.O. Box 1810, Kearney, NE 68848, (308) 865-2009).

Fifty dollars is the maximum monthly amount families can receive to pay respite providers. Respite care allows parents or caregivers of children with special needs a break. This grant funding is provided to PAN by Region III Behavioral Health Services and only covers the 19? counties in that region. Notify PAN if you are interested at (308)237-6025

CHAPTER 8

NEBRASKA STATE RESOURCES

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

Nebraska State Resources

Please note, many organizations and agencies have multiple offices throughout the state. Please call or visit the website to find a location closest to you.

State Agencies and Organizations

Age of Eligibility

Each state sets eligibility ages for services to children and youth with disabilities. For current information concerning this state, please contact the office listed under Department of Education: Special Education.

United States Senators

Honorable Chuck Hagel (R)
248 Russell Senate Office Building
Washington, DC 20510
(202) 224-4224
(202) 224-5213 (Fax)
E-mail: chuck_hagel@hagel.senate.gov
Web: <http://hagel.senate.gov>

Honorable Ben Nelson (D)
720 Hart Senate Office Building
Washington, DC 20510
(202) 224-6551
(202) 228-0012 (Fax)
E-mail Web Form: <http://bennelson.senate.gov/email.html>
Web: <http://bennelson.senate.gov/>

United States Representatives

To find the contact information for your representative in the House of the U.S. Congress, visit the House's Web site at: www.house.gov, or call: (202) 224-3121; (202) 225-1904 (TTY).

Honorable Mike Johanns
Office of the Governor
P.O. Box 94848
Lincoln, NE 68509-4848
(402) 471-2244
(402) 471-6031 (Fax)
E-mail Web Form: <http://gov.nol.org/Johanns/mail/govmail.htm>
Web: <http://gov.nol.org>

State Department of Education: Special Education

Administrator
Special Populations Office
Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-2471 (V/TTY);
Web: www.nde.state.ne.us/SPED/sped.html

Programs for Infants and Toddlers with Disabilities: Ages Birth through 2

Consultant
Special Populations Office
Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509
(402) 471-2463
Web: www.nde.state.ne.us

Department of Health and Human Services

Part C Co-Coordinator
P.O. Box 95044
Lincoln, NE 68509-5044
(402) 471-9329
Web: www.hhs.state.ne.us

Early Childhood Training Center

Director
6949 S. 110th Street
Omaha, NE 68128-5722
(402) 597-4820; (800) 892-4453
Web: www.esu3.org/ectc/ectchomepage.html

Programs for Children with Disabilities: Ages 3 through 5

Coordinator
Special Populations Office
Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-4319
Web: www.nde.state.ne.us

**Nebraska ChildFind, Rights, Resources, & Referrals for Children with Disabilities:
Birth through 21**

Statewide Coordinator
Nebraska ChildFind
5143 S. 48th Street, Suite C
Lincoln, NE 68516-2204
(402) 471-0734; (888) 806-6287 (in NE)
Web: www.nde.state.ne.us/ATP/childfind.asp

State Vocational Rehabilitation Agency

Director
Vocational Rehabilitation
Department of Education
301 Centennial Mall South, 6th Floor
P. O. Box 94987
Lincoln, NE 68509-4987
(402) 471-3649
Web: www.vocrehab.state.ne.us

Office of State Coordinator of Vocational Education for Students with Disabilities

Director
Career Guidance and Counseling
Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-4811
Web: www.nde.state.ne.us/CARED/career.html

State Mental Health Agency

Deputy Director
Department of Health and Human Services
P.O. Box 98925
Lincoln, NE 68509-8925
(402) 479-5117
Web: www.hhs.state.ne.us

State Mental Health Representative for Children and Youth

Program Administrator
Child and Adolescent Mental Health Program
Department of Health and Human Services
P.O. Box 98925
Lincoln, NE 68509-8925
(402) 479-5512
Web: www.hhs.state.ne.us

State Developmental Disabilities Programs

Administrator
Developmental Disabilities System
Office of Aging and Disability Services
Department of Health and Human Services
P.O. Box 98925
Lincoln, NE 68509-8925
(402) 479-5110
Web: www.hhs.state.ne.us/

State Developmental Disabilities Planning Council

Program Administrator
Developmental Disabilities Planning Council
Department of Health and Human Services
301 Centennial Mall South
P.O. Box 95044
Lincoln, NE 68509-5044
(402) 471-2330
Web: www.hhs.state.ne.us/dip/gpcdd.htm

Protection and Advocacy Agency

Executive Director
Nebraska Advocacy Services, Inc.
522 Lincoln Center Building
215 Centennial Mall South
Lincoln, NE 68508
(402) 474-3183; (800) 422-6691

Client Assistance Program

CAP Director
Division of Vocational Rehabilitation Services
Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-3656; (800) 742-7594 (In NE)
Web: www.cap.state.ne.us

The Nebraska Client Assistance Program (CAP) is a free service to help you find solutions if you are having problems with any of the following programs: Vocational Rehabilitation, Nebraska Commission for the Blind and Visually Impaired, Centers for Independent Living, or Worknet.

Programs for Children with Special Health Care Needs

Deputy Administrator
Office of Aging and Disability Services
Special Services for Children and Adults
Department of Health and Human Services
P.O. Box 95044
Lincoln, NE 68509-5044
(402) 471-9345
Web: www.hhs.state.ne.us

State Education Agency Rural Representative

Commissioner
Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-5025
Web: www.nde.state.ne.us

Regional ADA Technical Assistance Agency

Director
ADA Project
Great Plains Disability and Business Technical Assistance Center
University of Missouri/Columbia
100 Corporate Lake Drive
Columbia, MO 65203
(573) 882-3600 (V/TTY); (800) 949-4232 (V/TTY)
E-mail: ada@missouri.edu
Web: www.adaproject.org

University Centers for Excellence in Developmental Disabilities

Director
Munroe-Meyer Institute - UCEDD
985450 Nebraska Medical Center
Omaha, NE 68198-5450
(402) 559-5702
Web: www.unmc.edu/mmi

Technology-Related Assistance

Director
Nebraska Assistive Technology Partnership
5143 S. 48th Street, Suite C
Lincoln, NE 68516-2204
(402) 471-0734 (V/TTY); (888) 806-6287 (V/TTY)
Email: atp@atp.state.ne.us
Web: www.nde.state.ne.us/ATP/

Nebraska Educational Assistive Technology (NEAT)

Coordinator

1910 Meridian Avenue

Cozad, NE 69130

(308) 784-4525; (800) 652-0033 (V/TTY)

E-mail: neatcenter@esu10.org

Web: www.neatinfo.net

TechConnectors

1910 Meridian

Cozad, NE 69130

Web: <http://techconnectors.net>

State Mediation System

Consultant

Special Populations Office

Department of Education

301 Centennial Mall South

P.O. Box 94987

Lincoln, NE 68509-4987

(402) 471-2471

Web: www.nde.state.ne.us/SPED/mediation/index.html

Educational Services Units

ESU #1 - 211 Tenth St, Wakefield, NE 68784 (402) 287-2061

ESU #2 - 2320 N. Colorado, Box 649, Fremont, NE 68026 (402) 721-7710

ESU #3 - 6949 So. 110th Street, Omaha, NE 68128 (402) 597-4800

ESU #4 - 919 16th St., PO Box 310, Auburn, NE 68305 (402) 274-4354

ESU #5 - 900 West Court, Beatrice, NE 68310 (402) 223-5277

ESU #6 - 210 5th Street, Box 748, Milford, NE 68405 (402) 761-3341

ESU #7 - 2657 44th Avenue, Columbus, NE 68601 (402) 564-5753

ESU #8 - 106 West 3rd, PO Box 89, Neligh, NE 68756 (402) 887-5041

ESU #9 - 1117 E. South St, Box 2047, Hastings, NE 68902 (402) 463-5611

ESU #10 - 76 Plaza Blvd, Box 850, Kearney, NE 68848 (308) 237-5927

ESU #11 - 412 West 14th Ave, Box 858, Holdrege, NE 68949 (308) 995-6585

ESU #13 - 4215 Avenue I, Scottsbluff, NE 68361 (308) 635-3696

ESU #14 - PO Box 77, Sidney, NE 69162 (308) 254-4677

ESU #15 - 344 Main St, PO Box 398, Trenton, NE 69044 (308) 334-5160

ESU #16 - 314 W. First St., Box 915, Ogallala, NE 69153 (308) 284-8481

ESU #17 - PO Box 227, Ainsworth, NE 69210 (402) 387-1420

ESU #18 - 5901 "O" Street, PO Box 82889, Lincoln, NE 68501 (402) 436-1610

ESU #19 - 3215 Cuming St, Omaha, NE 68131 (402) 557-2020

Autism Spectrum Disorders Network

The Autism Spectrum Disorders Network consists of five regional teams, each with a Director, a Coordinator, and a multi-disciplinary team of education professionals. The Regional Teams provide the following services to school districts within each region:

School-based training and consultation in the following areas:

- * Verification and assessment
- * IEP/EFSP development
- * Educational programming

Dissemination of Information and Resources

- * Regional Resource Libraries
- * Information and resources provided through trainings

Informational website - www.nde.state.ne.us/autism

Autism Spectrum Disorders (ASD) Regional & State Coordinators

Western Region	Cheryl Svoboda	(308) 635-3696
Central Region	Dawna Sigurdson	(308) 237-5927
Southeast Region	Annette Wragge	(402) 761-3341
	http://www.seautism.esu6.org/index.htm	
Northeast Region	Sonja Schutte	(402) 564-0815
	http://teachers.esu7.org/sschutte/	
Metro (Omaha) Region	Bridget Cannon-Hale	(402) 597-4957
NE State ASD Coordinator	Laura L. Maddox	(402) 450-6298
	http://www.nde.state.ne.us/autism/	

Disability-Specific Organizations

The Arc of Nebraska

Executive Director
1672 Van Dorn Street
Lincoln, NE 68502
(402) 475-4407
E-mail: arcneb@inetnebr.com
Web: www.arc-nebraska.org

Asperger's Association of NE

Carolyn May
3032 Laredo Drive
Lincoln, NE 68516
402-421-8994

Attention Deficit Disorder - see CHADD below:

Autism Society of Nebraska

Cynthia Archwamety, President
1407 East 33 Drive
Kearny, NE 68847
(308) 234-4466
Email: arcofbuffalocounty@frontiernet.net

ChAdd of NE, Omaha, NE, 402-734-0681, support@chaddne.org

LIFE of the Midwest (formerly FEAT of NE)

Dr. Andrew Lepinski, President
8101 "O" Street, Suite 300
Lincoln, NE 68510
(402) 486-8228
Web: <http://www.lovaas.com/>

Learning Disabilities Association of Nebraska

President
P.O. Box 6464
Omaha, NE 68106-6464
(402) 348-1567
E-mail: ldaofneb@yahoo.com

Metro Omaha Autism Support Group

The Omaha Chapter of the Autism Society of Nebraska
<http://hometown.aol.com/mommys shock/Metro.html>

NAMI-Nebraska

Executive Director
1941 S. 42nd Street, Suite 517
Omaha, NE 68105
(402) 345-8101; (877) 463-6264
Web: <http://ne.nami.org/>

Nebraska Family Support Network

Executive Director,
215 Centennial Mall South, Suite 220
Lincoln, NE 68508-1895
(402) 477-2992; (800) 245-6081

Nebraska Speech-Language-Hearing Association

Angie Carman, Executive Assistant
455 S. 11th Street, Suite A
Lincoln, NE 68508-2105
(402) 476-9573
E-mail: angie@nlsa.org
Web: www.nslha.org

Unlocking Autism of Nebraska

Connie Shockley
mommyshock@aol.com

Organizations Especially for Parents

Family Partner

Nina Baker
PTI Nebraska
3135 North 93rd Street
Omaha, NE 68134
402-346-0525
nbaker@novia.ne

Family Voices

Anne Lauritzen
643 Eastridge Drive
Lincoln, NE 68510

FRCCN - Family Resource Center Coalition of Nebraska Inc.

5109 W. Scott Road, Suite 410
Beatrice NE 68310
402-223-6040
<http://www.frccn.org/>

Nebraska Childfind Program

1-888-806-6287

The Childfind hotline is a free service that offers help with answering questions about education related issues regarding children with special education needs between birth, or date of diagnosis, and 21 years of age.

The Ollie Webb Center

1941 South 42nd Street, Suite 122
Omaha, NE 68105-2942
Phone: (402) 346-5220
Fax: (402) 346-5253
www.olliewebb.org

The mission of the Ollie Webb Center is to improve the lives of people with mental retardation and other developmental disabilities and to provide information, education, and support to their families.

Parent-To-Parent

Sheila Waldron, Coordinator
Pilot Parents
1941 S. 42nd Street, Suite 122
Omaha, NE 68105
(402) 346-5220
E-mail: sheila6793@hotmail.com
Web: www.olliewebb.org

Parent Teacher Association (PTA)

President
Nebraska Congress of Parents and Teachers
3534 S. 108th Street
Omaha, NE 68144
(402) 390-3339; (800) 714-3374 (in NE)
E-mail: ne_office@pta.org
Web: www.nebraskapta.org

Parent Training and Information Center (PTI)

Executive Director
PTI Nebraska
3135 N. 93rd Street
Omaha, NE 68134
(402) 346-0525 (V/TTY); (800) 284-8520 (V/TTY in NE only)
E-mail: info@pti-nebraska.org
Web: www.pti-nebraska.org

Other Disability Organizations**AAMR - American Association on Mental Retardation**

Mary McAlpine
NE Chapter of AAMR
9927 Broadmoor Road
Omaha, NE 68114

APSE - Association for Persons in Supported Employment

President
ServiceLinc
145 South 56th St, Ste B
Lincoln, NE 68510
402-483-2929
srvcinc@ix.net
<http://www.apse.org/>

The Association for Persons in Supported Employment is a membership organization formed in 1988 to improve and expand integrated employment opportunities, services, and outcomes for persons experiencing disabilities.

Answers 4 Families

Project Manager
121 S. 13th Street, Suite 302
Lincoln, NE 68588-0227
(402) 472-9827; (800) 746-8420
E-mail: librarian@answers4families.org
Web: www.answers4families.org

BSDC - Beatrice State Developmental Center

Vincente Benjamin, CEO
3000 East Lincoln Blvd
Beatrice, NE 68310
402-223-6600

Community Alliance

Mental Health Rehabilitation
Director

4001 Leavenworth
Omaha, NE 68105
(402) 341-5128

To integrate individuals with mental illnesses into the broader community through a progression of community based rehabilitation and support services.

Easter Seals Nebraska

President/CEO
7171 Mercy Road, Suite 102
Omaha, NE 68106-2609
(402) 345-2200; (800) 650-9880
Web: www.ne.easter-seals.org

Nebraska Easter Seals

(Social Security Administration | Benefits Planning organization for NE)
2727 West 2nd Street, Suite 471
Hastings, NE 68901-4608
Phone 800-471-6425 (Can assist people throughout the state with questions.)

Great Plains Chapter of Paralyzed Veterans

Education Center
7612 Maple Street
Omaha, NE 68134
Provides educational, vocational, social, and recreational activities for people with a disability.

Independent Living

To find out the contact information for the Statewide Independent Living Council (SILC) in your state, contact:
Independent Living Research Utilization Project
The Institute for Rehabilitation and Research
2323 South Sheppard, Suite 1000
Houston, TX 77019
(713) 520-0232 (V); (713) 520-5136 (TTY)
E-mail: ilru@ilru.org
Web: www.ilru.org

To find out the contact information for centers for independent living (CILs) in your state, contact:
National Council on Independent Living
1916 Wilson Boulevard, Suite 209
Arlington, VA 22201
(703) 525-3406; (703) 525-4153 (TTY)
E-mail: ncil@ncil.org
Web: www.ncil.org

League of Human Dignity

Mike Schafer
1701 P Street
Lincoln, NE 68508
(402) 441-7871
TTY: (402) 441-7871
FAX: (402) 441-7650
EMAIL: lhd.schafer@alltel.net
<http://www.ilru.org/Directory/nebraska.html>

Welcome to the League of Human Dignity homepage. The League of Human Dignity is a private, non-profit corporation established by people with disabilities. We operate Centers for Independent Living and other programs which provide services for people with disabilities to use in living full, independent lives.

Madonna Adult Day Services

Supervisor
5401 South Street, Lincoln, NE 68506
(402) 483-9508

MHA - Mental Health Association of Nebraska

P.O. Box 23001
Lincoln, NE 68542-3001
1-800-422-6691
<http://www.mha-ne.org/>

MRA - Mental Retardation Association of Nebraska

Patricia Crawford
6506 Teton Drive
Lincoln, NE 68510

Mosaic (formerly Martin Luther Homes & Bethphage)

4980 S. 118th St. Ste. A
Omaha, NE 68137.
877-3MOSAICE
david.frye@mosaicinfo.org
www.mosaicinfo.org/

In 2003, these organizations consolidated, forming Mosaic, to continue serving a common mission in the lives of people with disabilities across the United States and throughout the world. Mosaic provides supports and advocacy in partnership with people who have disabilities.

Nebraska Family Support Network

215 Centennial Mall South, Ste 220
Lincoln, NE 68508
(800) 245-6081 24-hour Toll Free Number

1. An advocacy organization for families of children, 0 - 21 years, with psychiatric and/or behavioral disorders 2. Information and referral for children with mental illness or severe behavioral problems 3. Toll free access line for parents and professionals 4. Referrals and linkages with support groups, service providers and other families 5. Advocacy, including bilingual volunteers to advocate for and give support to non-English speaking families 6. Newsletter and lending library 7. Speakers

North American Riding for the Handicapped Association (NARHA)

This is the premier site for information on equine-assisted activities. NARHA is a national non-profit organization that promotes the benefit of the horse for individuals with physical, emotional and learning disabilities.

<http://narha.org/>

Sunrise EquiTherapy, Inc.
2115 S 214th
Eagle, NE 68347
(402)781-2781
woodsunrise99@msn.com.

Heartland Equine Therapeutic Riding Academy
NARHA Premier Accredited Center
PO Box 260
Valley, NE 68064
(402) 359-2432
edye@hetra.org
www.HETRA.org

Awill Away Therapeutic Riding Center
520 E Suburban Rd
PO Box 577
North Platte, NE 69103
(308) 534-7579
lkjo@nque.com

Take Flight Farms, Inc.
1004 Farnam St. Ste. 400
Omaha, NE 68124
(402) 930-3041
sstratta@am1st.com

Dream Catcher Therapeutic Riding Program, Inc.
4833 S. 69th St
Lincoln, NE 68516-1558
(402) 488-3057
nk14329@alltel.net

People First of Nebraska

345 S. G Street
Broken Bow, NE 68822
(308) 872-6490
E-mail: peoplefirstne@bigred.net
People First of Nebraska is Nebraska's only state-wide, non-profit, self-advocacy organization for the people with developmental and physical disabilities.

Special Olympics Nebraska

8801 F Street
Omaha Nebraska 68127-1506
1-800-247-0105 or 402-331-5545
Fax: 402-331-5964
sonesn@aol.com
<http://www.sone.org/>

Supporting Parents

Supporting Parents Coord.
PTI Nebraska
3135 North 93rd Street
Omaha, NE 68134
402-346-0525
dpeters@pti-nebraska.org

United Way, 1st Call for Help

Director
1805 Harney St
Omaha, NE 68102
402-444-6666

Additional Nebraska Resources

Omaha Metro Region

Behave'N Day Center Inc
8922 Cuming Street
Omaha, NE 68114-2732
Phone: 402.926.4373
e-mail:janiep@behavenkids.com
<http://www.behavenkids.com/>

Behave 'n Day Center, Inc. is committed to providing early intervention services to children who have severe or chronic behaviors problems. The goal of the program is for children to be successful at home, school and in their community. Behave 'n Day Center, Inc. is dedicated to work together with each child's family and community to enhance the child's success.

THERA PLAYCE - Children's Development Center
Special Needs Daycare & OT/PT
4930 L STREET
Omaha, NE 68117-0000
(402) 731-8888

Children's Respite Care Center Inc
14245 Q Street, Omaha, NE (402) 895-4000
4979 S. 118 St, Omaha, NE (402) 861-9900
2815 N. 108 St, Omaha, NE (402) 496-1000
Provides day services to children who are medically fragile and developmentally delayed.

Munroe-Meyer Institute for Genetics and Rehabilitation
University of Nebraska Medical Center
985450 Nebraska Medical Center
Omaha, NE 68198-5450
Telephone: 402.559.6402
Toll free: 800.656.3937
FAX: 402.559.5737
<http://www.unmc.edu/mmi/Services/index.htm>

Offers evaluative and therapeutic services for the following:

ADHD Clinic, Augmentative and Alternative Communication, The Autism Program (Project BEST-CASE), Behavioral Health, Botox Clinic, Brace Place, Developmental Medicine Clinic, Developmental TIPS (Tracking Infants Progress Statewide), Diabetes and Endocrine Clinic, Fetal Alcohol Syndrome, Feeding and Swallowing Team, Genetics Clinic, Metabolic Management, MHCP-CP (Medically Handicapped Children's Program – Cerebral Palsy), Midline Neurologic Clinic, Motion Analysis Laboratory, Neurobehavioral Clinic, Occupational Therapy, Pediatric Neuromuscular Clinic, Physical Therapy Outpatient Services, Scottish Rite Masons' Clinic for Children with Language and Literacy Disorders (Rite Care), and Seating and Power Mobility Clinic

Project BEST-CASE
Program Director
Munroe-Meyer Institute
University of Nebraska Medical Center
444.S. 44th St.
Omaha, NE 68198
(402) 559-6408

Project BEST-CASE stands for “Building Empirically Supported Treatments - Communication, Adaptive/Academic and Social Skills Education.”
Project BEST-CASE is supported by the Hattie B. Munroe Foundation and serves preschool children (under the age of 8) identified with Autistic Spectrum Disorders (Autism, Asperger’s Disorder, or a Pervasive Developmental Disorder).

Scottish Rite Foundation of Omaha
Munroe-Meyer Institute
985450 Nebraska Medical Center
Omaha, NE 68198-5450
(402) 559-6402; 800-656-3937
<http://www.scottishriteomaha.org/scottish.htm>

A non-profit, tax-exempt corporation located at the Munroe-Meyers Rehabilitation Institute. Their goal is to help children with speech and language disorders, and to provide educational opportunities for our youth.

ProCare3
13336 Industrial Road, Suite 105
Omaha, NE 68137-1124
Tel: 402 330 7891; Fax: 402 330 0826
Toll Free: 1 866 PTOTSLP (1 866 786 8757)
Toll Free Fax: 1 866 477 6273
ProCare3 is a Medicare/Medicaid certified rehabilitation agency providing Physical, Occupational, and Speech-Language Therapy.

Lincoln Region

Handprints & Footsteps
(Private Clinic for OT, PT, SLP)
5930 Vandervoort Dr
Suite A
Lincoln, NE 68516
(402) 420-2099

Scottish Rite Masons Clinic for Children with Language Disorders
University of Nebraska
253 Barkley Memorial Center
Lincoln, NE 68583-0731
Telephone: (402) 472-2071

Norfolk/Columbus Region

Scottish Rite Masons Clinic for Children with Language Disorders
Masonic Temple
907 Norfolk Avenue
Norfolk, NE 68701
Telephone: (402) 421-1112

Grand Island Region

Grand Island Physical Therapy Children's Center
611 N. Diers Ave.
Grand Island, NE 68803
(308) 398-5170

Scottish Rite Masons Clinic for Children with Language Disorders
Masonic Temple
411 North Hastings Avenue
Hastings, NE 68901-5162
Telephone: (402) 463-1518

Western Nebraska Region

Scottish Rite Masons Clinic for Children with Language Disorders
Scottish Rite Temple
123 West Third Street
Alliance, NE 69301
Telephone: (308) 762-4703

ADD Parent Support Group
209 East 20th
Scottsbluff, NE 69361
(308) 635-3898
Nancy Campbell, President

Buckboard Therapeutic Riding Academy
270388 CR U, Gering, NE 69341
(308) 783-2319 or 641-3937
Kathleen Gerhard-Gatch, Owner

Panhandle Region Disabilities
Panhandle Region Disabilities Council
P.O. Box 1327
Scottsbluff, NE 69363-1327
(308) 635-3941
Evelyn Pinneker, Chairperson

Pilot Parents-Support Group
P.O. Box 1327
Scottsbluff, NE 69361
(308) 632-3736

Summer Program/Handicapped Children-Camp Scott
211 East 27th
Scottsbluff, NE 69361
(308) 632-2651
Marcia Uglow, President

CHAPTER 9

NATIONAL ORGANIZATIONS

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

Autism National Organization and Agencies

Federal or Federally Funded Agencies

Administration for Children and Families: Administration on Developmental Disabilities

Commissioner, U.S. Department of Health and Human Services

Commissioner, Administration on Developmental Disabilities

Administration for Children and Families

U.S. Department of Health and Human Services

Mail Stop: HHH 300-F

370 L'Enfant Promenade, S.W.

Washington, D.C. 20447

202-690-6590

www.acf.dhhs.gov/programs/add/

This administration provides information on programs, policies, and activities related to partnerships with state governments, local communities, and the private sector that are assigned to help assist people with developmental disabilities reach their maximum potential through increased independence, productivity, and community integration.

Americans with Disabilities Act

(ADA) Information Line

U.S. Department of Justice

950 Pennsylvania Avenue, NW

Civil Rights Division

Disability Rights Section - NYAV

Washington, D.C. 20530

Phone: 800-514-0301; Fax 202-307-1197

TTY: 800-514-0383

www.usdoj.gov/crt/ada

The ADA, which was signed into law on July 26, 1999, prohibits discrimination on the basis of disability in employment, programs, and services provided by state and local governments, goods and services provided by companies, and in commercial facilities.

Department of Education, U.S.

400 Maryland Ave., SW

Washington, DC 20202-0498

Phone: 202-401-2000, Phone 800-USA-LEARN, TTY: 202-401-1032

www.ed.gov

Various offices of interest to families of individuals with disabilities, such as the Office of Special Education Programs (see below) and the Office of Special Education and Rehabilitation Services (see below), fall under the auspices of the U.S. Department of Education.

ERIC Clearinghouse on Disabilities & Gifted Education

1110 N Glebe Rd.

Arlington, VA 22201-5704

T: (703) 264-9475, (800) 328-0272v/TTY, (703) 620-2525 fax, ericec@cec.sped.org,

Web site: www.ericcec.org

National Council on Disability

1331 F St. NW, Suite 850

Washington, DC 20004

T: (202) 272-2004, F: (202) 272-2022, TTY (202) 272-2074 TTY

sbrown@ncd.gov

Web site: www.ncd.gov

Office of Special Education and Rehabilitative Services (OSERS)

U.S. Department of Education

330 C St., S.W.

Washington, D.C. 20202

T: 202-205-5465; F: 202-205-9252

www.ed.gov/offices/OSERS

Office of Special Education Programs (OSEP)

400 Maryland Ave. SW

Washington, DC 20202-2570

T: (202) 205-5507, F: (202) 260-0416

Web site: www.ed.gov

National Organizations

Association of University Centers on Disabilities

(formerly American Association of University Affiliated Programs)

1010 Wayne Avenue, Suite 920

Silver Spring, MD 20910

PH: 301-588-8252

FAX: 301-588-2842

<http://www.aucd.org/>

A non-profit organization that promotes and supports the national network of university centers on disabilities, which includes University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD), Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs and Developmental Disabilities Research Centers (DDRC).

American Association on Mental Retardation, 444 N Capitol St. NW #846,

Washington, DC 20001, (202) 387-1968, (800) 424-3688, (202) 387-2193 fax, Web site:

www.aamr.org

American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852-3279, (301) 897-5700, (800) 638-8255, (301) 571-0457 fax, (301) 897-0157 TTY, Web site: www.asha.org

Arc of the U.S., 1010 Wayne Ave. #650, Silver Springs, MD 20910, (301) 565-3842, (800) 433-5255, (301) 565-5342 fax, info@thearc.org, Web site: www.thearc.org

Asperger Syndrome Coalition of the United States

2020 Pennsylvania Ave., NW
Box 771
Washington, DC 20006
866-4-ASPRGR (866-427-7747)!
www.asperger.org

A nonprofit organization committed to providing the most up-to-date and comprehensive information on Asperger Syndrome and related conditions.

The Autism Network for Hearing and Visually Impaired Persons

c/o Dolores and Alan Bartel
7510 Oceanfront Avenue
Virginia Beach, Virginia 23451
voice: (804) 428-9036
fax: (804) 428-0019

Autism Network International (ANI)

PO Box 448
Syracuse, NY 13210-0448
(Organization run by and for individuals with autism)

Autism Research Institute

4182 Adams Avenue
San Diego, California 92116
voice: (619) 281-7165
fax: (619) 563-6840

Autism Services Center, PO Box 507, Huntington, WV 25710-0507, (304) 525-8014, (304) 525-8026 fax

Autism Society of America, Inc., 7910 Woodmont Ave. #300, Bethesda, MD 20814-3015, (301) 657-0881, (301) 657-0869 Fax, (800) 328-8476, Web site: www.autism-society.org

The Autism Society of America was founded in 1965 and today has 18,000 members working in over 220 chapters in 48 states. ASA is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families and the professionals with whom they interact. The Society and its chapters share a common mission of providing information and education, supporting research and advocating for programs and services for the autism population. Their Fax-On-Demand system is a very cool, efficient, and easy way to get information. Visit their site to get the number.

ARCH (Access to Respite Care and Help)

Chapel Hill Training-Outreach Project, Inc.

800 Eastowne Drive, Ste. 105

Chapel Hill, NC 27514

T: 919-490-4477 ext. 222

Email: mathers@chtop.org

www.chtop.com

ARCH develops and produces programs and strategies, including training, technical assistance, and public awareness, that will enhance the development of all children and their families. Young children who live in poverty, those with disabilities, and those at risk for abuse and neglect are of principal concern to project staff.

CAN, Cure Autism Now

5455 Wilshire Blvd., Suite 715,

Los Angeles, CA 90036

1-323-549-0500

1-888-8AUTISM

fax: 1-323-549-0547

email info@cureautismnow.org

Cure Autism Now is an organization of parents, physicians, and researchers, dedicated to promoting and funding research with direct clinical implications for treatment and a cure for autism.

Center for Law and Education, 43 Winter St., 8th Floor, Boston, MA 02108, (617) 451-0855, (617) 451-0857 fax, or 1875 Connecticut Ave. NW, #510, Washington, DC 20009-5728. (202) 986-3000, (202) 986-6648 fax, cle@cleweb.org, Web site: www.cleweb.org

Center for the Study of Autism

P.O. Box 4538

Salem, Oregon 97302

voice/fax: (503) 692-3104

web: Center for the Study of Autism

The Center for the Study of Autism (CSA) is located in the Salem/Portland, Oregon area. The Center was established in 1991 and was first located in Newberg. In 1994, the Center moved to Beaverton; and in 1996, the Center moved to Salem. The Center provides information about autism to parents and professionals, and conducts research on the efficacy of various therapeutic interventions. Most of the research is in collaboration with the Autism Research Institute in San Diego, California.

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD), 8181 Professional Place #201, Landover, MD 20785, (301) 306-7070, (301) 306-7090 fax, (800) 233-4050, national@chadd.org, Web site: www.chadd.org

Consortium for Appropriate Dispute Resolution in Special Education, PO Box 51360, Eugene, OR 97405-0906, (541) 686-5060, (541) 686-5063 fax, cadre@directionservice.org, Web site: www.directionservice.org/cadre

Consortium for Citizens with Disabilities, 22 Cedar Lane, Vienna, VA 22182, (703) 208-7489, (703) 698-0124 fax, info@c-c-d.org, Web site: www.c-c-d.org

Council for Exceptional Children (CEC), 1110 N Glebe Rd. #300, Arlington, VA 22201-5704, (703) 620-3660, (800) 224-6830, (703) 264-9446 TTY, (703) 264-9494 fax, service@cec.sped.org, Web site: www.cec.com

Disability Rights Education and Defense Fund (DREDF), 1629 K St. NW #802, Washington, DC 20006, (202) 986-0375, (202) 775-7465 fax, dredf@dredf.org, Web site: www.dredf.org

Easter Seals (National Headquarters), 230 W Monroe #1800, Chicago, IL 60606-4802, (312) 726-6200, (800) 221-6827, (312) 726-1494 fax, (312) 726-4258 TDD, info@easter-seals.org, Web site: www.easter-seals.org

Families and Advocates Partnership for Education (FAPE), PACER Center, 8161 Normandale Blvd., Minneapolis, MN 55437, (952) 838-9000, 800-53-PACER (in MN only), (888) 248-0822, (952) 838-0199 fax, (952) 838-0190 TTY, Web site: www.fape.org

FAAAS, Inc. Families of Adults Afflicted with Asperger's Syndrome
PO Box 514
Centerville, MA 02632

Our mission is to give support to the family members of adult individuals afflicted with Asperger's Syndrome. It is the spouses and the siblings and the children of those afflicted with Asperger's Syndrome whom we are trying to reach. Especially those whose relative has not been correctly diagnosed with Asperger's Syndrome until well into their adulthood.

Federation for Children with Special Needs

1135 Tremont St., Ste. 420
Boston, MA 02120
T: 617-236-7210; F: 617-572-2094
Email: fcsninfo@fcsn.org
www.fcsn.org

The Federation provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities, and is committed to quality education, healthcare for all, and protecting the rights of children.

Home School Legal Defense Association

PO Box 3000
Purcellville, VA 20134
T: 540-338-5600; F: 540-338-2733
www.hslda.org

This nonprofit, member organization was established to defend and advance the constitutional right of parents to direct the education of their children and to protect family freedoms.

Indiana Resource Center for Autism (IRCA)

Institute for the Study of Developmental Disabilities

2853 East 10th Street

Bloomington, IN 47408-2601

(818) 855-6508

(Provides information and publications on various issues concerning autism.)

International Dyslexia Association, The, 8600 LaSalle Road, Chester Bldg. #382, Baltimore, MD 21286-2044, (410) 296-0232, (800) 222-3123, (410) 321-5069 fax, info@interdys.org, Web site: www.interdys.org

Learning Disabilities Association of America, 4156 Library Rd., Pittsburgh, PA 15234-1349, (412) 341-1515, (412) 344-0224 fax, ldanat1@usaor.net, Web site: www.lidaamerica.org

Life of the Midwest , 2925 Dean Parkway, Suite 300, Minneapolis, MN 55416 (612) 925-8365, http://www.lovaas.com/

National Alliance for the Mentally Ill, Colonial Place Three, 2107 Wilson Blvd. #300, Arlington, VA 22201, (703) 524-7600, (800) 950-6264, (703) 524-9094 fax, Web site: www.nami.org

The National Alliance for Autism Research (NAAR)

66 Witherspoon Street, Suite 310

Princeton, New Jersey 08542

voice/fax: (908) 359-9957

e-mail: naar@naar.org

web: NAAR

The National Alliance for Autism Research (NAAR) is a national nonprofit, tax-exempt organization dedicated to finding the causes, prevention, effective treatment and, ultimately, cure of the autism spectrum disorders. NAAR's mission is to fund, promote and support biomedical research into the causes, prevention, effective treatment and, eventually, cure of the autism spectrum disorders.

National Association for the Education of African American Children with Learning Disabilities, PO Box 09521, Columbus, OH 43209, (614) 237-6021, (614) 238-0929 fax

National Association of Protection and Advocacy Systems, Inc., 900 2nd St. NE #211, Washington, DC 20002, (202) 408-9514, (202) 408-9520 fax, (202) 408-9521 TTY, firstname@napas.org, Web site: www.protectionandadvocacy.com

National Attention Deficit Disorder Association (ADDA)

1788 Second Street, Suite 200

Highland Park, IL 60035

(847) 432-2332

E-mail: mail@add.org

Web: www.add.org

National Autism Hotline / Autism Services Center

605 Ninth Street
Prichard Building, PO Box 507
Huntington, West Virginia 25710-0507
voice: (304) 525-8014
fax: (304) 525-8026

National Center for Learning Disabilities, 381 Park Ave. S, Suite 1401, New York, NY 10016, (888) 575-7373, (212) 545-7510, (212) 545-9665 fax, Web site: www.nclcd.org

National Information Center for Children and Youth with Disabilities (NICHCY), PO Box 1492, Washington, DC 20013-1492, (202) 884-8200 v/TTY, (800) 695-0285, (202) 884-8441 fax, nichcy@aed.org, Web site: www.nichcy.org

National Mental Health Association, 2001 N. Beauregard Street-12th Floor, Alexandria, VA 22311, (703) 684-7722, (800) 433-5959 TTY, (800) 969-6642 Toll-free, (703) 684-5968 fax, infoctr@nmha.org, Web site: www.nmha.org

National Organization on Disability

910 16th St., N.W., Ste. 600
Washington, DC 20006
T: 202-293-5960; F: 202-293-7999; TDD: 202-293-5968
Email: ability@nod.org
www.nod.org

NOD is committed to expanding the participation of people with disabilities in their own communities. NOD also provides referrals to various resources, such as independent living centers, disability research, and rehabilitation organizations.

National Parent Network on Disabilities (NPND)

1130 17th St., Ste. 400
Washington, DC 20036
T/TDD: 202-463-2299, F: 202-463-9403
Email: NPND@cs.net
www.npnd.org

The NPND serves organizations and families of individuals with disabilities and special health care needs, sharing information and resources to promote the power of parents to influence and affect policy issues concerning the needs of people with disabilities and their families.

National Parent to Parent Support and Information System, Inc.

PO Box 907
Blue Ridge, GA 30513
T: 800-651-1151; F: 706-632-8830
Email: judd103w@wonder.em.cec.gov
www.nppsis.org

NPPSIS is a nonprofit organization established to support, strengthen, and empower families through one-to-one parent contacts.

More Advanced Autistic People

PO Box 524
Crown Point, Indiana 46307
voice: (219) 662-1311
fax: (219) 662-0638
www.maapservices.org

O.A.S.I.S.

Online Asperger's Syndrome Information and Support
www.udel.edu/bkirby/asperger

PACER Center, Inc. (Parent Advocacy Coalition for Educational Rights), 8161
Normandale Blvd., Minneapolis, MN 55437-1044, (952) 838-9000, (800) 537-2237,
(952) 838-0199 fax, (952) 838-0190 TTY, pacer@pacer.org, Web site: www.pacer.org
(The federal government's designated national coordinating office of parent training and
information center for families of children with disabilities.)

Parent Information Center

155 Manchester, St.
PO Box 1422
Concord, NH 03301
603-224-6299
Contact: Judith Raskin, Director

**TEACCH (Treatment and Education of Autistic and Related Communication
Handicapped Children and Adults**

Division TEACCH, CB #7180
310 Medical School Wing E
Chapel Hill, NC 27599-7189
919-966-2174

Contact: Eric Schopler, Ph.D., Director

A comprehensive community-based program for persons with autism. Through North
Carolina's five regional TEACCH centers, provides diagnostic evaluation, individualized
treatment, parent and professional training, and consultation.

Unlocking Autism

P.O. Box 237
Walker, Louisiana 70785
(225) 665-7270

Unlocking Autism was founded primarily for the purpose of increasing awareness about
the disorder.

www.unlockingautism.org

Wings for Little Angels Program Medical Travel Assistance Program

"Helping Those With Autism Soar" through Unlocking Autism

If you have a child, or know of a child, in need of travel to medical care outside of the immediate area, Unlocking Autism may be able to help with your DOMESTIC (Not International) air travel. UA has been able to partner with several airlines to assist parents of children with Autism in getting to medical appointments in other states. Please use this form below to submit your information to us. We will contact you as soon as possible. If you are just wanting to donate your frequent flyer miles, fill in the legal guardian field, put NA for the rest of the fields and check the donation box at the bottom.

<http://www.unlockingautism.org/angelwings.htm>

VSA Arts, 1300 Connecticut Ave. NW #700, Washington, DC 20036, (202) 628-2800, (202) 737-0725, (202) 737-0645 TTY, Web site: www.vsarts.org

CHAPTER 10

WEBSITES

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

Autism Resources Definition of Autism

Overview of Autism <<http://www.autism.org/overview.html>>

The Center for the Study of Autism <<http://www.autism.org/>>

What Is Autism? <<http://www.autism-society.org/autism.html>>

The Autism Society of America <<http://www.autism-society.org/>>

The Autism Society of North Carolina at The Division TEACCH Home page
<<http://www.unc.edu/depts/teacch/>>

CHADD <<http://www.chadd.org>>

PACE <<http://www.ncnow.com/pace/>>

NIMH Guide <<http://www.nimh.nih.gov/publicat/autism.htm>>

Glossary of Autism Terms <<http://www.vaporita.com/autism/autismfaq-glos.html>>

Overview of Autism <<http://www.autism.org/overview.html>> - Dr. Stephen Edelson,
Center for the Study of Autism. In several languages

Advocating for Your Child
<http://www.wrightslaw.com/advoc/articles/advocacy_intro.htm>

Autism/PDD Basics 101 <<http://autism.about.com/library/blautism101.htm>>

Autistic Spectrum Disorders: Sorting It Out
<<http://www.pediatricneurology.com/autism.htm>>

20 Questions & Answers Autism Checklist
<<http://www.geocities.com/EnchantedForest/1142/checklist.html>>

Autism Checklist <<http://www.autism-society.org/checklist.html>>

Autism Society America Autism, Myths, And What You Can Do
<<http://www.autistickids.org/autinfo1.html>>

"Getting Started" <http://www.autism-society.org/packages/getting_started.pdf>Autism
Society's Package

"Wrightslaw Game Plan
<http://www.wrightslaw.com/advoc/articles/plan_new_parent.html>

General Information

The Center for the Study of Autism <<http://www.autism.org/>> (A "Must Visit" site)

Autism Society of America <<http://www.autism-society.org/>> (A "Must Visit" site)

Autism/PDD Resources Network <<http://www.autism-pdd.net/>>

Autism Resource Guide <<http://pages.prodigy.com/dporcari/index.html>>

The Andrew Project <<http://expage.com/page/projectdrw>> - Resource Directory listing of various organizations that deal with issues of childhood disabilities

Autism Society of America <<http://www.autism-society.org/packages.html>> - Information Packages

Resources from Internet Resource for Special Children autismconnect <<http://www.autismconnect.org/>> - a FREE web site, which aims to be the first port of call for anyone interested in autism, providing news, events, world maps, and rapid access to other web sites with information on autism.

The Autism Depot <<http://home.ptd.net/~rjd/autism/>>

General Resources Autism from SERI <<http://www.hood.edu/seri/autism.htm>>

General Resources The Autism Homepage
<<http://communities.msn.com/TheAutismHomePage/>>

General Resources Autism-PDD Resources Network <<http://www.autism-pdd.net/>> -

Autism Patient Centered Guides <<http://www.patientcenters.com/autism/>>

Autism Resources Page <<http://www.autism-resources.com>>

John Wobus' organized list of net resources. Autism Resources
<<http://www.unc.edu/~cory/autism-info/>>

Beyond Autism <<http://trainland.tripod.com>> - autism help, autism links, autism resources

Disability Direct: Information on Disabilities for Americans <<http://disability.gov/>> - a wide variety of information about topics concerning disability from across the federal government.

Information is power! disABILITY Information and Resources
<<http://http://www.makoa.org/>>

General Resources The "All Disability" Link Page
<http://www.jsrd.or.jp/dinf_us/disability_resources/all.htm> - contains tons of links of resources.

Disability Resources <<http://busboy.sped.ukans.edu/disabilities/>> - Courtesy of the Department of Special Education at the University of Kansas

Exceptional Parent Resource Guide <<http://www.eparent.com/resources/default.htm>> - This resource guide contains more than 2000 information sources on: specific disabilities; parent support, vocational rehabilitation, Canadian organizations, and more....

The National Clearing House of Rehabilitation Training Materials
<<http://www.nchrtm.okstate.edu/>> - provides a wide variety of disability related training resources, locates, collects and distributes a wide variety of training materials such as participant and trainer manuals, videos, syllabi and curricula from publicly funded rehabilitation training programs for rehabilitation practitioners in state, federal and private agencies nationwide.

National Information Center for Children and Youth with Disabilities -NICHCY (USA)
<<http://www.nichcy.org/>> - the national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. Our special focus is children and youth (birth to age 22)

General Resources PDD Support Home Page
<<http://www.thelaughtongroup.com/pddsupport/index.html>>

General Resources Social Security Online Disability Programs
<<http://www.ssa.gov/disability/>>

Supplemental Security Income (SSI) <<http://www.ssa.gov/notices/supplemental-security-income/>> - a Federal (USA) income supplement program funded by general tax revenues (not Social Security taxes): It is designed to help aged, blind, and disabled people, who have little or no income; and It provides cash to meet basic needs for food, clothing, and shelter.

Social Security Administration: Redbook on Employment Support (available from SSAoffices and website)
www.ssa.gov/work

Program Operations Manual System (on-line and free)
www.policy.ssa.gov/poms.nsf/poms?OpenView

Rural Institute at University of Montana website: www.ruralinstitute.umd.edu or Griffin-Hammis Associates: www.GriffinHammis.com (includes "SSI Manager")

University of Missouri Rehabilitation Community Education Program (RCEP):
www.rcep7org/ssa

TalkAutism <<http://www.talkautism.org>> - talkAutism's interactive databases allows access to up-to-date resources and perspectives, while it builds a database for future inquiries. TalkAutism also develops complementing new communication technologies to connect and assist the autism community. talkAutism is a turnkey service to organizations, groups, and companies.

Understanding Medicaid Home and Community Services: A Primer
<<http://aspe.hhs.gov/daltcp/reports/primer.htm>>

PRELUDE <<http://preludetherapy.home.att.net/>> - Our mission is to serve children and adults with special needs through sharing information; creating and publishing music therapy strategies; and giving workshops and presentations to professionals, parents, and students.

Asperger's Syndrome

Yahoo's list of Asperger's Syndrome websites
<http://www.yahoo.com/health/diseases_and_conditions/asperger_s_syndrome/>.

On-Line Asperger's Syndrome Information and Resources
<<http://www.udel.edu/bkirby/asperger/>> (O.A.S.I.S. a.k.a. Asperger's Syndrome Resources; Excellent page)

Asperger's Disorder Homepage <<http://www.aspergers.com/>>

Asperger Syndrome Coalition of the United States <<http://www.asperger.org/>>

Asperger's <http://www.familyvillage.wisc.edu/lib_aspe.htm>

Family Village <<http://www.familyvillage.wisc.edu/>>

Asperger's Syndrome Information Package <<http://www.autism-society.org/packages/aspergers.html>>

What is Asperger Syndrome? Center for Autism & Related Disabilities Fact Sheet
<<http://card-usf.fmhi.usf.edu/cardpubs/factsheet/Engsheets/EngFactsheets5.pdf>>

Online Autism Courses

The Doug Flutie, Jr. Foundation for Autism, Inc. was established by professional football player Doug Flutie and his wife, Laurie Flutie. Named after their son, the organization is the Flutie's life-long commitment to make a difference in the lives of autistic children and their families. WebED works in partnership with DFJ Foundation to develop and maintain a curriculum surrounding the subject of autism.
<http://www.webed.com/parents/default.asp>

The Autism Society of America offers Free online courses on autism. You can register at: <http://autism.altviatech.com/>

Methods, Treatments, Programs

How to Determine If a Treatment Really Helped

<<http://www.autismtoday.com/determinetreat.htm>> - Written by Stephen M. Edelson, Ph.D.

Wobus Treatment FAQ <<http://www.vaporio.com/autism/autismfaq-trea.html>>

Quack Watch <http://www.quackwatch.com/cgi-bin/aglimpse/24/home/sbinfo/public_html?lines=1&query=autism> Query: Autism

How To Become An Autism Expert <<http://www.autistics.org/library/autexpert.html>> - Autistic humor

Pharmacology: Pediatric Pharmacology: Autism

<<http://www.vh.org/Providers/Conferences/CPS/41.html>>

Autism Society of America's package on Treatment Options <<http://www.autism-society.org/packages/treatment-options.html>>

TEACCH

Treatment and Education of Autistic and related Communication Handicapped Children - TEACHH <<http://www.unc.edu/depts/teacch>>

Lovaas Method/Applied Behavioral Analysis/Behavioral Therapy/Discrete Trial Training (ABA; DTT)

The Recovery Zone <<http://pages.prodigy.net/damianporcari/recovery.htm>> (site dedicated to Applied Behavioral Analysis)

Info on The ME-List <<http://php.iupui.edu/~rallen/mlfaq.html>>, a private mailing list which provides a forum for discussion of discrete-trial-based interventions (also referred to as "behavior modification" and as "Lovaas" therapy) for autism and related disorders.

ABA-PRO mailing list dedicated to the discussion of ABA as a technology and science.

It is located at listserv@maelstrom.stjohns.edu

<<mailto:listserv@maelstrom.stjohns.edu>>

#aba is an IRC chat forum dedicated to Applied Behavior Analysis.

Richard Saffron's ABA resources <<http://members.tripod.com/~RSaffran/aba.html>>

Teaching Children Through Behavior Management (Notes from Lecture Series)

<<http://Kohala.huskynet.com/carol/aba/>>

Autism Behavior Therapy Alliance website <<http://www.autismbehaviortherapy.org>>

ABA Information <<http://members.aol.com/sheeanaa/aba.html>>

Autism <http://www.behavior.org/sections/autism/autism_home.html>

GUIDELINES FOR CONSUMERS OF APPLIED BEHAVIOR ANALYSIS SERVICES TO INDIVIDUALS WITH AUTISM <<http://www.wmich.edu/aba/Austimwebfile.htm>>

ABA4autism.com <<http://store.yahoo.com/aba4autism-store/>> - Your first step in getting help for autism and behavioral problems.

www.ABAconnections.com <<http://www.abaconnections.com/>>

ABA Databases <<http://www.addr.com/~me-list/databases> >

ABA FAQ <<http://members.tripod.com/RSaffran/faq.html>>

Association for Advancement of Behavior Therapy <<http://www.aabt.org/>> - a professional, interdisciplinary organization which is concerned with the application of behavioral and cognitive sciences to understanding human behavior, developing interventions to enhance the human condition, and promoting the appropriate utilization of these interventions

Autism & ABA Main Page <<http://www.bridgesabatapes.com/autism.html>>
Autism. Hand in Hand Educational Portal <<http://www.autismhandinhand.com/>> - a resource for anyone who is involved in home based ABA program or education of children with ASD.

Autism Treatment Based on Applied Behavioral Analysis: What Does the Current Research Tell Us? <<http://www.ctfeat.org/research.html>> - By Richard Irwin. (Parent of a Child with an Autism.

Bridges for Children with Autism <<http://www.bridgesabatapes.com/>> - a complete training program developed to help parents, teachers, physicians and other caregivers establish an Applied Behavior Analysis (ABA) program for children with autism.

Cambridge Center for Behavioral Studies <<http://www.behavior.org>>

Center for Autism and Related Disabilities (CARD) <<http://www.centerforautism.com>> - .

FEAT (Families for Early Autism Treatment)
<<http://www.feat.org/FEATorg/priorities97.htm>>
Education, Advocacy and Support for Early Autism Treatment using Lovaas Method.

Journal of Applied Behavior Analysis

<<http://www.enrmed.rochester.edu/wwwrap/behavior/jaba/jabahome.htm>> - a psychology journal that publishes research about applications of the experimental analysis of behavior to problems of social importance.

KidAccess <<http://www.kidaccess.com/html/main.html>> - From Goals to Data and Back Again

Lovaas Institute <<http://www.lovaas.com/>> - The Lovaas Institute for Early Intervention is a research based Institute that specializes in teaching pre-school aged children with autism, pervasive developmental disorders, and related developmental disabilities. The behavioral intervention program was developed in the Psychology Department of UCLA under the direction of Dr. O. Ivar Lovaas. It is based on extensive clinical experience and more than 35 years of scientific research.

PRT

HOW TO TEACH PIVOTAL BEHAVIORS TO CHILDREN WITH AUTISM: A TRAINING MANUAL <<http://www.users.qwest.net/~tbharris/prt.htm>>

<http://psy.ucsd.edu/autism/prtraining.html>

PIVOTAL RESPONSE TRAINING < PRT2.html? ~vcestone psy.ucsd.edu http:> - PRT is a naturalistic treatment approach developed by: Robert L. Koegel & Laura Schreibman. Pivotal Response Training (PRT) is a behavioral treatment intervention based on the principles of applied behavior analysis (ABA).

Pivotal Response Training (PRT) <<http://www.users.uswest.net/~tbharris/prt.htm>>

Pivotal Response Training <<http://www.spectrumcenter.org/autismplanning.html>>

Social Stories

Social Stories Seminar <<http://www.canterbury.ac.uk/xplanatory/seminars/s1ss1.htm>>

Social Stories <<http://www.canterbury.ac.uk/xplanatory/seminars/ss1menu.htm>>

Social Stories, Comic Book Conversations, Thinking Stories
<<http://www.udel.edu/bkirby/asperger/socialcarolgray.html>> - by Carol Gray

Social skills and Behavior Resources <social-behavior.htm>

Facilitated Communication

The Facilitated Communication Institute's Page <<http://soeweb.syr.edu/thefci/>>

DEAL <<http://www.vicnet.net.au/~dealccinc/>>

The Facilitated Communication Information and Interactive Community Network
<<http://members.delphi.com/QIM/>>

Chris Borthwick. "Facilitated Communication and its Critics"
<<http://www.vichealth.vic.gov.au/~borth/FCcritic.htm>>

Medication

Medication and Autism (1) <<http://osiris.sunderland.ac.uk/autism/psdur.html>>

Medication and Autism (2) <<http://osiris.sunderland.ac.uk/autism/drug.htm>>

Medication and Autism (3) <<http://osiris.sunderland.ac.uk/autism/pharm3.htm>>

Medication -Anafranil- Clomipramine <<http://www.mentalhealth.com/drug/p30-a01.html>>

Medication -Anti-epileptics <<http://osiris.sunderland.ac.uk/autism/pharm3.htm>>

Medication - Haldol- Haloperidol <<http://www.mentalhealth.com/drug/p30-h02.html>>

Medication and Autism -Naltrexone <<http://www.autism.org/naltrex.html>>

Therapeutic Options: On the Rational what Use of Naltrexone in Autism
<<http://www.autism.com/lost&found/naltrex.htm>> - Jaak Panksepp

Medication - Prednisone <<http://aheadwithautism.com/pred01.html>>

Medication List <<http://www.mentalhealth.com/p30.html>>

Be MedWise <<http://www.bemedwise.org/>> - a public education initiative by the National Council on Patient Information and Education (NCPIE) – a nonprofit coalition of over 150 government, consumer, patient advocacy and public health organizations. NCPIE serves as a trusted source of reliable information about the proper use of medicines, and Be MedWise seeks to promote a better understanding that over-the-counter (OTC) drug products are serious medicines and must be taken with care.

Secretin

ARRI Article excerpts <<http://www.autism.com/ari/secretin.html>>

John Wills Lloyd. "Autism and Secretin"

<<http://curry.edschool.virginia.edu/go/cise/ose/information/secretin.html>>

Eliminating Dietary Gluten and Casein

Autism Network for Dietary Intervention (ANDI) <<http://www.autismndi.com/>>

Sara's Diet - A Comprehensive Dietary Approach to Autism

<<http://personal.atl.bellsouth.net/~sojmed/sara's-diet.html>>

ANDI <<http://www.autismndi.com/>>

GFCFDiet <<http://www.gfcfdiet.com/>>

Mercury, Chelation, and Vaccine Information and Resources

Autism and Mercury <<http://www.autism-mercury.com/>>

Autism and Mercury <<http://www.alkaliser.com/Mercola.autism.htm>> - by Tim O'Shea,DC

Autism and Mercury <<http://groups.yahoo.com/group/Autism-Mercury>> - Yahoo Group

Autism: A Unique Type of Mercury Poisoning

<<http://www.autism.com/ari/mercurylong.html>> - Sallie Bernard * Albert Enayati, B.S., Ch.E., M.S.M.E. ** Teresa Binstock Heidi Roger Lyn Redwood, R.N., M.S.N., C.R.N.P. Woody McGinnis, M.D.

Autism The Mercury Poisoning Connection

<http://www.geocities.com/autism_mercury/>

Autism Questionnaire <<http://www.autismresearchproject.net/>> - Vaccines and Autism Is There a Link?

Is Mercury Toxicity an Autoimmune Disorder?

<<http://www.thorne.com/townsend/oct/mercury.html>> - by Keith W. Sehnert, M.D., Gary Jacobson, D.D.S., Kip Sullivan, J.D.

Learn How Mercury Is Affecting You and the Ones You Love

<<http://www.mercola.com/domains/nomercury.htm>>

Mercury in Drug and Biologic Products
<<http://www.fda.gov/cder/fdama/mercury300.htm>>

Mercury Detoxification <<http://www.autism.com/ari/mercurydetox.html>> - Autism Research Institute

Autism and Mercury Detoxification
<http://autism.about.com/gi/dynamic/offsite.htm?site=http%3A%2F%2Fwww.mercola.com%2F2000%2Foct%2F1%2Fmercury_autism.htm>

Autism linked to metal disorder <<http://www.wnbc.com/cgi-bin/gx.cgi/AppLogic+FTContentServer?pagename=FutureTense/Apps/Xcelerate/Render&c=NBCArticle&cid=NBCBUPZFLNC&preview=true>>

Chelation Therapy
<<http://autism.about.com/gi/dynamic/offsite.htm?site=http%3A%2F%2Fwww.paralumun.com%2Fchelation.htm>>

Chelation Therapy
<<http://autism.about.com/gi/dynamic/offsite.htm?site=http%3A%2F%2Fwww.wellness.demon.co.uk%2Fcheleng.htm>>

Chelation Therapy article <<http://autism.about.com/library/weekly/aa010901a.htm>>

Introduction to Chelation Therapy
<<http://autism.about.com/gi/dynamic/offsite.htm?site=http%3A%2F%2Fwww.healthy.net%2Fclinic%2Ftherapy%2Fchelate%2Fintro%2Findex.asp>>

Autism & Vaccines: A New Look At An Old Story
<<http://www.909shot.com/NVICSpecialReport.htm>>

Immunization Action Coalition <<http://www.immunize.org>>

Institute of Medicine (IOM) Committee Rejects Causal Relationship Between Measles-Mumps-Rubella Vaccine and Autism Spectrum Disorder
<<http://www.immunizationinfo.org/features/featurearchivedetail.cfm?id=26>>

Pro-Vaccine Information <<http://www.access1.net/via/PROVAX/toc-provax.htm>>

Science Finds No Link Between MMR Vaccine and Autism
<<http://www.immunizationinfo.org/features/featurearchivedetail.cfm?id=8>>

Occupational Therapy

PACE <<http://www.ncnow.com/pace/>> (Occupational Therapy & Autism)

Amy and Miles' Homepage

<<http://www.geocities.com/Heartland/Fields/6979/index.html>>

Activities for Developing Fine Motor Co-ordination

<<http://www.geocities.com/calicocookie/finemotor.html>>

Fine Motor Art Activities

<<http://www.sbcss.k12.ca.us/sbcss/specialeducation/ecthematic/farm/motor.html>>

Fine Motor Manipulatives

<<http://www.ci.shrewsbury.ma.us/Sps/Schools/Beal/readiness/finemotoractivities.html>>

More Fine Motor Activities

<<http://www.juststeve.com/paula/OTResources/FMactivities.html>>

Working with Clay

<<http://www.edbydesign.com/specneedsres/specialart/artideas1.html>>

The Sensory Side

Occupational Therapy <<http://www.geocities.com/Heartland/Fields/6979/ot.html>>

Henry's Occupational Therapy Services <<http://gtcs.com/sponsors/henry/>> - Bringing Sensory Integration to Schools, Homes and Businesses

How Can Occupational Therapy Help the Individual with Autism?

<<http://www.aota.org/featured/area6/links/link02d.asp>>

An Interview with Carol Kranowitz

<http://www.comeunity.com/disability/sensory_integration/carol-kranowitz.html> - author of The Out-of-Sync Child

Behaviors of Children with Sensory Integration Differences

<<http://www.geocities.com/Heartland/Fields/6979/Slactivities.html>>

"Importance of Sensory Modulation and Maintaining a Sensory Diet In Early

Intervention" <<http://www.saveachild.com/parentspeak/phillips.htm>> - from the Unicorn Foundation

My Experiences with Visual Thinking Sensory Problems and Communication Difficulties

<<http://www.autism.org/temple/visual.html>> - by Temple Grandin, Ph.D.

The Relationship of Learning Problems and Classroom Performance to Sensory Integration <<http://www.nmark.com/si/>>

Sensory Diet <http://www.bbbautism.com/sensory_diet.htm> - A Sample
Sensory Integration <<http://www.autism.org/si.html>> - Cindy Hatch-Rasmussen, M.A.,
OTR/L

Sensory Integration FAQ
<<http://www.sinetwork.org/ParentFrequentlyAskedQuestions.htm>>

Sensory Integration International <<http://home.earthlink.net/~sensoryint/>>

Sensory Integration Resources
<http://www.comeunity.com/disability/sensory_integration/resources.html>

The Torture of Touch: Raising a Child with Sensory Integration Dysfunction
<<http://childrentoday.com/resources/articles/dsi.htm>>

Auditory Integration Training

Society for Auditory Integration Training <<http://www.teleport.com/~sait/>>

Pamela Steed's page <<http://www.mi.net/ait/aihome.htm>>

Tomatis Americas Network <<http://www.tomatis.com/>>

The Counseling Center <<http://www.vision3d.com/adhd/>>

Music Therapy

The Boston Institute For Arts Therapy <<http://www.biat.org/>> - Reaching autistic children and adults through the power of music

The Healing Music Organization (HMO) <<http://www.healingmusic.org/>> provides information, resources, tools, and a forum for dialogue to people interested in the healing power of sound and music.

Musical Motivation in Health Care
<<http://researchmag.asu.edu/stories/motivation.html>>,
Music Therapy & Autism <<http://www.mtabc.com/autism.html>>

Music Therapy and Language for the Autistic Child <<http://www.autism.org/music.html>>
- by Myra J. Staum, Ph.D., RMT-BC Director and Professor of Music Therapy
Willamette University, Salem, Oregon

Music Therapy Info Link <<http://members.aol.com/kathysl/index.html>> - a place to gather information, help open the lines of communication and networking, and educate the public about the field of music therapy.

THERAPEUTIC OPTIONS: Effects of Music on the Brain
<<http://www.autism.com/lost&found/music.htm>> - Jaak Panksepp

Expressive Arts Therapy Links <<http://www.biat.org/links.html>> - from The Boston Institute for Arts Therapy

Visual

A BENEFICIAL INTERVENTION FOR DEVELOPMENTAL DISABILITIES
<<http://www.autism.org/visual.html>> - by Sally Brockett, M.S.,

Colour in the treatment of visual stress -
<<http://www.essex.ac.uk/psychology/overlays/>>

Comprehensive vision therapy information
<http://www.vision3d.com/eye_care/eye_care.html> - faqs, links..

Irlen Lens <http://www.irlen.com/index_autism.html>

Irlen Lens System - Scotopic Sensitivity Syndrome <<http://www.autism.org/irlen.html>>

Irlen Syndrome
<<http://www.planet.eon.net/~judypool/demo1.htm>[http://www.planet.eon.net/~judypool/de](http://www.planet.eon.net/~judypool/demo1.htm)
mo1.htm> - demo

Irlen Syndrome <<http://www.dilam.com/irlen.html>> - Dilam Inc. Canada

Irlen Syndrome <<http://www.irlenclinic.com>> - lenses

Vision Therapy <<http://www.childrensvision.com/links.htm>>

Vision Therapy <<http://www.autism.org/interview/kaplan.html>> - Ambient Lenses.
Interview with Melvin Kaplan, O.D.

Vision Therapy, Autism, and Sensory Integration
<<http://www.visionhelp.com/autism.htm>>

Vision Therapy <<http://www.opt.indiana.edu/vtlit/vtlit.html>> - Literature Reference List

WHAT IS VISION THERAPY? <<http://www.visiontherapy.org/>>

What is Vision Therapy? <http://www.children-special-needs.org/vision_therapy/what_is_vision_therapy.html> - Definitions and FAQs by various eye doctors and visual health organizations

The World of Misperception <<http://www.latitudes.org/learn02.html>> - Irlen Colored Filters

Misc

Biochemical therapy <<http://www.hriptc.org/>>

Center for Autism and Related Disabilities (CARD)
<<http://neurosci90.health.ufl.edu/card.html>> - Gainesville FL

Carnitine <<http://www.rettsyndrome.org/digests/00006.htm>> - Levocarnitine or L-Carnitine (trade name Carnitor) is an amino acid.

Chelation Therapy <mercvac.htm> - Chelation Therapy, Mercury and Vaccine Links

Circle of Friends <<http://www.udel.edu/bkirby/asperger/socialcircle.html>> - a program for children who have difficulties making friendships

Cod Liver Oil <<http://www.kirkmanlabs.com/products/articles/codliver.htm>>

CranioSacral Therapy - Autism – Observations, Experiences and Concepts John E. Upledger, D.O., O.M.M. <<http://www.upledger.com/Clinic/autism.htm>>

Daily Life Therapy <<http://www.autismni.org/bostonhig.html>>

Higashi Home Page <<http://www.bostonhigashi.org/>>

Detoxification <http://www.newmilmed.com/html/body_detox_info.html> - Dr. DeOrio's detoxification program

Scientific Studies on Dimethylglycine (DMG)
<<http://www.bulkmsm.com/DMG/dmg4.htm>>

Dimercaptosuccinic Acid (DMSA) <<http://www.thorne.com/altmedrev/fulltext/dmsa3-3.html>> - Dimercaptosuccinic Acid (DMSA), A Non-Toxic, Water-Soluble Treatment For Heavy Metal Toxicity by Alan L. Miller, N.D.

What is dolphin assisted therapy?
<<http://www.educ.ls.toyaku.ac.jp/~s977103/projectc.html>>

Dolphins - Human Dolphin Institute <<http://www.human-dolphin.org>> - a Conservation Society in the State of Florida. It is dedicated to the better understanding of humans, dolphins, and their relationship.

Efalex <<http://www.healing-arts.org/dbasics/wwwboard/board/messages/267.html>>

Serenaid <http://www.klaire.com/product_details.php?product_id=38> - Background and Source

SerenAid™ <<http://www.serenaid.org/>>

EnZymAid <<http://www.kirkmanlabs.com/products/articles/enzymaid.htm>>

Gentle Teaching <<http://www.gentleteaching.nl/>>

The Handle Institute <<http://www.handle.org/>> - a holistic approach to neuro-development and learning efficiency. - an effective, non-drug alternative for identifying and treating most neurodevelopmental disorders across the lifespan.

North American Riding for the Handicapped Association - NARHA <<http://www.narha.org/>> - This is the premier site for information on therapeutic riding

Holding Therapy <<http://http://www.nas.org.uk/archive/hold.html>>

Holding Therapy <<http://www.geocities.com/luznmymind2/autism2.html>>

Holistic Manual Therapy <<http://www.holistic-therapy.4t.com/>> - Rick Holzschuh Sator B.Sc.P.T.

Temple Grandin's 'Hug Box' <<http://www.autism.org/temple/hugbox.html>> - Article

Immunology - Autism Autoimmunity Project <<http://www.gti.net/truegrit/>> - Addressing Autism With Immunology

Immune Response To Brain Myelin In Autistic Children <<http://hunter.apana.org.au/~cas/autism/myelin.html>> - by Vijendra K. Singh, Reed P. Warren, Dennis Odell Utah State University, July 1992

Autoimmunity aspect of vaccines in autism <<http://www.house.gov/reform/hearings/healthcare/00.06.04/singh.htm>>

Autism, Autoimmunity and Immunotherapy <<http://www.vaccinationnews.com/DailyNews/January2002/AutAutoimm&Autoimmther.htm>>

Interactive Metronome <<http://www.interactivemetronome.com/>>

Intravenous Immunoglobulin <<http://www.edelsoncenter.com/ivgg.htm>> - (IVGG: Intravenous Gamma Globulin)

The Miller Method <<http://www.millermethod.org>> - The Miller Method addresses children's body organization, social interaction, communication and representation issues in both clinical and classroom settings.

Nambudripad's Allergy Elimination Techniques - NAET <<http://www.NAET.com/>>

Naturopathy <<http://www.cnra.org/what.is.a.naturopath.html>> - What is a Naturopath?

Omega Fatty Acids and Autism <<http://www.autismfundamentals.org/Phase%201%20-%20Fundamentals/7fattyacids1.html>>

Play Therapy <<http://www.play-therapy.com/parents.htm>> - PARENTS' PAGE ON PLAY THERAPY

Texas Association of Play Therapy <<http://txapt.org/>>

Positive Reinforcement: A Self-Instructional Exercise <<http://server.bmod.athabascau.ca/html/prtut/reinpair.htm>> - exercise to teach the concept of positive reinforcement

Sphingolin <<http://www.naturalhealthconsult.com/Monographs/sphingolin.html>> - myelin basic protein (MBP) from bovine spinal cord with 30 mg of Vitamin C.

Stem Cell Therapy <<http://www.healing-arts.org/children/>>

Supplement Reference <http://www.patientcenters.com/autism/news/sup_reference.html>

Yoga and Autism <<http://www.specialyoga.com/autism.htm>>

Mind Alive <<http://www.mindalive.com/>> - Audio-visual entrainment (AVE),

The Picky Eater <<http://www.autism.org/picky eater.html>> - by Kelly Dorfman, M.S.

Self-Injurious Behavior <<http://www.autism.org/sib.html>> - by Stephen M. Edelson, Ph.D.

Stereotypic (Self-Stimulatory) Behavior <<http://www.autism.org/stim.html>> - by Stephen M. Edelson, Ph.D.

Stimulus Overselectivity : Tunnel Vision in Autism <<http://www.autism.org/tunvsn.html>> - by Stephen M. Edelson, Ph.D.

Toe Walking <<http://www.autism.org/toewalk.html>> - Stephen M. Edelson, Ph.D.

Research and Studies

Pub Med <<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed>>

Medscape <<http://www.medscape.com/>>

Albert Einstein College of Medicine of Yeshiva University - The Children's Evaluation and Rehabilitation Center <<http://www.aecom.yu.edu/cerc/>>

Allergy induced Autism <<http://www.kessick.demon.co.uk/aia.htm>> - dedicated to identifying the underlying causes and biochemical effects of autistic spectrum disorders

Al-Quds University Research
<<http://www.alquds.edu/or/funding/announcements/can.html>>

The American Autoimmune Related Diseases Association AARDA
<<http://www.aarda.org/>>

Arizona State University Autism Research Information
<<http://www.eas.asu.edu/~autism/>>

Autism and Computing <<http://www.autismandcomputing.org.uk/>>

The Autism Autoimmunity Project <<http://www.gti.net/truegrit/>>

The Autism File - Center for Current Research
<<http://www.lifestages.com/health/autism.html>>

Autism Genetic Resource Exchange (AGRE) <<http://www.agre.org/>>

Autism Research at the National Institute of Mental Health
<<http://www.nimh.nih.gov/publicat/autismresfact.cfm>> - Fact Sheet

The Autism Research Group <<http://www.stanswartz.com/autismres.htm>>

Autism Research Institute <<http://www.autism.com/ari/contents.html>>

Autism Society of America Foundation <http://www.autism-society.org/foundation/asaf_index.html>

Behavioral Research Summaries from FEAT <<http://www.feat.org/autism/default.htm>>

CDC's Autism Research Efforts
<<http://www.cdc.gov/nip/vacsafe/concerns/autism/autism-res-cdc.htm>>

Center for the Study of Autism <<http://www.autism.com/>>

Cincinnati Children's Hospital Research Foundation
<http://www.cincinnatichildrens.org/Research/Divisions/Developmental_Disabilities/research.htm>

Collaborative Program of Excellence in Autism (CPEA) Centers
<<http://www.nichd.nih.gov/about/crmc/mrdd/autism/cpeacenters.cfm?sortby=center>>

The Coriell Institute for Medical Research Autism Research Resource
<<http://locus.umdnj.edu/autism/>>

Current Research Projects <<http://www.udel.edu/bkirby/asperger/research.html>>

The National Academy for Child Development (NACD)
<<http://www.nacd.org/index.html>>

The National Alliance for Autism Research, NAAR <<http://www.naar.org/>> - dedicated to finding the causes, prevention, effective treatment and, ultimately, cure of the autism spectrum disorders.

NIDS <<http://mat.org/>> - The NIDS Research Institute, which consists of the NIDS Parents Coalition and the NIDS Scientific Board, is dedicated to increasing the public's awareness of the likely connection between neuro-immune and/or auto-immune dysfunction and conditions such as Autism, ADD, Alzheimer's, ALS, CFS/CFIDS, MS and other immune-mediated diseases.

NICHD Autism Research
<<http://www.nichd.nih.gov/about/crmc/mrdd/autism/research.cfm>> - The NICHD is involved in a variety of research on autism.

CHAPTER 11

BOOK REVIEWS

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

Autism Book/Newsletter/Journal Reviews

Included in this section is a listing of books, newsletters, and journals which may be helpful as you begin your journey with Autism and Asperger's Syndrome. There are many more printed resources available than can be listed in this brief publication. Be certain to check your local library, the Autism Society Chapter and the State Autism Regional Center in your area to see if the books you are interested in are available for checkout.

BOOKS

Personal Experience

If you could see what I hear - by Catherine Maurice
A mother's journey with autism

Beyond the Wall - By Stephen Shore
An autobiography about Stephen's life and view of the world through Autism/Asperger's

The Sound of a Miracle: A Child's Triumph over Autism - by Annabel Stehli
The riveting story of Georgiana Stehli's progress from autistic and functionally-retarded to gifted.

Autism through a Sister's eyes - By Band, Eve B. and Emily Hecht
A young girl's view of her brother's autism.

Just this Side of Normal - by Elizabeth King Gerlach
A mother's story of life from diagnosis to acceptance. The ASA awarded this book the ASA book of the year.

Unraveling the Mysteries of Autism and PDD - by Karyn Seroussi
A mother's story of recovery and discovery.

Emergence: Labeled Autistic - by Temple Grandin
Follow her journey through the autistic world to becoming a well-known professor.

Thinking in Pictures - by Temple Grandin
Seeing the world through her perspective.

Pretending to be Normal - by Dr. Liane Holliday-Willey
Insight into living in the Asperger's world.

Eating an Artichoke - a Mother's Perspective on Asperger Syndrome - by Echo R. Fling

One small starfish - By Anne Addison

A mother's guide to success in home with a special needs child.

Breaking Autism's Barriers - by Bill Davis

A father's point of view on Autism

Facing Autism - by Lynn Hamilton

Asperger's

Asperger Syndrome and Sensory Issues - by Brenda Smith Myles and Katherine Tapscott Cook

Discusses the sensory issues with Asperger's Syndrome and how to interpret them.

The OASIS Guide to Asperger Syndrome: Advice, Support, Insight, and Inspiration - by Patricia Romanowski Bashe, Barbara L. Kirby, Tony Attwood

Asperger's, Huh - by Rosina Schurr

A child's perspective

Asperger Syndrome A Guide for Educators and Parents - by Brenda Smith Myles and Richard L. Simpson

Addresses basic issues related to children with these disabilities and also outlines basic methods to facilitate growth and development.

Asperger Syndrome - By Tony Attwood

A great source of information for helping parents and professionals who deal with Asperger's Syndrome kids

Asperger Syndrome and Adolescence - Practical Solutions for School Success

- by Brenda Smith Myles and Diane Adreon

Addresses middle school years and the transitions that go along with this particular age group.

Asperger Syndrome and Difficult Moments - Practical Solutions for Tantrums, Rage, and Meltdowns - by Brenda Smit Myles and Jack Southwick

Discusses characteristics of AS and their impact upon behavior and etc. provides solutions for parents

Asperger Syndrome and Sensory Issues - Practical Solutions for Making Sense of the World - by Brenda Smit Myles, Katherine Tapscott Cook, Nancy E. Miller, Louann Rinner, and Lisa A. Robbins

Covers the impact of the sensory system on behavior and reviews relevant formal and informal assessment as well as interventions.

Right Address, Wrong Planet - Children with Asperger Syndrome Becoming Adults - by Gena Barnhill

A mother writes this book in the perspective of her son, Brent with Asperger Syndrome

Asperger's Syndrome - Crossing the Bridge - Liann Holliday Willey and Tony Attwood

A book that focuses upon life of Lian Holliday Willey and her life with Asperger's

Social Skills/Relationships

Relationship Development Intervention with Young Children: Social and Emotional Development Activities for Asperger Syndrome, Autism, PDD and NLD

- By Steven E. Gutstein, Rachelle K. Sheely

Autism/Asperger's: Solving the Relationship Puzzle - By Steven Gutstein

A ground-breaking developmental program that opens the door to lifelong social & emotional growth for persons with Autism, Aspergers', PDD.

Navigating the Social World - By Carol Gray

Curriculum for educating individual with Autism/Asperger's and high-functioning Autism and how to get along in the social world.

Comic Strip Conversations - by Carol Gray

This books contains information on how to write and use comic strip illustrations for intervention purposes

Tobie Learns to Make Friends - by Diane Murrell

Learning how to make friends with social skills delays.

No One to Play with - by Osman

A book to help with social problems

Reaching Out Joining In - by Mary Janie Weiss and Sandra L. Harris

A guide to assist with social skill delays.

Autism & PDD Social Skills Lessons - by Pam Britton Reese & Nena C. Challenner

This set of books provides pictorial stories and with easy reader social stories in many settings

How Rude! The Teenagers Guide to Good Manners, Prop Behavior and Not Crossing People Out - by Alex Packer

Covers the basics of good behavior for teens - very humorous book

Do Watch Listen Say Social and Communication Intervention for Children with Autism - by Kathleen Ann Quill

A book about assessment and ideas to promote social and communication skills

Skillstreaming the Adolescent - by Ellen McGinnis & Arnold P. Goldstein
Discusses teaching an extended curriculum of many skills to adolescents lacking these competencies

Skillstreaming in Childhood - Same authors as above
Lessons that teach children to be socially competent.

Skillstreaming the Elementary School Child - Same authors
Using step by step curriculum

Autism/Asperger's & Sexuality -Puberty and Beyond - By Jerry and Mary Newport
A husband and wife with Asperger's Syndrome give valuable advice to and for teens and adults going through this difficult period.

Siblings of Children with Autism: A Guide for Families - By Sandra Harris
A guide to understanding sibling relationships and how autism affects these relationships.

Hope for Families - by Perske
This book which shows how to overcome fears of families who have special needs children

Living with a Brother or Sister with Special Needs - by Meyer
For siblings of children with special needs

Teaching Playskills to Children with ASD - by Melinda Smith, M.D.

Behavioral Issues

Behavioral Intervention for Young Children - Steven Gutstein and Rachelle K. Sheely
A guide to assist with social delays.

Solving Behavior Problems in Autism - by Linda A. Hodgson
A book packed with strategies guaranteed to provide practical help for educators and parents who face behavior and self-management challenges from students with AS spectrum disorders

Treasure Chest of Behavioral Strategies for Individuals with Autism - by Beth Fouse and Maria Wheeler
A book on behavior strategies that is easy to understand and implement

Temper Tamers - An eight session Anger Management Pull Out Program - by Kathryn Pearson
Advocates helping children manage their anger

Nonaversive Intervention for Behavior Problems - by Meyer

Teaching students with Behavior Disorder - by Gallagher
Textbook teaching techniques and activity ideas

Biomedical/Medicine

Lucy's Story: Autism and other Adventures - A woman with autism tells about her life. - by Lucy Blackman
Biomedical Interventions

Taking the Mystery Out of Medications with Autism - by Luke Tsai M.D.
A guide for parent's and professionals.

Children with Starving Brains - A Medical Treatment Guide - by Jacquelyn McCandless
Takes the mystery out of medical interventions with Autism.

Biological Treatments for Autism and PDD - by William, Ph.D. Shaw

Detoxification and Healing - by Sidney Baker

Heal your Heartburn - by Sherry Rogers

Taking the Mystery out of Medication in Autism/Asperger Syndrome - by Luke Tsai
Provides information that educates you to respond with knowledge to judgments offered by physicians

Straight Talk About Psychiatric Medications for Kids - by Timothy Wilens, M.D.

What Your Doctor May Not Tell You About Childhood Vaccinations - by Stephanie Cave, M.D.

Special Education Instruction/Law

Don't Shoot the Dog - by Karen Pryor
The new art of teaching and training.

CoTeaching Students with Autism - by Judi Kenney and Debbi Fischer
Tips from teachers

How to be a Para Pro - by Diane Twachtman-Cullen
A training manual on autism and ways to direct academic, social, play and etc.

Inclusive Programming for Elementary Students with Autism - by Sheila Wagner
Offers benefits of inclusion exercises and programs that make inclusion a comfortable process

Inclusive Programming for Middle School Students with Autism - by Sheila Wagner
Same as above except for middle school students.

Incorporating Social Goals in the Classroom - by Rebecca Moyes
Provides practical , hands on strategies to writing IEP goals to these students in areas of social deficits. Lesson plans are included

Pyramid Approach to Education - Lesson Plans for Young Children - by Randy Bondy, Kate Dickey, Diane Black, and Sarah Buswell

Achieving the Complete School - by Biklen
Examines principles and strategies for successful mainstreaming of students

Beyond Separate Education - by Lipsky
Collection of articles on special education and mainstreaming

Chances and Choices - by Fullwood
A book on making integration work

Comprehensive Local School - by Sailor
A guide for getting all students education in local public schools

Guide for Educating Mainstreamed Students - by Mann

I Make a Difference - by Tamaren
A curriculum guide for building self-esteem and sensitivity in the classroom

Instructional Planning for Exceptional Children - by Meyen
Filled with essays

Learning Games for Exceptional Children - by Wedemeyer
150 activities for teaching children K-6

Children with Special Needs in Early Childhood Settings - by Paasche
Basic information for educators concerned with early intervention

Early Intervention for Handicapped and At-Risk Children - by Peterson
A textbook for educators who work with handicapped kids

Implementing Early Intervention - by Tingey
Basic for development of intervention in early education

Preschool Provision for Children with Special Needs - by Robson

Unlocking Potential - by Scheiber

Advice about Post-secondary disabled child

The Sixth Sense I and II - By Carol Gray

Explains autism and Asperger's to inclusive classrooms.

Better IEPs - Barbara Bateman

Discusses writing of IEPs

Creating a Win-Win IEP For Students with Autism - by Beth Fouse

Wrightslaw: Special Education Law - by Peter W. D. Wright, Pamela Darr Wright

Wrightslaw: From Emotions to Advocacy - The Special Education Survival Guide

- by Peter W. D. Wright, Pamela Darr Wright

Dictionary of Special Education and Rehabilitation - by Vergason

Due Process in Special Education - by Budoff

Parents rights in special education

Exceptional Children in Today' School - by Meyen

Sensory Integration

Unlocking the Mysteries of Sensory Dysfunction - by Elizabeth Anderson and Pauline Emmons

A book to read about Sensory Dysfunction.

The Out of Sync Child - by Carol Stock Kranowitz

A guide to dealing with sensory issues with your child.

The Out-of-Sync Child Has Fun - by Carol Stock Kranowitz

Answers to Questions Teachers ask about Sensory Integration - by Carol Stock Kranowitz and Stacey Szklut and others

Contains helpful information for teacher and those who work with special kids

Applied Behavioral Analysis

Behavioral Intervention for Young Children with Autism - By Catherine Maurice

Parents' Education as Autism Therapists - Applied Behavior Analysis in Context
- by Mickey Keenan, Ken P. Kerr, and Karola Dillenburger
Useful introduction to ABA

When Everybody Cares: Case Studies of ABA with People with Autism - by Bobby Newman

Raising a Child with Autism: A Guide to Applied Behavior Analysis for Parents -
By Shira Richman

Applied Verbal Behavior

Assessment of Basic Language and Learning Skills - by James Partington and Mark Sundberg
Assesses language and learning skills with those with Autism

Teaching Verbal Behavior: An Introduction to Parents Teaching Language - by Dr. James Partington. VIDEO - 50 minutes
Dr. Partington follows the first 10 months of a child's program, describing the processes in affect in detail.

A Collection of Reprints on Verbal Behavior - by Drs. Mark Sundberg and Jack Michael.
Research and analyses published by Sundberg and/or Michael and their collaborators over the past 15 years in journals such as The Analysis of Verbal Behavior, JEAB, JABA, Behaviorism, and The Behavior Analyst.

Visual Supports

The Picture Exchange Communication System Training Manual - Second Edition -
by Lori Frost, MS, CCC/SLP and Dr. Andrew Bondy

Visual Recipes - A Cookbook for Nonreaders - by Tabitha Orth
Addresses the needs of young children with disabilities.

Begin Where They are - by Nurek and Wendelburg
Activity book to develop and improve visual skills for those with Autism

Making Visual Supports Work in Home and Community: Strategies for Individuals with Autism and Asperger's - by Jennifer Savner and Brenda Smith Myles

Pics for PECS - Colorful Symbols for Visual Communication - Illustrated by Rayna Bondy with vocabulary by Lori Frost

Activity Schedules for Children with Autism - Teaching Independent Behavior - by Lynn E. McClannahan and Patricia Krantz

Discusses what is necessary in order to develop successful activity schedules

Visual Strategies for Improving Communication - by Linda Hodgdon

Focuses upon a child's learning style with charts, pictures, and visual schedules

Language

Teach me Language - to children with Autism and PDD - by Sabrina Freeman

Just for Kids - Autism - by Martha Drake

Discusses activities that foster receptive, expressive and social language development.

Speech and Language - by Thomas

Addresses specific problems and how to correct and provide intervention

Teaching Language-Disabled Children - by Conant

A description of Communication games that help children with language

Oral Language Activities for Special Children - by Mannix

Over 100 worksheets on problem-solving, conversational skills, communication skills.

General Information

Autistic Children: a Guide for Parents & Professionals - by Lorna Wing

A guide for parents, educators, and physicians which shows how an autistic child see his/her world. Reviews the behavioral and emotional problems of Autism.

The ADHD-Autism Connection - by Diane Kennedy

Children with Autism-A Parent's Guide - by Michael D. Powers

Covers areas of special concern to parents. It provides up to date information regarding Autism.

Special Children, Challenged Parents - by Robert Naseef, Ph.D.

Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders - By Eric Schopler

Over 300 anecdotes from parents of autistic and developmentally disabled children and it discusses many problem-solving solutions.

More Than Words - By Fern Sussman

Contains information about autism and various techniques to assist you with intervention.

The Primer for Parents - by Abby Ward Collins

An easy, concise book covering the basics.

Pervasive Developmental Disorders: Finding a Diagnosis and Getting Help

- by Mitzi Waltz

Offers practical, understandable and balanced covering of diagnosis, treatment approaches, and medications

Laying Community Foundations for your Child with a Disability - by Linda J. Stengle

The future starts now - a practical guide to establish network of support for you and your child

ADHD Autism Connection - by Diane M. Kennedy

Looks at the possibility of a connection between the 2 disorders.

Autism & PDD Concept Development - by Pam Britton Reese & Nena C. Challenner

This book presents certain concept themes and assist with comprehension and generalization issues

Targeting Autism - by Shirley Cohen

Discusses everything about Autism

Autism Treatment Guide - by Elizabeth King Gerlach

Gives you the latest Autism resources.

The Power of Positive Parenting - by Dr. Glenn Latham

A guide to parenting in a positive manner.

Working Together for a Brighter Future - by Marilyn F. Hays

How to educate high-functioning students with autism.

The Language of Toys - by Schwartz

Discusses how to use toy to teach communication

Misc

Developing Leisure Time Skills for Person with Autism - By Phyllis Coyne, Colleen Nyberg, and Marylou Vandenburg
Discusses the challenges of finding and encouraging leisure time activities - discusses how to teach this skill.

Laughing and Loving with Autism - by Wayne Gilpin
A humorous look at the different perspectives people with autism offer.

Toilet Training for Individuals with Autism and Related Disorders - by Maria Wheeler
A guide through the special difficulties associated when toilet training a special needs child.

Toilet Training for Individuals with Autism and Related Disorders - by Maria Wheeler
200 tips and more than 40 case examples

Too Smart for Bullies - by Robert Kahn
Learn how to deal with bullies

The Wounded Spirit - by Frank Perretti
A wonderful book about bullying problems in schools and how to prevent it. It talks to parents, teachers, and also offers helpful advice to victims, offers advice to other youth about helping the underdog

500 Five Minute Games - By Jackie Silberg
Games to teach and play with your child

Taking Autism to School - by Adreanna Edwards
For children 5 to 10, it promotes understanding of children with autism

Everything you need to know when a brother or a sister has Autism - by Marsha Sarah Rodenberg
For middle and upper elementary students - a guide and information

Everybody is Different - by Fiona Bleach
A book for young people who have siblings with Autism

Clinical Practice Guidelines - Redefining the Standards of Care for Infants, Children, and Families with Special Needs - by Unicorn Children's Foundation
Answers questions to the most challenging developmental disorders which include autism - discusses in clinical depth and detail

Play and Imagination in Children with Autism - by Pamela J. Wolfberg
Discusses how to bring about pretend play and imagination in children with Autism

Psychiatry of Handicapped Children and Adolescents - by Gerring

Computers, Education, & Special Needs - by Goldenberg

Introduction to computer use by people with special needs

Helping Children Overcome Learning Difficulties - by Rosner

An instructional program to help children learn specific perceptual and motor skills

Right from the Start - by Sandra Harris and Mary Jane Weiss

Short, easy to read guide for harried parents about their child with Autism

NEWSLETTERS

****Prices for printed newsletters may have changed. If interested, contact the publisher for current prices.*

Jenison Autism Journal : Creative Ideas in Practice - ed

By Carol Gray - creator of social stories. Articles by experts focusing upon play, social skills, bullying and practical concerns. Includes a penpal registry \$20 per year

The Gray Center, 2020 Raybrook SE, Suite 101, Grand Rapids, MI 49546

Phone: 616-954-9747, Fax: 616-954-9749,

The MAAP

A quarterly newsletter for families of more advanced individuals with autism, Asperger's and PDD- NOS, ed. By Susan Moreno - articles by and about people with autism. \$22

per year Maap Services, Inc. , PO Box 524, Crown Point, IN 46308. 219-662-1311

Fax 219-662-0638

Autism/Asperger's Digest

Excellent articles by experts from USA and around the world. \$49.95 per year. Future Horizons, 721 W. Abram Street, Arlington, TX 76013

Autism Resource Network

Quarterly newsletter - 5123 Westmill Rd, Minnetonka, MN 55445 phone 612-988-0088

Autism Research Review

Published by Bernard Rimland - 4182 Adams Ave, San Diego, CA 92116 Phone 612-281-7165

Advocate

National Newsletter of the Autism Society of America

2200 S. Main St. Suite 317, Lombard, IL 61048

Peak Parent Center

Provides curriculum and Materials focused upon disabilities

PEAK Parent Center, Inc. 6055 Lehman Drive Suite 101 Colorado Springs, Co 80918

Exceptional Parent

Monthly publication of parents with children with special needs
To subscribe 1-800 562 -1973

Different Roads to Learning

Catalog full of stuff useful to parents of special needs children
To order 1-800-853-1057

The Morning News

Jenison Public Schools 2140 Bauer Rd Jenison, MI 49428

Family Resource Center on Disabilities

20 E. Jackson Blvd #900, Chicago, IL 60604, 312-939-3513

The Indiana Resource Center for Autism Training Sourcebook

Contact 812 -855-6508

Indiana Resource Center for Autism, Indiana University, 2853 East Tenth St,
Bloomington, IN 47408-2601

Focus on Autistic Behavior - Teaching Functional Social Skills to Children with Autism- Published by Aspen Publishers Inc - 1600 Research Blvd, Rockville, MN 20850

Autism Research Review International

Autism Research Institute, 4182 Adams Ave, San Diego, CA 92116

Effective Special Services Management - monthly newsletter dedicated to improving the management skills administrators responsible for ensuring cost effective and quality services to those with special needs. Contact: National Professionals Resources, Inc. Dept B2 25 S. Regent St. Port Chester, NY 10573

Inclusive Education Programs: Advice on Education Students with Disabilities in Regular Settings, contact: LRP Publications 747 Dresher Rd, Suite 500 PO Box 980 Horsham, PA 19044-0980 Phone # 1-800-341-0272 or fax 215-784-9639

Teaching Exceptional Children and Exceptional Children, Contact: Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589, Phone #703-264-8955, out of state 1-800-328-0272

Pro Ed Journals 8700 Shoal Creek Blvd, Austin, TX 78757-6897 Phone # 512-451-3246 or fax 512-451-8542

Research Journals

Journal of the American Medical Association (JAMA)

<http://jama.ama-assn.org/>

New England Journal of Medicine

<http://content.nejm.org/>

Education

American Journal of Education - <http://www.journals.uchicago.edu/AJE/>

AJE, quarterly, encourages a dialogue between educational scholars and practitioners. From the University of Chicago Press.

Beyond Behavior - <http://www.beyondbehavior.com>

The CCBD practitioner journal, published three times each year. The purpose of this journal is to publish material of special relevance to teachers and other practitioners working with students with emotional and behavioral disorders.

Contemporary Educational Psychology

- <http://www.idealibrary.com/servlet/useragent?func=showAllIssues&curlIssueID=ceps>

Author information, subscription details and online access for subscribers for this journal which publishes articles covering the application of psychological theory and science to the educational process.

Current Issues in Education - <http://cie.ed.asu.edu/>

A peer-reviewed scholarly journal available in full text without cost. Published by the College of Education at Arizona State University.

Psychology - Behavior Analysis

The Analysis of Verbal Behavior - <http://www.wmich.edu/aba/avb.html>

Primarily for the original publication of papers relevant to a behavioral analysis of verbal behavior.

Behavioral Technology Today -

http://www.behavior.org/journals_BTT/BTT_index.cfm

Web-based journal about the application of the results of behavioral research to problems of general public concern. Written for understandability.

Journal of Applied Behavior Analysis -

<http://www.envmed.rochester.edu/wwwrap/behavior/jaba/jabahome.htm>

Psychology journal that publishes research about applications of Behavior Analysis to problems of social importance.

Journal of the Experimental Analysis of Behavior -

<http://www.envmed.rochester.edu/wwwrap/behavior/jeab/jeabhome.htm>

JEAB is a psychology journal primarily for the original publication of experiments relevant to the behavior of individual organisms. It also publishes reviews and book reports.

Psychology - Child Psychology

Child and Family Behavior Therapy -

<http://www.haworthpressinc.com/store/product.asp?sku=J019>

Scholarly articles concerning behavior therapy for children and adolescents. Empirical research, case studies and book reviews.

Clinical Child Psychology and Psychiatry -

<http://www.sagepub.co.uk:80/frame.html?http%3A//www.sagepub.co.uk/journals/details/jc0063.html>

Journal listings, with abstracts for each article.

Contemporary Issues in Early Childhood - <http://www.triangle.co.uk/ciec/index.htm>

Online international journal publishes research reports, book reviews and commentaries.

Developmental Psychology - <http://www.apa.org/journals/dev.html>

Print journal of empirical research about human development across the lifespan.

Journal of Pediatric Psychology - <http://jpepsy.oupjournals.org/>

Publishes theory, research and professional practice articles exploring the relationships between the psychological and physical well-being of children, adolescents and families.

Cognitive Psychology - <http://www.sciencedirect.com/science/journal/00100285>

Empirical, theoretical, and tutorial papers, methodological articles, and critical reviews concerned with advances in the study of memory, language processing, perception, problem solving, and thinking.

Cognitive Science - <http://www.umich.edu/~cogsci/about.html>

The official journal of the Cognitive Science Society

Developmental Review: Perspectives in Behavior and Cognition -

<http://www.idealibrary.com/links/toc/drev>

Journal provides child and developmental, child clinical, and educational psychologists with articles that reflect current thinking and cover scientific developments.

Child Neuropsychology - <http://www.szp.swets.nl/szp/journals/cn.htm>

Journal covering neuropsychological dimensions of development in childhood and adolescence.

CHAPTER 12

HOW TO KEEP SANE

The information and resources contained in the Nebraska Autism Parent Booklet are for educational and informational purposes only. Information provided through this Booklet should not be used as a substitute for care by a qualified Developmental Pediatrician, Pediatric Neurologist, Behavioral Psychologist, Behavior Analyst, Speech and Language Pathologist, Attorney, or other appropriate professional.

A Few Words Of Advice

(From the Autism Society of Illinois - Harrisburg)
(Reprinted with permission)

Before starting your research for available resources and services, listen to what parents of children with disabilities suggest.

Parents who have been there say that locating the information and services their child requires can be confusing and time consuming. To start, it's difficult to figure out where, exactly, to begin. Then, there's knowing the right questions to ask.

First, work closely with your health care provider. Second, check the information in the Resources Chapter carefully. Finally, be certain to include the following key information when calling for information about services:

- * Your child's age;
- * Your child's diagnosis or your main concern, and
- * Where you live (city and county).

Now, with all that in mind, this is what parents of children with developmental disabilities advise.

BE PERSISTENT

It's about not giving up....about asking lots of questions. Why? Because it's your child. You simply can't quit. Here's what parents advise.

- * Keep calling...keep asking questions (there are no unimportant questions.);
- * Ask everyone you talk with for the names and telephone numbers of other people or organizations you can contact.
- * If the recorded voice information seems confusing with it. Staying on the telephone line will often get you connected with a person, and
- * Written requests and/or e-mail sometimes result in better and more timely responses.

TAKE AND KEEP NOTES

It's important to get organized. When you call an agency, write down the date and time of the call, who you talk with and what the conversation is about. You are going to need that information at some point and you'll need to remember the important points.

Keep track of:

- * The agency's or organization's name;
- * The name of the person you talk with and their telephone number;
- * Important information you receive;
- * What you and they agree to do - and by what date, and;
- * Other people, agencies, and/or organizations to contact.

EDUCATE YOURSELF

As a parent, you need to enhance your-self. You need to learn all you can about your child's disability. To better understand your child's disability;

- * Check with your doctors, the local library, other parents or the Internet for articles or other informational materials, and;
- * Be certain the information you gather is accurate and up-to-date.

LEARN THE LANGUAGE

Realize that you need to possess the 'right language' to know how to ask the 'right questions'. To get the appropriate care and services, you need to know the 'buzz' words and acronyms (abbreviations). Listen carefully to the words and abbreviations people with government agencies and not-for-profit organizations throw at you during the course of conversation.

- * Ask about any words or abbreviations you don't understand;
- * Write the words or abbreviations down. Then write down what the words or abbreviations mean (if necessary, have the person you're talking with spell it all out and give you an exact definition), and;
- * Practice using these words and/or abbreviations in your conversations.

LOOK TO OTHER PARENTS

Your greatest resource is other parents of children with a developmental disability. Among the very first things you should do is make connections with other parents. No one can better relate to your situation than the parents of a child in a similar situation than the parents of a child with a similar situation or disability.

Parents recommend that you:

- * Find a support group near you;
- * Ask your child's health care providers, teachers and other professionals if they can help connect you with other families who have a child with the same diagnosis or similar needs;
- * If you don't find someone at first contact, keep trying. Connecting with other parents can give you energy, and;
- * Make contact with such parent-to-parent organizations as the Ollie Webb Center and the Parent Training and Information Center (PTI).

SHARE WHAT YOU LEARN

Because your child's disability is something you have to deal with on a daily basis, you need to know as much or more about your child's condition than your doctor or the many health care professionals you'll encounter. Equally important, share the knowledge you have acquired. Everyone benefits when knowledge is exchanged.

It is especially important that you:

- * Tell the people you contact how they've helped you;
- * Call back if you discover a great resource they don't know about, and;
- * Pass what you learn on to other parents

Ways To Keep Sane

(A few pointers from parents in the trenches)

There are many ways that I have chosen to help myself to keep sane during this journey. Here are some examples, exercise, mediate, reading - everything you can get your hands on, stay educated, see a therapist, join a support group, become an advocate, consult your clergy and try and deepen your faith, join a statewide or national group to stay involved and for support, assist in any research project which has to do with autism, educate others - speak in public, respite care, hire a staff to come and help you with your child, find a hobby, find sometime each week to be by yourself and finally, let yourself cry!! You need to grieve and you will grieve sometimes more than other times, but let yourself do that so you can stay sane. Your child needs you and you have to take care of yourself so that you can take care of them.

- Jennifer

To reduce stress when I'm having a particularly bad day, I find it most helpful to call a friend (who understands what I'm going through) and either just talk with her or better yet, go out someplace to have fun. Go someplace that you really enjoy - - get some physical exercise or find something to laugh about. Laughter is the best remedy! Look at your life and the things that have happened with a little comedy. Try not to take things so seriously. (I realize that's not so easy at times) but don't dwell on how bad things are or how miserable you think your life may be. Get a group of parents together and talk about all the things that your children have done - - it can be very amusing! Remember, you're not alone. When my son was younger and I was feeling like things weren't going very well or he wasn't making much progress, I would look back at where he was when he was younger and I could see the tremendous strides he's made. Sometimes you have to remind yourself of the progress your child has made and appreciate how far he's come. Give yourself break! Take one day at a timeand laugh!

- Roxanne

When first facing the world of autism, it seems incredibly overwhelming and it can be but know that many parents have gone through and faced many of the same challenges that you find yourself facing now. Take a deep breath, get out a clean notebook, pick up the phone and start calling. Among your greatest resources by far will be other parents. Not only will you find information on resources, therapies, and opinions to be considered, but you'll have access to a group of people who understand better than anyone what you're going through because they've already walked in your shoes. In a world where, frankly, the world doesn't comprehend living with autism day in and day out, it's refreshing to have other parents to call and have an *understanding* shoulder to cry on. Keep those names, numbers, and e-mails in your book and don't be afraid to ask questions.

Educating yourself is also key and there is a lot to know. Keep a list of anyone who's willing to teach you more. Surf the Internet, talk to parents/professionals, read books and keep both an open mind and question everything. Research into autism is in it's infancy and there is no known cause at this time and while there are a lot of theories, there is no one, accepted cause. One thing you'll find out early on is that there are as many differing opinions on autism as there are people affected by this condition. It's left, in large part, up to parents to weed through the anecdotal evidence to find what may work for their child.

Given that our children can be very different and respond to different approaches differently, it's important to consider what I call the 'shopping care method'. Take what you consider parts of a program/therapy that will work for your child and adapt it into your child's overall program. If you have a main therapy, you may want to consider bringing in additional therapies as a supplement. No one program will work for every child nor for every child's needs. Bring up to date on current therapies is important as well as knowing who to go to when you're ready to try something new. Modification is a constant.

Keep organized. It will be time consuming in the beginning but it will save you from a lot of frustration further down the line. Under this topic I also address us 'non-routine' folks. One of the most important things for our kids (and for typical kids as well) is routine. Children with autism do better overall when they know what's expected of them and what's coming up next. Setting up routines and schedules around the house can help make life easier. As our children tend to be visual learners, PECs, visual schedules, social stories, and books on routines as well as various kinds of reward systems can be very beneficial. For those of us who are 'non-structured' (myself included), my advice is to just buckle down and do it. The benefits will far outweigh the aggravation of dealing with a system that doesn't conform to your personality. The goal is less family strife.

Take time for yourself. The demands of a family can be draining, the demands of a family with a special needs child will cause burn out. Take time for yourself to get away from the stress whenever possible. Allow time for you to relax, enjoy a hobby, read a book that has nothing to do with autism, listen to music, watch comedy shows, arrange for respite if possible, take a bubble bath, or go out on a date with your spouse. Many parents also find the need to go through grieving. Allow yourself this necessary process. It's not selfish. If you need to work through issues with a therapist, don't deny yourself the very real need. This may take work but it's well worth it. A happy homemaker makes for a happy home. Cliché but very, very true.

Don't try to do everything yourself or all at once. Coordinate between school and other therapists to work on goals that need to be addressed. Those of us with other children, or where both parents work outside the home, time is often limited and it may feel like all the expectations are impossible to meet. Trust me, it will get better. And in the meantime, if all you can take on is one or two issues at home, take them on with *consistency*. Get them ingrained into family life until it becomes a habit and then move onto other issues. Try to be the manager of your child's program without trying to do all the work or burnout will quickly ensure.

By Connie

The Twelve Commandments for Parents and Children with Disabilities

1. Thou shalt be thy child's best and most consistent advocate.
2. Thou shalt share your valuable information about your child with the professionals who need your input.
3. Thou shalt put it in writing and keep a copy.
4. Thou shalt try to resolve problems at the lowest level but not hesitate to contact a higher authority if a problem is not resolved.
5. Thou shalt keep records.
6. Thou shalt seek out information when needed.
7. Thou shalt take time to think through information before making a decision.
8. Thou shalt have permission to be less than perfect. Important lessons are learned from both successes and failures.
9. Thou shalt not become a martyr. Decide to take a break now and then.
10. Thou shalt maintain a sense of humor. It is great for your emotional well being and that of your child.
11. Thou shalt always remember to tell people when they are doing a good job.
12. Thou shalt encourage thy child to make decisions, because one day he or she will need to do so.

By Virginia Richardson. Source: The Greater Rochester Attention Deficit Disorder Association

WELCOME TO HOLLAND

by Emily Perl Kingsley.

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

The Special Mother by Erma Bombeck

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit.

This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen?

Somehow I visualize God hovering over earth selecting his instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

"Armstrong, Beth; son. Patron saint...give her Gerard. He's used to profanity."

"Forrest, Marjorie; daughter. Patron saint, Cecelia."

"Rutledge, Carrie; twins. Patron saint, Matthew."

Finally He passes a name to an angel and smiles, "Give her a handicapped child."

The angel is curious. "Why this one God? She's so happy."

"Exactly," smiles God, "Could I give a handicapped child to a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel.

"I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she'll handle it."

"I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I'm going to give her has her own world. She has to make her live in her world and that's not going to be easy."

"But, Lord, I don't think she even believes in you." God smiles, "No matter, I can fix that. This one is perfect - she has just enough selfishness." The angel gasps - "selfishness? is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a 'spoken word'. She will consider a "step" ordinary. When her child says 'Momma' for the first time, she will be present at a miracle, and will know it!"

"I will permit her to see clearly the things I see...ignorance, cruelty, prejudice....and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life, because she is doing My work as surely as if she is here by My side".

"And what about her Patron saint?" asks the angel, his pen poised in mid-air.

God smiles, "A mirror will suffice."

The Mountain

by Jim Stovall
(circa 1997)

There were two warring tribes in the Andes, one that lived in the lowlands and the other high in the mountains. The mountain people invaded the lowlanders one day, and as part of their plundering of the people, they kidnapped a baby of one of the lowlander families and took the infant with them back up into the mountains.

The lowlanders didn't know how to climb the mountain. They didn't know any of the trails that the mountain people used, and they didn't know where to find the mountain people or how to track them in the steep terrain.

Even so, they sent out their best party of fighting men to climb the mountain and bring the baby home.

The men tried first one method of climbing and then another. They tried one trail and then another. After several days of effort, however, they had climbed only several hundred feet.

Feeling hopeless and helpless, the lowlander men decided that the cause was lost, and they prepared to return to their village below.

As they were packing their gear for the descent they saw the baby's mother walking toward them. They realized that she was coming DOWN the mountain that they hadn't figured out how to climb.

And then they saw that she had the baby strapped to her back. HOW COULD THAT BE?

One man greeted her and said, "We couldn't climb this mountain. How did you do this when we, the strongest and most able men in the village couldn't do it?"

She shrugged her shoulders and said, "It wasn't your baby."

CHAPTER 13

SPECIAL EDUCATION ABBREVIATIONS AND DEFINITIONS

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Special Education Abbreviations and Definitions

AAC: Assistive Augmentative Communication. A speech-language therapists' term for communication using a picture board or recorded messages activated by buttons, etc.

AB: Adaptive Behavior. The ability to adjust to new environments, tasks, objects, and people and to apply new skills to those new situations.

ABA: Applied Behavior Analysis. A method of teaching designed to analyze and change behavior in a precisely measurable and accountable manner. Also called behavior modification.

ABC: Autism Behavior Checklist. Diagnostic device for autism.

ADA: Americans with Disabilities Act. A civil rights law passed in 1990 that does not allow discrimination against people with disabilities in employment, public service, and public accommodations.

Adaptive Development - development of the child in comparison to other children the same age. This might include the child's ability to dress himself, feed himself, toilet training, how he/she plays with other children, how he/she plays along, understanding dangers in crossing the street, how he/she behaves if mother leaves the room, etc.

ADD: Attention Deficit Disorder.

ADHD: Attention Deficit Hyperactivity Disorder. Student exhibits poor attention, distractibility, impulsivity, and hyperactivity.

ADI-R: Autism Diagnostic Interview - Revised. A diagnostic scale for autism being developed by the Medical Research Council in London. Fairly technical: more precise than CARS.

ADOS: Autism Diagnostic Observation Scale.

Advocate - someone who takes action to help someone else (as in "educational advocate"); also, to take action on someone's behalf.

Age norms - the average performance of an individual in various age groups

AIT: Auditory Integration Training. Developed by Dr. Guy Berard, an Ear, Nose and Throat physician, to rehabilitate disorders of the auditory system, such as hearing loss.

Annual goals - yearly goals documented in the Individualized Education Plan

AOS: Apraxia of Speech. An oral motor disorder characterized by disordered speech.

APE: Adaptive Physical Education. A related service; an individual program of developmental activities, games, sports and rhythms suited to the interests, capacities, and limitations of students with disabilities who may not safely or successfully engage in unrestricted participation in the vigorous activities of the general physical education program.

Aphasia - loss of ability to use or understand words.

Apraxia - a neurologically-based disorder which occurs in adults, often (but not exclusively) as a consequence of stroke. The person has difficult sequencing movements in the service of a goal. e.g., he may have the ability to raise his arm and to wave his hand, but not when he consciously intends to do so. Apraxia may be specific to speech (e.g., "apraxia of speech") or to the movement of other body parts (e.g., "limb apraxia").

ARC: Association of Retarded Citizens, formally known as Association for Retarded Citizens

ARI: Autism Research Institute

Articulation disorders - difficulty with the production of speech sounds

AS: Asperger's Syndrome

ASA: Autism Society of America

ASD: Autism Spectrum Disorders

ASHA: American Speech-Language Hearing Association. A credentialing association for speech-language pathologists.

ASL: American Sign Language most common sign language for deaf adults in North America. It has its own grammar.

Assessment - a collecting and bringing together of information about a child's needs, which may include social, psychological, and educational evaluations used to determine services.

Assessment Plan - the description of the battery of tests (psychological, achievement, language, etc.) to be used in a particular student's assessment.

Assessment Team - a team of people from different backgrounds who observe and test a child to determine his or her strengths and weaknesses.

AT: Assistive Technology

Atypical autism - A general term for conditions that are close to but don't quite fit the set of conditions or autism or other specific conditions. See "PDD-NOS" under "".

Auditory discrimination - the ability to detect differences in sounds

Auditory Processing - the ability to understand and use information that is heard, both words as well as other non-verbal sounds.

Augmentative communication - special devices that provide an alternative for spoken language

Autism - a disability; characterized by severe language and communication deficits, lack of normal relatedness, bizarre movement and self-stimulatory patterns, lack of normal handling of toys and other objects, and lack of most normal functional skills.

Autistic savant - an autistic individual who displays incredible aptitude for one or two skills.

Autistic Spectrum Disorders - Term that encompasses autism and similar disorders. More specifically, the following five disorders listed in DSM-IV: *Autistic Disorder, Aspergers Disorder, PDD-NOS, Childhood Disintegrative Disorder, and Retts Disorder.*

Baseline - the current level the child is functioning at before instruction

BD: Behavior Disorders

BIP: Behavior Intervention Plan

Community Advisory Committee for Special Education (CAC) - a group of parents and professionals, mandated by law, that advises the Board of Education, Superintendent of Schools and school district administration about special education programs and policies.

CAN: Cure Autism Now

CAPD: Central Auditory Processing Disorder. Difficulty understanding and/or processing spoken language, in the absence of hearing loss.

CARS: Childhood Autism Rating Scale. A test developed at TEACCH to diagnose autism. The child is rated in 15 areas on a scale up to 4 yielding a total up to 60, than ranges are considered to be non-autistic, autistic, and severely autistic.

CCD: Consortium for Citizens with Disabilities

CEC: Council for Exceptional Children

CEU: Continuing Education Units

CF or c/f: casien free

CHADD: Children and Adults with Attention-Deficit/Hyperactivity Disorder

CHAT: Checklist for Autism in Toddlers - A checklist to be used by General Practitioners at 18 months to see if a child has Autism. Described in Baron-Cohen S; Allen J; Gillberg C. "Can autism be detected at 18 months? The needle, the haystack, and the CHAT." *British Journal of Psychiatry*, 1992 Dec, 161:839-43. (UI: 93130306)

Chronologically Age-Appropriate - making the activities, behaviors, or settings of a disabled child as similar as possible to those of a non-disabled child of the same age.

Cognitive - a term that describes the process people use for remembering, reasoning, understanding, and using judgment; in special education terms, a cognitive disability refers to difficulty in learning.

Criterion referenced test - child is evaluated according to own performance, not in comparison to others

DAN: Defeat Autism Now

DAN Doctor: a physician who uses the DAN protocol to diagnose autism and attended a DAN conference. A list of DAN doctors can be found at the DAN website.

DAN Protocol: an assessment protocol which examines the underlying disorders causing autism

D/APE: Developmental/Adapted Physical Education

DAS: Developmental Apraxia of Speech. An oral motor disorder characterized by disordered speech. Children who have apraxia of speech due to an unknown cause are referred to as having "developmental apraxia of speech".

DD: Developmental Delay. A child who acquires skills after the expected age

DD: Developmental Disabilities a condition that prevents a child from developing normally and often results in mental retardation or autism

DD ACT: Developmental Disabilities Assistance and Bill of Rights Act

DH: Developmentally Handicapped

Diagnosis - the problem identified after an evaluation

DOE: Department of Education

DREDF: Disability Rights Education and Defense Fund

DSE: Director of Special Education or Division of Special Education

DSI: Dysfunction of Sensory Integration. Ineffective integration of sensory information.

DSM-III, DSM-III-R, & DSM-IV: Diagnostic and Statistical Manual. A manual published by the American Psychiatric Association (APA) which describes all of the diagnostic criteria and the systematic descriptions of various mental disorders.

DTT: Discrete Trial Training - (Note: it's also been referred to as "Discrete Trial Therapy" and "Discrete Trial Teaching") Term has been applied to Lovaas's ABA-based method for treating autistic children, and been used as a term for the "drilling" aspect of ABA. The term is also often used in a less specific way, as a synonym for ABA.

Due Process Hearing - A term for a hearing at which parents have the opportunity to show that the school district is not properly educating their child

DVD: Developmental Verbal Dyspraxia. Developmental verbal dyspraxia is, for most practical purposes, synonymous with developmental apraxia of speech. It is an oral motor disorder characterized by disordered speech.

DX: Diagnosis

Dyslexia - Learning disability affecting reading ability. Persons with dyslexia may have difficulty remembering, recognizing, and or reversing written letters, numbers, and words, might read backwards, and have poor handwriting

Dyspraxia - Term for a neurological symptom: a problem with "praxis", i.e. planning, initiating, sequencing, and carrying out volitional movements. I think "dyspraxia" and "apraxia" mean the same thing, having been coined in different professional circles. See the variants of apraxia and dyspraxia under "".

Dysfluency - a break in the smooth flow of speech, stuttering

Dyslexia - learning disability which impairs the child's reading ability

EC: Early Childhood

ECE: Early Childhood Education

Echolalia - Repeating back something said to you. Delayed Echolalia is repeating it later. Both behaviors are found in many autistics. Functional echolalia is using a quoted phrase in a way that has shared meaning, for example, a child who sings the Barney jingle to ask for a Barney videotape, or says "Get your shoes and socks" to ask to go outside.

ECSE: Early Childhood Special Education

ECSU: Educational Cooperative Service Unit

Early intervention services - identifying and treating children before the age of 3

EEG: Electroencephalogram. A test consisting of recording brainwaves as picked up by electrodes. It is used to identify seizures. It is also used to differentiate LKS from other disorders in with autistic symptoms.

EI: Early Intervention

Early Intervention Services - programs or services designed to identify and treat a developmental problem as early as possible, before age 3 (services for 3-5 year olds are referred to as preschool services)

EKG: Electrocardiogram

ELAP: Early Learning Accomplishment Profile. Evaluation checklist for children used by some professionals

ERIC: Educational Resources Information Center

ESY: Extended School Year

Expressive Language - the ability to use gestures, words, and written symbols to communicate.

Extinction - A procedure in which reinforcement of a previously reinforced behavior is withheld.

FAB: Functional Analysis of Behavior

FAPE: Free Appropriate Public Education. A requirement that all school-aged children (up to age 21) despite having a disability, be provided services in the public school system

FBA: Functional Behavioral Assessment

FC or f/c: Facilitated Communication

FEAT: Families for Early Autism Treatment

FERPA: Family Educational Rights and Privacy Act of 1974 (P.L. 93-380)

Fine motor - relating to the use of the small muscles of the body, such as those of the hands, feet, fingers and toes.

Fragile X Syndrome - A genetic condition in which one part of the X-chromosome has a defect. The condition causes mental retardation.

GARS: Gilliam Autism Rating Scale

GF or g/f: Gluten Free

GF/CF: Gluten-Free/Casein-Free diet (wheat and dairy)

Gross motor - relating to the use of the large muscles of the body.

HHS: Health and Human Services

Hyperlexyia - Ability to read at an early age, but often without linking the words to what they words mean.

IDEA: Individuals with Disabilities Education Act. Federal legislation (Public Law 105-17) passed in 1997 as a reauthorization of the Education of the Handicapped Act (EHA) passed in 1975. Provides mandate and some funding for certain services for students who have disabilities.

IEE: Independent Education Evaluation If a parent believes a school has not properly evaluated his/her child, the parent is entitled to an IEE at school's expense under certain circumstances.

IEP: Individualized Education Plan a yearly education plan written by teachers, therapists, psychologists, etc. and the child's parents for school age children with disabilities for someone who needs special education. The IEP addresses the student's needs and the educational supports and services required to meet those needs.

IFSP: Individualized Family Service Plan an education plan written by teachers, therapists, psychologists, etc. and the child's parents for a child birth through 2 years old with disabilities

Inclusion - disabled children receive services in their home school and are placed in the same classroom with non-handicapped children

Interdisciplinary team - various individuals from different disciplines that assess children's needs (speech therapist, occupational therapist, nurse, psychologist, etc.)

IPP: Individual Program Plan

IRP: Individual Rehabilitation Plan (Program)

Individual Transition Plan (ITP) - an educational plan designed to facilitate a student's move from one setting to another (e.g. from one classroom or school to another, or from school to work).

Language impairment - difficulty understanding and/or using language

LD: Learning Disabled

LDA: Learning Disability Association

LEA: Local Education Agency. The educational agency that has the financial obligation to see that for each student for which it is responsible receives FAPE.

Learning disability - a child with average or above average potential has difficulty learning in one or more areas (such as reading or math) and exhibits a severe discrepancy between their ability and achievement

LRE: Least Restrictive Environment. A child should be educated in the least restrictive environment for his or her disability and which meets his or her needs. An educational setting which gives students with disabilities a place to learn to the best of their ability and also have contact with children without disabilities

MA: Mental Age. The level of intellectual functioning based on the average for children of the same chronological age

Mainstreaming - Placement of a disabled child with non-disabled peers in a regular classroom. some or all of the child's day is spent in a regular classroom

MDT: Multidisciplinary Evaluation Team. A group of people (including the child's parents) responsible to evaluate abilities and needs of a child referred for evaluation and to determine whether or not the child meets the eligibility criteria.

Mediation: Mediation is a free dispute resolution process available to parents of children with disabilities. If you are in disagreement with the school district, you can ask for mediation. A third party mediator will be assigned to try and help resolve the issues.

MH: Mentally Handicapped

Moderately Mentally Disabled – a disability; having a moderate delay in the ability to learn and to function independently in the everyday environment; a moderate delay is defined as a rate of development and learning 25% to 50% of what is expected of a child the same age.

MR: Mentally Retarded or Mental Retardation

MRI: Magnetic Resonance Imaging. A diagnostic tool in the sense of an X-ray machine or Cat scanner, which like them, creates internal images of the selected parts of the body. Rather than sending X-rays through the body, it builds its image data by testing the magnetism of the body tissue.

NADDCC: National Association of Developmental Disabilities Councils

NAEYC: National Association for the Education of Young Children

NAMI: National Alliance for the Mentally Ill

NARIC: National Rehabilitation Information Center

NCLD: National Council for Learning Disabilities

Neurologist - a physician specializing in medical problems associated with the brain and spinal cord.

Neurotransmitter - the chemical substance between nerve cells in the brain which allows the transmission of an impulse from one nerve to another.

NICHCY: National Information Center for Children and Youth with Disabilities

NIMH: National Institute for Mental Health

Norm referenced tests - a child's performance is compared to others the same age

NPND: National Parent Network on Disabilities

NT: Neurologically Typical. Short for "Neuro-typical" or "Neurotypical". This term is used in discussions of autistic people to refer to people who are not autistic.

Object permanence - the child is aware that an object still exists even when it is taken away

OCD: Obsessive Compulsive Disorder

ODD: Oppositional Defiant Disorder

OHI: Other Health Impaired

Oral motor - relating to the movement of the muscles in and around the mouth.

Orthon-Gillingham: A form of instruction used with children who have dyslexia, Orton-Gillingham is a multi-sensory based form of phonetic instruction that is sequential and systemic in nature.

OSEP: Office of Special Education Programs

OSERS: Office of Special Education and Rehabilitative Services (Federal)

OT: Occupational Therapy or Occupational Therapist. A therapist that focuses on daily living skills, sensory integration, and fine motor skills. An Occupational therapist would provide Sensory Integration Therapy.

PACER: Parent Advocacy Coalition for Educational Rights

PCMR: President's Committee on Mental Retardation

PDD: Pervasive Developmental Disorder. A group of developmental disabilities which are neurological and usually of an unknown origin. Characteristics include reduced ability to understand language, communicate, and interact with others, and a limited variety of activities and interests. Types of pervasive development disorder include autism, Retts Syndrome, Hellers Syndrome, and Aspergers Syndrome.

PDD:NOS: Pervasive Developmental Disorder Not Otherwise Specified

PECS: Picture Exchange Communication System

Perserveration - obsessive-like continued immediate repetition of a behavior.

Pica - ingestion of nonfood items.

PIRC: Parent Information and Resource Center

PLEP: Present Level of Educational Performance

PMR: Profoundly Mentally Retarded

POHI: Physically and Other Health Impaired

PRT: Pivotal Response Training

PT: Physical Therapy/Therapist. Provides evaluation and treatment of physical disabilities to help the person improve the use of bones, muscles, joints, and nerves through exercise and massage

PTI: Parent Training and Information Center

Public Law 94-142 (now called IDEA-Individuals with Education Act) - a law passed in 1975 that requires public schools to provide a free and appropriate public education to school-aged children ages 3-21 regardless of disability

Public Law (P.L.) 102-119, passed in 1991 - an amendment to the Individuals with Disabilities Education Act (IDEA) to provide funds for states to serve infants and toddlers (ages birth through 2 years) with disabilities

Receptive language - the understanding of spoken and written communication as well as gestures

Related services - Other support services that a child with disabilities requires such as transportation, occupational, physical and speech pathology services, interpreters, and medical services etc..

Referral – the request to identify and assess a child’s special education needs; a referral may be made by a parent, teacher, medical personnel, or anyone with specific knowledge of the child.

Reinforcement - providing a pleasant consequence (positive reinforcement) or removing an unpleasant consequence (negative reinforcement) after a behavior in order to increase or maintain that behavior.

Related Services - transportation and developmental, corrective, and other support services that a child with disabilities requires in order to benefit from education; examples of related services include: speech pathology and audiology, psychological services, physical and occupational therapy, recreation, counseling services, interpreters for the hearing impaired, and medical services for diagnostic and evaluation purposes.

Resource room - a room that serves the children’s needs to learn specific skills within the least restrictive environment for part of the day

Respite care - skilled adult or child care and supervision that can be provided in your home or the home of a care-provider. Respite care may be available for several hours per week or for overnight stays.

Reverse Mainstreaming - when non-disabled children go to the special education classroom to play and learn with children who are disabled.

SAT: Student Assistance Team. A group of people utilizing problem solving and intervention strategies to assist the teacher(s) in the provision of general education.

SEAC: Special Education Advisory Committee

Self contained class - a classroom specifically for special education students

Sensorimotor - Pertaining to brain activity other than automatic functions (respiration, circulation, sleep) or cognition. Sensorimotor activity includes voluntary movement and senses like sight touch and hearing.

Service Coordinator - someone who acts as a coordinator of an infant's or toddler's services, working in partnership with the family and providers of special programs; service coordinators may be employed by the early intervention agency.

SI: Sensory Integration: The way in which the brain and the body interpret sensory information.

SI: Speech Impairment

SID: Sensory Integration Dysfunction. Ineffective integration of sensory information.

SIT: Sensory Integration Therapy

SLI: Speech Language Impairment

SLP or S-LP: Speech-Language Pathologist. A person qualified who improves and/or corrects communication problems

Son Rise - The name of a book by Barry Neil Kaufman about his autistic son and the name of a program for treating/educating autistic children that Kaufman started

SPED: Special Education

SRRI: Selective Serotonin Reuptake Inhibitor

SSDI: Social Security Disability Insurance. This money has been paid into the Social Security system through payroll deductions on earnings. Disabled workers are entitled to these benefits. People who become disabled before the age of 22 may collect SSDI under a parent's account, if the parent is retired, disabled, or deceased.

SSI: Supplemental Security Income. This is available for low-income people who are disabled, blind, or aged. SSI is based on need and income, not past earnings paid into the system.

Stereotypy - (stereotypic behavior) - purposeless movement such as hand flapping which are repetitive and odd.

Stim - (e.g. stimming) short for "self-stimulation", a term for behaviors whose sole purpose appears to be to stimulate ones own senses. An example is rocking ones body. Many people with autism report that some 'self stims' may serve a regulatory function for them (ie. calming, adding concentration, shutting out an overwhelming sound). Other examples: hand-flapping, toe-walking, spinning, echolalia.

Tactile - relating to touch

Tactile defensiveness - child overreacts or avoids any kind of touch

TEACCH: Treatment and Education of Autistic and Related Communication Handicapped Children

TOM: Theory of Mind

Transition: Schools are responsible to provide transition services to assist a child with disabilities to successfully access the adult world, through work experiences and/or through postsecondary options and related. Transition services must be individually tailored to the child's needs and skills.

TX: Treatment

Vineland Adaptive Behavior Scales - test sometimes used to evaluate students possibly requiring special education.

Visual discrimination - ability to detect differences in objects, forms, letters or words

Visual memory - the ability to remember visual stimuli by significant features on a short and long term basis

VR: Vocational Rehabilitation

VSA: Very Special Arts

WED: Work-Experience Disadvantaged Program

WEH: Work-Experience Handicapped Program

WEP: Work Experience Program

WISC: Intelligence Scale for Children Wechsler Intelligence Scale for Children (WISC)