

Information about:

Nonverbal Learning Disability (NLD)

Revised 2013



Vermont
Family
Network

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Introduction

Information About Nonverbal Learning Disability (NLD) is part of a series of information packets developed by the Vermont Family Network (VFN). Designed to provide basic information, the packet includes fact sheets, articles, advocacy tips, and resources for families of children with special needs and for the professionals working with them.

After reading the packet, we hope that you'll have a greater understanding of nonverbal learning disability (NLD) and the ways in which parents and professionals can support children at home, in school, and in the community. We've selected information from a variety of sources, and many articles are on the Internet.

Thank you to BEST (Building Effective Strategies for Teaching), Vermont Agency of Education, for making this publication possible. Thanks also to the organizations and authors who gave us permission to use their articles and fact sheets. Use of any specific articles in this packet is meant for information purposes only and doesn't indicate any endorsement on the part of VFN of the views and opinions of the authors.

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Nonverbal Learning Disability

By Gayle Zieman, PhD

What is a nonverbal learning disability?

Children and teens with a nonverbal learning disability (NLD) have poor visual, spatial, and motor skills. They also have trouble recognizing and understanding nonverbal cues such as body language and facial expression.

Children with an NLD usually start out learning to read fairly well. They also have large vocabularies. They tend to have more trouble after second grade.

NLD is the least recognized among the learning disorders. Children with this problem may not be properly diagnosed and may not get the help they need.

What is the cause?

The brain has 2 hemispheres, right and left. NLD is caused mostly by weaker skills involving the right side of the brain. NLD may be called the "right hemisphere disability." The more common learning disabilities mainly involve problems in the left side of the brain.

Many children and teens with an NLD had medical problems during their mother's pregnancy or birth. Some of the common pregnancy and birth difficulties are:

- very long labor at birth
- having the umbilical cord wrapped around the neck
- premature birth or low birth weight
- serious infections as a young infant

NLD is more common when the mother smoked and drank alcohol during the pregnancy. Mothers who were ill during their pregnancy are also more likely to have children with an NLD.

Nonverbal learning disabilities are much less likely to run in families than other learning disabilities. NLD is as common in girls as in boys.

What are the symptoms?

A child with an NLD does not have trouble with phonics and sounding out words. For this reason the NLD child usually does fairly well with reading words in kindergarten through second grade. NLD children do not have trouble learning to talk or use language. In fact, many children with NLD talk early and have excellent verbal skills.

Nonverbal Learning Disability (continued)

What are the symptoms? (continued)

A child with an NLD usually has trouble:

- learning how to make the shapes of the letters, especially letters like K and Y
- copying and drawing shapes
- writing on lines and remembering to keep margins
- having legible handwriting
- spacing words apart (written sentences often jumble words together)
- keeping columns of numbers straight in long division and multiplication problems
- drawing and doing art projects

Children with NLD often have problems with spelling. Problems are usually with words that cannot be sounded out (like the word "enough") or with words that could be spelled phonetically several ways, such as the word "puzzle."

Many children with an NLD have trouble immediately recognizing words that they have previously sounded out over and over. Trouble visually recognizing words quickly can make the NLD child a slow reader. They often stop to sound out words which others their age recognize right away.

Math is almost always difficult for the NLD child. Visual aids designed to help learn math are often not very helpful. Talking through the steps of math problems is often much more helpful.

Many NLD children also have coordination difficulties. These children are often:

- clumsy and have many small accidents, such as spilling things
- slow in learning to kick or catch a ball, ride a bicycle, or tie their shoes
- older than other children before they can tell left from right

Children and teens with the more severe forms of a NLD often have social difficulties. They often:

- miss or misinterpret facial gestures and body language cues
- have trouble tracking the flow of conversations and social interactions
- seem out of touch with others in social situations and conversations
- take things too literally and so misunderstand jokes or sarcasm

Nonverbal Learning Disability (continued)

How is it diagnosed?

Your child's healthcare provider or a mental health therapist will ask about the child's symptoms, medical and family history, and any medicines the child is taking. Sometimes a CT scan of the brain or an EEG will be done to screen for any physical problems. Your child will be evaluated to see if there are other problems such as ADHD or other learning disabilities.

The healthcare provider can refer you to a specialist. NLD is diagnosed by a psychologist or an educational expert trained in testing for learning disabilities.

Public schools are required by federal law to test children when a learning disability is suspected. Many public school tests, however, cannot tell whether a child has NLD or some other learning disability.

How is it treated?

There are no cures or direct treatments for an NLD. Medicines are generally not helpful for NLD, but may help with some symptoms.

Tutoring and special instruction in the areas of weakness are helpful. Some children may need special education classes at school for some or all academic subjects.

Seeing a pediatric occupational therapist is often helpful. Occupational therapy helps your child learn better visual processing skills. This will help with drawing, keeping spaces between words, and handwriting. The therapist may also use sensory integration (SI) therapy. SI therapy involves special activities that help children overcome problems with senses such as touch, sight, hearing, and movement. This may improve their behavior and ability to pay attention.

Children who have social skill problems often need training in how to respond socially. Counseling can help to teach social skills and help deal with low self esteem.

Nonverbal Learning Disability (continued)

How long will the effects last?

Children do not just "grow out of" learning disabilities. They often continue to have problems in adulthood. However, most children with NLD do very well with extra help and learning how to cope with their weaknesses.

NLD children very often excel at music and tasks that use their language skills. They are often very bright and eager to gain and share their knowledge. They often do well with oral presentations and creative writing.

What can I do to help my child?

- Ask your child's school about testing your child for a learning disability.
- Ask if your child can have more time for work that involves handwriting, spelling, and math.
- If your young grade-school child prints poorly, practice printing at home. Also ask the teacher if you can start teaching cursive writing. Many NLD children do better with cursive writing than printing.
- If your young grade-school child has messy handwritten papers, work with them on staying on the lines and putting spaces between words. A handy rule to teach is to keep one pinky-finger-width between words, one-index-finger width between sentences, and 2 finger widths as margins on both sides of the page.
- If your child has messy handwritten papers, start teaching them to use a computer word processor for written papers.
- Teach the steps to math operations (like long division and working with fractions) by talking through the steps. Encourage your child to say the steps aloud as they go.
- Teach the spelling of difficult words by having your child write them over and over. Often writing the words large, like on a white board, is more helpful than writing them on paper.
- Talk with your child's teachers about when your child can use a calculator and spelling checker to help with their work.
- Help your child identify emotions and the meanings that go with facial expressions and body cues and figure out appropriate responses.
- Ask the school counselor or teachers to help teach your child how to interact better with other children and how to interpret the reactions of others.
- Children with NLD may be anxious and depressed. Professional counseling may be helpful.

Nonverbal Learning Disability (continued)

When should I seek help?

If your child or teenager has the symptoms of NLD, contact his or her school about testing. Ask specifically if the tests are sensitive to nonverbal learning disabilities. If the tests available through the school are not designed well for spotting NLD, you may need to find private testing. For more information, see:

[NLD on the Web](#)

[The Learning Project](#), WETA Public Television

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What Are Nonverbal Learning Disabilities?

By Patty Brace

Nonverbal learning disabilities (NLD) are less well known than language-based learning disabilities such as dyslexia.

Nonverbal learning disabilities often go undiagnosed because reading ability tends to be regarded as the chief indicator of academic well-being by most public school systems. Because it has a pronounced effect on social interaction, as well as academic performance, nonverbal learning disabilities present a unique challenge to parents, teachers and adult consumers.

When people with nonverbal learning disabilities are assessed, typically, their performance IQ is significantly lower than their verbal IQ, because of visual-spatial weaknesses.

Young Children

Young NLD children tend to stray from home or groups and get lost easily. They often spill things at mealtime because of problems with motor coordination and have trouble dressing themselves for the same reason. Problems with spatial skills appear in a weak understanding of nonverbal information (e.g. pictures, cartoons, passage of time) and nonverbal tasks like puzzles.

Many children with NLD use words in an adult fashion and learn to read before school age because of their auditory strengths. Thus, they often try to gain information about the world around them by asking endless questions of adults rather than by exploring on their own. The inaccuracy of their visual perception, physical awkwardness and difficulty integrating information in space and time make it harder for them to make sense of the physical world. This compensation can compound the problem, however, for the less the child engages in physical exploration, the less she/he learns about relationships between objects in space.

Academic Issues

Students with NLD generally appear to possess above-average cognitive skills because of their verbal strengths, but often show academic difficulties as they reach secondary levels.

What Are Nonverbal Learning Disabilities? (continued)

Academic Issues (continued)

Spatial and coordination problems make printing and writing, learning math, telling time, reading and coloring maps and keeping one's place on the page difficult from early grades. By secondary school more complex verbal language is based on nonverbal processes like spatial relationships (in science, for example), logical ordering, and sequencing (both skills necessary for writing essays.) This can cause problems in subject areas other than math. For example, students often experience difficulties with sense of time, arranging written material on a page, making change, and sewing and typing, all of which demand good spatial awareness.

Throughout the school years, children with NLD are often inattentive and poorly organized because they have trouble integrating and interpreting incoming information. They tend to pay attention to each detail as it comes in, rather than combining them into more meaningful wholes. The effort quickly leads to information overload, with which these students will often cope by clinging to familiar habits and routines that help them to structure their world. Sometimes this means of coping appears as misbehavior.

In later secondary and post-secondary education, information is frequently presented in lecture form. For students with NLD, problems arise because they have to integrate information they hear with the act of writing, already difficult because writing is often awkward and slow. In addition, students who attend equally to individual details as they appear have enormous difficulty separating important from unimportant information.

Teachers can support students with NLD by outlining material to be covered, using overheads containing central points while lecturing, providing clear schedules of the day's events, breaking down complex tasks into smaller, sequenced pieces, using discussion rather than lectures to develop and integrate ideas, and using students' strengths in rote learning to help them develop habits and routines to organize themselves and their work.

Social and Emotional Issues

Possibly the biggest area of concern for children and adults with NLD is social skills. One result of having trouble processing nonverbal and spatial information is missing or misinterpreting subtle social cues like facial expressions, gestures and tones of voice. For example, a phrase like "nice going" means something different when you've just dropped a ball or tripped over a skipping rope (again) than when you've gotten a perfect score on a spelling test. Confusing the two can spell "disaster" on the playground.

What Are Nonverbal Learning Disabilities? (continued)

Social and Emotional Issues (continued)

Unlike a student who has difficulty reading but does well with social and sports activities, students with NLD are affected in all areas. This can lead to social isolation which children will sometimes try to alleviate by interacting only with adults, who are more appreciative of their verbal strengths and less concerned about physical awkwardness or violations of social conventions. However, because children with NLD are highly verbal, parents and teachers tend to attribute their academic and social failure to laziness or poor character. This can lead to emotional problems like depression and anxiety that may be expressed in physical ways (e.g. nail and cuticle biting, headaches, stomach problems, phobias).

Parents and teachers can help children with NLD learn more effective social skills by talking about social rules and playing games in which children guess the feelings that go with facial expressions and tones of voice, and figure out appropriate responses. Friends and spouses of adults with NLD can help by pointing out social rules and articulating the information often carried by a look or a gesture.

Typically, people with nonverbal learning disabilities show:

- excellent memory for things they hear
- poor memory for things they see
- good reading ability
- very poor arithmetic ability
- excellent verbal expression and verbal reasoning
- problems with written expression (often because of poor handwriting)
- problems with sense of direction, estimation of size, shape, distance
- problems reading facial expressions, gestures, social cues, tones of voice

What Are Nonverbal Learning Disabilities?

Social and Emotional Issues (continued)

The chief characteristics of nonverbal learning disabilities include:

- tactile-perceptual deficits, usually on the left side of the body
- coordination difficulties, again often more marked on the left side of the body
- problems with visual-spatial organization
- extreme difficulty adapting to new and complex situations
- reliance on rote behaviors (which may or may not be appropriate) in new situations
- trouble understanding nonverbal feedback in social situations
- problems with social perception, social judgment and social interaction
- distorted sense of time
- very strong rote verbal abilities (e.g. large vocabulary)
- reliance on language as the primary means for social relating, information-gathering and relief from anxiety
- difficulties with arithmetic and, later, with scientific concepts and theories
- inattention and hyperactivity earlier in childhood; and social withdrawal and isolation later

Brace, P. (n.d.). What are Nonverbal Learning Disabilities? Learning Disabilities Association of Ontario (LDAO). Retrieved from <http://www.ldao.ca/introduction-to-ldsadhd/ldsadhs-in-depth/articles/about-lds/what-are-nonverbal-learning-disabilities/>

Nonverbal learning disabilities

By Anastasia Hubbard, M.S., Brenda Smith Myles, Ph.D.

Read answers to some of the most common questions about this well-publicized -- but somewhat controversial -- disorder.

Locating consistent, reliable information about nonverbal learning disabilities (often referred to as NLD or NVLD) is a challenge for parents because it has yet to be clearly defined and accepted by many educators and other professionals as a distinct disorder. Nevertheless, parents often seek information about this often-publicized and somewhat controversial disorder. In this article, we will answer some of the most common questions parents ask about nonverbal learning disabilities.

What is nonverbal learning disability (NLD)? Is it a distinct diagnostic category?

Nonverbal learning disability (NLD) is believed by some to be a neuropsychological disability. Although it has been studied for the past 30 years (by Byron Rourke, Ph.D. and others), it has not yet been included as a diagnostic category in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV TR). Many characteristics associated with NLD are similar to those that describe other, more "established" disorders, such as Asperger's Syndrome and specific learning disabilities.

For a professional's perspective on NLD, we turned to Brenda Smith Myles, Ph.D., an associate professor at the University of Kansas and editor of *Intervention in School and Clinic*, a practitioner-oriented journal designed to provide practical, research-based ideas to educators who work with students with severe learning disabilities and emotional/behavior problems. Dr. Smith Myles says, "Additional research and better diagnostic tools are required to clearly define the characteristics of NLD and determine whether or not it can be considered a distinct disorder."

For the time being, let's review how this disorder is defined - and how it might apply to your child.

Nonverbal learning disabilities (continued)

What characteristics are associated with NLD?

NLD is usually defined by a distinct pattern of specific strengths and difficulties.

Individuals thought to have NLD typically demonstrate strengths in the following areas:

- Intelligence quotient (IQ) which is typically in the average to above-average range. Children with NLD tend to have verbal IQ scores that are higher than their performance scores, a factor that distinguishes them from kids with language-based learning disabilities such as dyslexia.
- Rote verbal and expressive and receptive language skills, such as the ability to memorize and repeat a great deal of information presented to them in spoken form. They also exhibit early language development.
- Auditory processing skills, which entail learning better through hearing information, rather than seeing it (visual processing)

Individuals thought to have NLD generally experience difficulties in several broad categories:

- Motor skills, such as graphomotor skills (related to printing and cursive writing), physical coordination, and balance
- Complex conceptual skills involved in problem-solving, understanding cause-effect relationships, and seeing the "big picture" versus focusing on details
- Visual-spatial-organizational skills, such as visualizing information and understanding spatial relations
- Social skills, such as using and understanding nonverbal communication (e.g., gestures, facial expressions), dealing with new information and situations, transitioning between situations, conversation skills, and understanding the nuances of spoken language (e.g., hidden meanings, figurative language)
- Activity level: hyperactivity (when younger), and hypoactivity (as they grow older)

Nonverbal learning disabilities (continued)

What type of professional is qualified to identify NLD, and what type of testing is used?

The "diagnosis" of NLD is normally made by neuropsychologists and clinical psychologists. Such professionals assess NLD using a battery of tests that cover abilities such as:

- intelligence
- motor and psychomotor
- tactile-perceptual
- visual-spatial-organizational
- auditory-perceptual
- auditory and visual attention/memory
- problem solving
- language
- academic achievement
- personality/adaptive behavior

NLD is difficult to diagnose because its manifestations change significantly depending on the child's age. In general, the deficits involved in NLD get worse as the child gets older. For example, a preschooler with NLD may have exceptional verbal skills and speak like a little adult. During his younger years, the challenges a student with NLD faces are often overlooked because of his high intelligence level and verbal strength. As the child matures and encounters school work and social situations that require abilities such as abstract thinking and nonverbal communication, his deficits in those areas will become more apparent and problematic.

Parents tell us they get conflicting information about NLD from educators and other professionals. Is there consensus among professionals regarding the validity of NLD as a syndrome?

Brenda Smith Myles explains, "One reason why parents receive mixed messages about the existence of NLD is the fact that the disorder is viewed very differently by the psychological and education communities. At this time, very few schools will acknowledge that a child has NLD based on neuropsychological test results alone. However, if standardized testing reveals a discrepancy between the child's IQ and his academic performance, some schools will refer the student for special education services."

Nonverbal learning disabilities (continued)

How might having NLD affect a child's academic performance?

Students thought to have NLD generally do well in areas that relate to concrete thinking but have difficulty in areas that relate to abstract thinking. The research done to date has yet to prove how the cognitive limitations of NLD directly impact a child's academic performance. Nevertheless, consider how having NLD might apply to math, reading, and conceptual learning.

- It may be difficult for a child with NLD to understand math concepts and solve problems, but he may have no trouble applying a mathematical formula which he has been explicitly taught. Additionally, due to his poor spatial-organization ability, he may have difficulty aligning problems on a page to solve them correctly.
- With regard to reading, a student with NLD may have strong word decoding skills, but may experience difficulty with reading comprehension, as he may miss inferences, have difficulty visualizing a story, and may not see the "big picture."
- Children with NLD also experience difficulty when information on assignments and tests is not presented in the exact format in which it was taught. For example, if a child with NLD learned about neighborhoods in social studies using a matching format he may have trouble answering true/false questions about the same information.

How does NLD impact a child's social life and communication skills?

Because of their uneven profile of strengths and challenges, children with NLD may experience difficulty in their interactions with adults and peers. Children with NLD usually have strong verbal skills; consequently, adults may hold unreasonably high expectations of them. Peers may not understand a child with NLD; for example, peers may be unaware of the child's inability to understand nonverbal communication and therefore may not know how to interact with him. A child with NLD tends to take things literally and often misses the point of humor or misinterprets good-natured teasing.

Nonverbal learning disabilities (continued)

Does having a diagnosis of NLD mean a child is eligible for special education services?

Children who have been identified as having NLD may qualify for special education services under the "learning disabilities" or "other health impairments" category included in the Individuals with Disabilities Education Act or under Section 504 of the Rehabilitation Act. At this time, only one state, New Hampshire, appears to recognize nonverbal learning disability as a specific learning disability. Because the categorization of NLD varies from state to state, parents will want to check on the education laws in their particular state.

Looking to the future

Much remains to be learned about the nature and characteristics of NLD, as well as the most effective ways to work with and support children with the disorder. Future research and the development of effective diagnostic tools will facilitate a better understanding of this complex disability.

Hubbard, A. and Smith Myles, B. (n.d.). Nonverbal learning disabilities. Retrieved from <http://www.greatschools.org/special-education/LD-ADHD/907-nonverbal-learning-disabilities.gs?page=all>

School Environment and Placement

By Pamela B. Tanguay

The success or failure of most NLD children is based on the environment in which they are required to function. As a result of their unique problems, it is very difficult for these children to understand the requirements of a particular situation, as well as how to adapt to it. Parents generally respond instinctively to the eccentricities of their children, without giving it much conscious thought. Therefore, the parent of an NLD child has likely adapted the home environment to suit the unique needs of their child.

Once she begins school, the child's life becomes far more challenging. She no longer understands what is expected of her, and almost always has tremendous difficulty adapting to the new environment. Also, coping in multiple settings is quite difficult for this child. In addition to managing her home environment, she may also be required to spend a portion of her day in a before and/or after school daycare situation. The more settings that the NLD child is forced to cope with, the less able she will be to manage any of them well. Although it may not be possible, the ideal situation for this child is to have only two settings to cope with - home and school. If before and/or after school care is necessary, it would be best to have someone care for her in her own home.

Providing the right environment at home, and insisting on an equally appropriate one at school, will likely win the parent of an NLD child the irritating title of "overprotective." The fact is that you *must* be very protective of this child, and for quite some time. It is important for parents to "hang tough" when school officials tell a parent that their child is too dependent on them. The child's parent(s) is her anchor, and she needs to know that someone will "protect" her when the need arises.

This chapter will address the environmental issues at school which need to be considered in order for the NLD child to function effectively, as well as the appropriate educational placement for this student. Environmental issues cover things such as the physical layout of the classroom and school, the cafeteria, lights and sounds, crowds, routines and schedules, etc.. Placement relates to which educational option you decide is most suitable for your NLD child. There are basically three placement options to choose from. The first is the public school system. This may be either a program for learning disabled youngsters, or a regular education program. The second option is a private school, whether it is one that is specifically geared to learning disabled children, or has primarily a regular education program. The third option is homeschooling, where the parent is both teacher and program coordinator, and has the freedom to create an environment specifically designed for their child.

School Environment and Placement (continued)

The needs of these youngsters change over time. Actually, let me correct that. The NLD child's needs remain constant, but the demands of a typical school change over time. In a traditional program, student support is withdrawn at the same time that demands increase, and the child's environment becomes more complex. What we normally see in schools is that, for the early years, there is a considerable amount of concrete direction, the children are with one teacher for the majority of their school day, they do everything together, and are always accompanied by an adult. As children get older, the direction becomes less concrete, students are with multiple teachers during their school day, schedules become more complex, and children are expected to be more independent in the learning process. As support is being withdrawn, and demands increase, the NLD child will be unable to adapt. She is *unable* to respond to the demands of a traditional educational environment after the early elementary years. Usually the warning signs of her inability to adapt are fairly apparent by third or fourth grade, and generally quite pronounced when she is required to transition to middle school, which unfortunately often coincides with adolescence. It is absolutely critical to accommodate this student's needs in order for her to develop both scholastically and emotionally.

Environment

The unique needs of this child may not be readily apparent in the younger years, but that doesn't mean that they aren't real. Although she may *look* like a typical five or six year old, she is not at the development level of her age mates. It is important to understand the disorder, and its implications, in order to provide the appropriate environment for her. Don't be fooled by this child's well-developed vocabulary, or even apparent giftedness. As a society, we often equate intelligence with language skills. Because of this student's early strength in this area, she may appear to be far more able than she actually is. Remember, she is using her strength (verbal skills) to compensate for her deficits in other areas. This child's developmental disability is a major impediment to her learning and must be accommodated to meet her particular needs. The following are recommendations appropriate for this child's school environment.

Educational Setting

The NLD youngster requires a tremendous amount of consistency. She needs a highly structured day, which is very predictable. During the early years, the maximum class size should be between six and eight children, with fewer children being the ideal. There should be both a teacher and an aid, so that one of them is always available to assist the NLD child when she is struggling.

School Environment and Placement (continued)

Educational Setting (continued)

It is very difficult for the NLD student when her primary teacher is replaced by a substitute teacher. She does not understand the expectations or teaching style of the substitute teacher, and generally, the substitute teacher does not understand the needs of the NLD student. To address this situation, there should be one individual identified as a consistent substitute teacher for the class. The primary teacher should educate the identified substitute teacher at the beginning of the school year about the particular needs of the NLD student. Providing this continuity will alleviate the undue stress placed on the NLD student by having to cope with a change in circumstances.

As the child progresses through her elementary years, her need for a relatively small class size continues, as does the need for a classroom aid to be available to assist her as the need arises. Unfortunately, this option may not be available. The appropriate placement for the NLD child *may* be a regular education class. If so, it is likely that there will be between 22 to 25 students in the class. However, it is important to understand that every step that is taken away from what this child needs - in this case, a small number of students - compromises her ability to succeed. If she is required to participate in a regular education classroom of 22 to 25 students, it is *imperative* that an aid be in the classroom at all times, with specific responsibility to assist the NLD child. The aid must be qualified to teach, since the NLD youngster will often need individual instruction in a particular assignment.

When the child reaches middle school, which is generally in sixth or seventh grade, the traditional educational environment becomes totally overwhelming for an NLD student. It is absolutely *imperative* that this student continue to have the same type of consistent, predictable, highly supportive environment that was required for her elementary education. Many school systems are able to meet the needs of a one-teacher class, with a limited number of students, *and* an aid during the elementary school years. However, most are not equipped to readily provide this environment for middle school and beyond. If the school does in fact provide small class instruction, they are generally designed for either behaviorally challenged students, or for those who are academically below grade level. *Neither* of these situations is appropriate for the NLD student. She should not be placed in a class with behaviorally challenged students or those who are performing below grade level in order to meet the requirement of a small class. Either placement would seriously undermine this student's education.

School Environment and Placement (continued)

Classroom Setting

In the early elementary years, activities are often conducted with the children seated on the floor in a circle, which is sometimes referred to as "circle time." Since this is not an effective teaching environment for the child, she will benefit from direct guidance from an adult. During "circle time," the NLD child should be seated directly next to the teacher or aid.

Most classrooms for young children are highly decorated, providing significant visual stimulation. For the NLD student, these decorations are serious barriers to learning. What most youngsters find appealing - pictures on the walls, items suspended from the ceiling, bulletin boards with work samples scattered about - the NLD child finds distracting and frustrating. The most effective way to deal with this situation is to seat the NLD child in the front row of the class, keeping the front wall clear of distracting material. The blackboard should be kept clean of any extraneous writing or other material, only having information on the board that directly relevant to the lesson which is being taught.

The classroom should be arranged so that all of the children sit at desks, which face forward, rather than being grouped in pods. It is important to remember that the NLD student is an auditory learner, whose related issues must be accommodated. A seating of front and center is best, with quiet students seated on both sides and behind her. The NLD child must always be seated facing the teacher, and not be distracted by the children around her. Desks should not touch each other, as the child may feel crowded - her personal space invaded. Since this child is an auditory learner, her hearing is likely acute so that normal classroom noises are amplified to this child, and far more distracting. Therefore, she should not be seated next to a fidgety child who is constantly shifting around in his or her chair, so that the chair/desk make scraping sounds on the floor. Nor should she be seated near a student who continuously taps a pencil, or makes other distracting noises which will interfere with the NLD child's ability to concentrate on what the teacher is saying.

The classroom setting that is required during the early elementary years remains necessary for the NLD student through middle school and beyond. The classroom should be arranged with all desks facing forward, and not touching. The child should continue to be seated front and center, with quiet students around her. Visual distractions should be confined to the side and rear walls, leaving the front wall uncluttered, and the blackboard free of everything except the material related specifically to the class instruction.

School Environment and Placement (continued)

Other Considerations

Due to this child's social and communication impairment, she should not be left unsupervised during unstructured time. Whether the child is at recess, in the corridors before and after school, or eating in the cafeteria, an aid should be assigned to observe her. If the NLD youngster is having difficulty with social interactions, or with independent skills such as getting hot lunch or milk, the aid should step in and assist her. NLD students are most vulnerable while in unstructured settings, and will need assistance for quite some time. Initially, the aid should be more involved with helping the child, and as she becomes somewhat more independent, the aid can "shadow" the child, only stepping in when it is clear that the situation warrants it. Remember that NLD children are targets for unkind youngsters and bullies and should be protected from harmful situations.

If this child is required to be transported to and from school on a bus, arrangements should be made for pick-up in front of the child's home. Due to her spatial and social difficulties, this should be an accommodation that is fairly easy to secure. A parent or other adult should observe the child while she waits for her bus, to insure that she is not teased or bullied by other youngsters. The NLD child should have an assigned seat on the bus, next to a kind child, and close to the bus driver. The driver should be aware of the NLD child's disability and prevent any taunting or teasing of the child while on the bus. An adult should be available to meet the bus, again with drop-off in front of the child's home, or wherever she is cared for after school. If the child finds the bus ride stressful, she might enjoy listening to a music audiotape or CD during the trip, allowing her to relax and block out extraneous distractions.

"Specials," such as library, art, gym, and so forth are generally less structured than other classes. Often, even in the earliest school years, children have these subject areas in a specialized location, rather than in their classroom. It is doubtful that teachers who only see the NLD child a few times a week, and possibly for only a few months during the school year, will understand this student's needs. Combined with the fact that these classes tend to be less structured than those in the student's primary classroom, the NLD child is left in a vulnerable position. An aid should be assigned to attend these classes along with the NLD youngster in order to insure that her needs are met, and provide assistance where appropriate.

School Environment and Placement (continued)

Other Considerations (continued)

To repeat . . . every step that is taken away from what this child needs, compromises her ability to succeed. *If the child displays unacceptable behavior, whether she is acting out or seems overly sensitive, the problem is almost certainly with the environment, and not with the child! Always look at the appropriateness of the demands and expectations being placed on this child before assuming that there is a behavior problem. Determine what is causing the behavior, and then correct it. The behavioral problem will almost certainly disappear once the environmental problem is corrected.*

Placement

The ultimate decision-maker in the educational placement of the NLD child is always the parent. The parent knows best what type of environment is most suitable for their child and compatible with the family's personal goals, such as educational philosophy, standards, values, or possibly religious principles.

There are three available options for educating a child - public school, private school, or homeschool. If you select a public or private school, it is imperative that the teachers and other school staff members are supportive, flexible, *and* appreciate the pervasive nature of NLD. If they are new to the condition, they should be receptive to learning about Nonverbal Learning Disabilities.

Hopefully, the educational choice will be selected based on parental preferences, and not as a result of the public school system's failure to meet the special needs of their child. The following provides additional information on the three available educational placement options, and the implications for the NLD child.

Public School

It is the right of every school-aged child to receive a free, appropriate public education, which means that the student's education will be provided at the taxpayers' expense. Generally, this right is fulfilled through the public school system. The most common educational programs provided through the public school system are regular education, and special education. Regular education is provided to those children who are not considered to need 'special' assistance, and special education is provided for students who have been identified as needing 'special' assistance as a result of a qualified disability, which significantly affects their ability to learn. Although we generally think of special education as it relates to learning disabilities and academics, it also encompasses other disabilities, such as vision and hearing impairments, physically challenged youngsters, and serious health problems. It is important to understand that special education is a *process, not a place*.

School Environment and Placement (continued)

Public School (continued)

For the young NLD child, a regular education program offered by the town's public school system may effectively meet the child's needs. Some youngsters will need additional support services such as special education and/or related services. School districts manage their special education programs in various ways. Some schools have self-contained classrooms for their special education students. Others have full inclusion programs, where special education students and regular education students are taught in the same classroom by two teachers - one being a regular education teacher and the other a special educator. Still other programs have Resource Rooms, where students spend the majority of their day in their regular classroom, and go to the Resource Room for special education or assistance in specific areas, such as reading, math, etc.

Services administered by the school's speech and language specialist may be indicated in order to develop the NLD child's communication skills (particularly pragmatics). Also, the services of an occupational therapist may be warranted in order to assist the child with her fine motor difficulties and self-help skills. Although each child must qualify for these and other services, they are free within the U. S. public school system, and if provided, will be incorporated into the child's school schedule.

Many public schools have the ability to appropriately support the NLD child during the elementary school years, where a high level of structure and direction are the norm. However, most school districts, if not all, have far more difficulty meeting the needs of this student in middle school and beyond. The curriculum-driven approach in middle and high school, where there is a separate teacher for each subject, is contra-indicated for the NLD student who does best with a single teacher. The typical environment of 1,000 or more students, class and teacher changes for each period, complex schedules which often change from day to day, and the expectation of independent learning, are all inappropriate for the NLD student.

School Environment and Placement (continued)

Public School (continued)

In order for the public school system to effectively accommodate an NLD student in middle and high school, they need to be creative. However, the constraints of their typical educational environment makes creativity difficult. The advent of charter and magnet schools may be one answer. Charter schools receive public funding, but are run separately from the traditional public school. They are managed by groups such as teachers, parents, or foundations, are free of many district regulations, and are often tailored to community needs. Magnet schools also receive public funding, and were originally designed to attract students from elsewhere within a school district. These schools generally place special emphasis either on overall academic achievement or within a particular area such as science, the arts, or technology. Charter and magnet schools are typically much smaller than regular public schools, and as a result of their smaller size, are able to be more flexible and creative than a traditional public school setting. If there are charter and/or magnet schools within the district, this may be a consideration for the NLD student. These public educational placement options should be considered when determining the most appropriate environment for the child, particularly in middle and high school.

Private School

Private schools are divided primarily into two classifications - independent schools and parochial schools (those with a religious affiliation). Within these two categories, are both regular and special education schools. There are residential schools, day schools, and a combination of residential and day schools. Private schools are supported through student tuition, which varies tremendously from school to school. The choices can be overwhelming, making it difficult to select the appropriate placement for the NLD child.

As you consider various schools, keep the needs of the child in mind. Some schools are quite impressive, and we can forget what our original criteria was. The best placement for the NLD child may not be the most impressive school. In fact, many of the impressive private schools are too socially demanding for NLD youngsters. The ideal placement for this child has the following:

School Environment and Placement (continued)

Private School (continued)

- A creative, flexible staff who is knowledgeable about NLD, or clearly excited about the prospect of becoming knowledgeable.
- A physical lay-out that is easy for the child to navigate within - straight corridors, well-marked doors, etc.
- A very small total student population, with 50 or less being ideal, but no more than 200.
- Very small class size, with 6 to 8 students plus a classroom aid for the younger child, and 10 to 12 students plus a classroom aid for the older student.
- Student continuity - students stay together from one year to the next, so that the NLD child can develop an understanding of the group dynamic, and form meaningful relationships.
- Teacher continuity - the student has the same teacher(s) for multiple years, and there are a limited number of teachers working with the NLD youngster.
- A school philosophy of teamwork, and a policy of zero tolerance for bullying.

Remember that although this is considered to be the ideal placement, each step taken *away* from the ideal will significantly compromise the education of the NLD student. Remain open-minded and flexible in looking at various placement options. You might unwittingly pass on a school that would have been an ideal situation for your child. For instance, you may determine that a special education school is the appropriate placement for your child. However, the school under consideration may be geared to more left-hemisphere learning disabilities such as dyslexia, have a large student population, and assign multiple teachers to your child. You may have rejected a local Christian school because your family isn't terribly religious, and they don't have a special education program. However, they have a very small school population of under 50 students, a caring and supportive staff with a philosophy to recognize and support the uniqueness of each child, a zero tolerance for bullying, and require uniforms (allowing your child to fit in by looking like all of the other students) . . . a little gem of a school that could have easily been overlooked. It is important to consider *all* possible educational placements, because it is unlikely that you will find a perfect situation. First identify the most critical components, and then locate a school that most closely fulfills the criteria.

School Environment and Placement (continued)

Private School (continued)

Generally, it is best to do the initial school research without directly involving the NLD child. She may become overly anxious about the prospect of change. On the other hand, if she is in a situation which is causing her extreme distress, it may be reassuring for her to know that there are alternatives to her current placement. Some private schools will accept a mid-year transfer, but most prefer, or require, that a student transfer at the start of a new school year. When considering a school, it is very important to have an on-site interview with the Director, a tour of the facility, and observe classes while they are in session. Above *all* else, trust your instincts! Once the school search has been narrowed down to one or two potential placements, it is time for the NLD child to visit. No amount of research will replace the NLD student's impression of the proposed environment. Only she can truly determine whether or not she will be comfortable there. The most important criteria for her will be whether or not she feels accepted and safe.

Homeschool

Homeschooling is an educational option which is exploding across the United States, *and* gaining in popularity around the world. Many parents who elect to homeschool their children do so for reasons other than a developmental or learning disability. However, it is often a viable option for NLD youngsters, and should not be discarded lightly either as a temporary solution while a long-term program is being developed, used in conjunction with a traditional educational program, or for an extended period of time.

Parents are justifiably concerned with how they might handle the challenge of homeschooling their child. Homeschooling is legal throughout the United States. Laws and regulations vary by state, and interpretations of the laws vary between school districts. The State Department of Education can provide information on state laws and local regulations. Some homeschool families prefer the convenience and security of having a prepackaged curriculum, while others choose to make their own decisions about what is important to learn, and what materials they will use. Many colleges, universities and vocational institutes across the nation are accepting homeschooled students, and more will follow as the homeschool population continues to grow.

School Environment and Placement (continued)

Homeschool (continued)

In most situations, the parent(s) of an NLD child will be faced with consideration of alternative education options at some point during their child's school years. For many, this happens at the point of middle school, when the demands of a traditional school overwhelm the NLD adolescent. The important parental consideration is to remain open to *all* available options if their child's educational environment can't be sufficiently modified to meet her unique needs.

There is quite a lot of available support if homeschooling appears to be the most appropriate educational alternative for the NLD child. Please refer to the appendices at the back of this book, and the website *NLD on the Web!* at <http://www.nldontheweb.org>, for homeschooling resources.

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This document is excerpted from the author's book Nonverbal Learning Disabilities At School: Educating Students with NLD, Asperger Syndrome and Related Conditions.

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Parents' Commonly Asked Questions About NLD

By Pamela B. Tanguay

1. How do I deal with family and friends who provide “helpful” advice, which is actually thinly disguised criticism?

Our society prizes language skills, and often equates language skills with a level of maturity and ability. Due to the NLD child's precocious language skills, friends and family members will often see what they believe to be a bright, socially-engaged child. Many are unable to see the child's difficulties and assume that if there is a problem, it is as a result of poor parenting rather than a disability. Unfortunately these individuals are often family members which makes the situation that much more difficult. Suggestions and comments such as: you are far too protective...let her learn from her mistakes...all she needs is a good spanking...are all inappropriate. Trust your instincts, and do not cave in to the advice of uninformed individuals. Provide family and friends with information about NLD, and encourage them to ask you questions about your child. If they respond positively, that's great. If they ignore or discount the material which you provide, and all attempts to educate them about NLD fail, then you should distance yourself from these individuals. They do not have you or your child's best interest at heart. Easier said than done, but better to distance yourself before your child is placed in a dangerous situation as a result of their ignorance, or your attempts to educate them escalate to the point of a nasty situation.

2. Are there subtypes of NLD? My child has some of the characteristics of NLD, but not all of them.

There is no research evidence which indicates that there are NLD subtypes. There is one established set of criteria for the Syndrome of NLD, which was developed by Dr. Byron P. Rourke. However, there can be a significant difference between the presentation in children who have the Syndrome of NLD and those who do not have the full syndrome, but *do* have learning disabilities in the nonverbal domains (e.g. dyscalculia, dysgraphia, social deficits, organizational difficulties, etc.). It is important for parents to know whether their child was diagnosed with the NLD Syndrome, or with a nonverbal learning disability.

Parents' Commonly Asked Questions About NLD (continued)

3. What is the difference between NLD and Asperger Syndrome?

There is a tremendous amount of controversy about what differentiates NLD and Asperger Syndrome (AS). The short answer seems to be that children with AS have more significant behavioral issues and a narrow area of interest which impedes their ability to learn. The AS researchers at Yale indicate that the vast majority of individuals with AS also have NLD. Dr. Rourke states that his research indicates that all individuals with AS have NLD. Unfortunately, there are many children who have been diagnosed with AS but do not meet the DSM criteria. Within this group are likely many who actually have autism, but were given a diagnosis of AS either because their symptoms were milder than what the diagnostician would consider to be autism, or in order to spare the child the label of autism. This creates confusion as to the learning style of the child, since AS and NLD children's preferred learning modality is auditory, while autistic children generally respond better to visual teaching strategies.

An additional issue which many are unaware of is that the diagnoses of Asperger Syndrome and NLD come from two different disciplines. AS is researched and diagnosed in the field of psychology/psychiatry, and NLD is researched and diagnosed in the field of neuropsychology. AS is diagnosed through patient history, observations, and tests which deal primarily with the presentation of the disorder - how the person acts/responds in various situations. A psychologist/psychiatrist will not diagnose a patient with NLD since it is not listed in the DSM, which is the classification manual published by the American Psychiatric Association. NLD is diagnosed through patient history, and an extensive testing protocol which identifies how the individual's brain functions due to their specific neuropsychological assets and deficits. As a result of this profile, a determination can be made as to what the individual's strengths and weaknesses are, and as a result, how they are likely to act/respond in various situations.

4. As a parent, how can I help my child make, and keep, friends?

If your child is still young, you can create play dates with another child. It is wise to have these play dates at your own home so that you can facilitate each one. Provide considerable structure for the children, and have activities planned ahead of time so that the children do not have to figure out what to do on their own. If your young child is invited to a birthday party, you should also attend. Observe your own child at the party and facilitate his/her interaction with the other children if necessary, or explain the rules of a game that the children will play.

Parents' Commonly Asked Questions About NLD (continued)

4. As a parent, how can I help my child make, and keep, friends? (continued)

For the older child, also have social engagements at your home, again with activities planned ahead of time. However, for the older child, you should plan the activities together, and script how he/she should handle different eventualities. Make sure that the activities are something that the other child is interested in, and insure that he/she has a very pleasant time at your home in order to increase the chance that they will return again. Supervise the play time, but do not hover. Be close by so that you can hear what is happening, and step in when necessary.

It is best to keep social contacts to one-on-one, since NLD kids do best in these situations. If possible, avoid sleepovers, especially at another child's home. For the NLD child, a sleepover is just an accident waiting to happen. If the child absolutely insists on a sleepover, have it in your own home, keep the number in the group very small, with a schedule and planned activities for the time that the children will be awake. Remain within hearing distance of the party so that you can step in if necessary in order to assist your child.

5. What types of activities are beneficial for NLD kids?

To improve eye-hand coordination and problem solving skills, computer games and handheld electronic toys such as Game Boy are excellent activities for NLD children. Skills with these types of activities may also prove socially beneficial, as the child's skill will be prized by his or her peer group.

To improve gross motor skills, physical coordination, and dexterity, consider the following activities: swimming, archery, canoe/kayak, dog obedience, in-line skating, hiking (with good boots and a walking stick), art, and music. It is wise to begin with private lessons, and if the child develops a basic level of proficiency, then small group lessons may be socially beneficial. Avoid team sports, since NLD children have a great deal of difficulty with the rules of the game and the complexity of the social interaction involved. The goal is to build competence AND confidence.

Structured organizations (such as scouts, 4-H, church youth groups, etc.) are generally the safest social outlets for NLD children. However, *always* make sure that the facilitator is aware of your child's strengths and weaknesses so that he/she is not left to socially fend for themselves.

Parents' Commonly Asked Questions About NLD (continued)

6. What type of educational environment is best for my NLD child?

There is no one environment which meets the needs of all children with NLD. However, most NLD children benefit from the following:

4. A small school in terms of the actual facility, student population and class size;
5. A teacher *and* paraprofessional/aid in the classroom;
6. A limited number of teachers and class changes;
7. Continuity of teachers and students;
8. A high level of structure, predictability, and routine;
9. A caring staff, accepting students, and zero tolerance for bullying;
10. Reduced visual and auditory distractions;
11. Supervision and assistance for social and spatial challenges;
12. A nurturing environment for the little ones, weaning to supportive, rather than independent, for the older students.

7. What educational placement options are available and appropriate for my child?

There are various educational options to consider, from the public school system (including charter and magnet schools), to private schools (both independent and parochial), and homeschooling. Although traditional public schools may be able to appropriately support the NLD child in the early to middle elementary grades, they are less able to do so in middle and high school. It is important to prioritize the child's needs when making your placement decision, since it is unlikely that you will find a school that meets 100% of your requirements. If the child is overwhelmed by a large school and multiple teachers, then a high priority should be placed on the size of the school. If the child needs significant intervention, then a high priority should be placed on special educational strategies specific to the child's learning style.

8. What is the difference between IDEA and 504? Are services under one better than the other?

IDEA, which stands for the Individuals with Disabilities Education Act, is a non-funded federal entitlement law. Qualifying conditions are stated within the law, and parents' rights are specified. Although the entitlements of disabled children are federally mandated under IDEA, it is unfunded legislation, meaning that the expense rests with the school district, town, and state, often placing an undue burden at the local level. As a result, there is often friction between school administrators who are trying to control expense and parents who are trying to secure the best services for their child.

Parents' Commonly Asked Questions About NLD (continued)

8. What is the difference between IDEA and 504? Are services under one better than the other? (continued)

Section 504 of the American's with Disabilities Act (ADA) is a non-discrimination law, which requires that the barriers to learning be removed. All children who meet the qualifying conditions under IDEA automatically meet the criteria for 504. However, many more children qualify for a disability under 504 than under IDEA. Many school districts only allow student accommodations and modifications under a 504 Plan. However, a student is actually entitled to all of the same services under 504 that he/she is entitled to under IDEA, and can have an IEP under both a 504 and IDEA classification.

Parents need to know that states are free to expand the benefits under a federal law, however they are not legally allowed to restrict the law to a narrower definition. It is critical to learn how the law is interpreted in your particular state in order to secure the appropriate services for your child.

9. How do I secure services for my NLD child?

In order to secure services for your child, there are two thresholds you must cross. First is the qualifying condition. Many school districts reject NLD as a valid diagnosis, however there are other definitions of disabilities which may qualify your child for services. The second threshold is determination of need. Is the child disabled *enough* to qualify for services?

1st threshold - Qualifying condition. If your state does not recognize NLD as a specific qualifying condition, some other options which they may recognize are:

- Neurologically impaired or Encephalopathy (brain damage of unknown origin).
- PDD-NOS (Pervasive Developmental Disability - Not Otherwise Specified) - this diagnosis is often made when the child has autistic-like symptomatology, but does not meet the criteria for autism or another pervasive developmental disability. It is specifically listed in the DSM.
- LD-NOS, which is specifically listed in the DSM.
- Developmental Coordination Disorder (DCD), which is specifically listed in the DSM.
- Semantic Pragmatic Disorder, which is a recognized communication disorder, and would result in a communication handicapped classification.
- Asperger Syndrome, which is specifically listed in the DSM under the category of pervasive developmental disability.

Parents' Commonly Asked Questions About NLD (continued)

9. How do I secure services for my NLD child? (continued)

2nd threshold - Level of performance

Once the qualifying condition has been determined, the next step is to prove that the condition significantly compromises the child's ability to learn and/or participate in all of the activities that are offered to his/her peer group. Under IDEA, each state develops criteria for determining the disparity between the child's ability and level of performance. It can be quite difficult to meet the criteria established at this second threshold, which is why many NLD students are serviced under a 504 Plan with accommodations and modifications, but denied the full range of services that they rightly deserve. It may be necessary to hire an educational advocate or an attorney in order to secure all of the services which your child requires.

10. I have heard that NLD kids can't do math past the fifth grade level. Is this true?

Generally NLD children are very good at rote memory activities such as math facts, especially if they are taught auditorily. Other math ability depends on the degree of the impairment, and the method of instruction which is used. Math must always be taught in a very direct and step-by-step fashion. If each step is not specifically taught, the child will not be able to learn how to do the required operation. NLD children commonly make calculation errors, often due to misalignment of columns of numbers. Long division, estimates, place values and fractions are generally particularly troublesome. Higher level math (algebra, geometry, etc.) will likely be quite difficult, and the child may need to be taught in a one-on-one manner, rather than in a classroom setting. When the learning style of the NLD child is applied, many are able to accomplish math well beyond the fifth grade level, but it will almost always be quite difficult. It will require a lot of patience, and there will likely be gaps in their learning (e.g. fractions) which should be accommodated through the use of a calculator or other aid.

Parents' Commonly Asked Questions About NLD (continued)

11. If children with NLD are auditory learners, does this mean that they can't learn visually?

In individuals with NLD, of the visual, tactile, and auditory senses, hearing appears to be the most preserved of the three, resulting in a preference for learning through the auditory modality. Depending on how significant the visual and tactile impairment, the individual may or may not be able to learn visually or tactilely. Visually, the deficit is generally most pronounced with complex (lots of small type or problems on a page) or fleeting (facial expressions) visual images and tasks that require visual tracking (reading and math calculations). However, the use of icons (simple visual representations) are often a very effective teaching strategy for NLD students.

12. In our home, homework time is a nightmare. Should NLD children be required to do homework?

Generally it is beneficial for the NLD child to do homework. However, this assumes that the child is being appropriately supported at school, and that any homework assignment is a *review* of material which has already been covered in class. If homework becomes difficult, the assignments should be modified. Ideally, the teacher should tell the parent how long the assignment is expected to take. The parent should implement the use of a timer, setting it for the recommended duration. The child completes only what he or she is able to within the time limit, and then be graded only on what was completed. Class work should be handled the same way - by grading on what the child is able to complete during the assigned time limit in class. Unfinished class work should *never* be assigned as additional homework.

13. How much parental homework help is too much?

It is important to remember that homework assignments and special projects are simply tools for learning. As long as a parent is helping the child to *learn*, no amount of help is too much. However, once the parent crosses the line into actually *doing* the assignment, the opportunity for learning is lost. If the child is unable to do a particular assignment, it is far better to write a note to the teacher explaining the problem, rather than do the assignment on behalf of the child. The school should always be aware of the amount of assistance which was required by the parent so that they are aware of the child's abilities and limitations.

Parents' Commonly Asked Questions About NLD (continued)

- 14. Should my child be required to take standardized tests at school? If so, should he/she have modifications such as extra time or a separate room?**

It is wise to consider having your NLD child participate in all standardized testing, without accommodations. Repeated exposure to standardized testing makes the task less novel, and increases the likelihood that the student may perform well over an extended period of time and exposure (a child may be expected to do poorly in elementary school, but much better by high school). Also, it is important to remember that the benefit derived from accommodations for standardized testing (such as extended time) may mean that the child misses classroom instruction time which they desperately need.

Another very important consideration is that the results of standardized testing may be the only objective measure of whether or not your child is actually learning. Often, grades are quite subjective, and may not be an accurate measure of your child's ability. If your child is getting good grades in school and has scored well on standardized testing as a result of accommodations, it will be difficult to secure services. However, even if your child is getting good grades, if he/she does poorly on standardized testing, the parent is in a stronger position to request help for their child.

- 15. My child doesn't seem to respond when I talk with him/her. The teachers have asked me to have his/her hearing checked. How can this be, if the NLD profile indicates that these kids are auditory learners?**

There seems to be a period, generally during middle elementary school, when some NLD children develop CAPD (central auditory processing disorder). This apparently lasts a relatively short period of time - one to three years - and then often seems to disappear. During this period, the use of an FM Receiver is often quite beneficial, allowing the teacher to speak directly to a student while in a regular classroom setting.

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Advocating for Your Child: 25 Tips for Parents

By David Fassler, M.D.

According to the Surgeon General, 1 child in 5 will experience significant problems due to a psychiatric disorder. The good news is that we can help many, if not most, of these youngsters. The real tragedy is that so few, less than 1 in 3, are receiving the comprehensive treatment they really need.

Children and adolescents with emotional and behavioral problems deserve access to the best possible mental health care. Unfortunately, such services are often difficult to obtain. Parents can help by being informed, involved and persistent advocates on behalf of their children.

The following outline offers specific tips and suggestions which parents may find useful in such advocacy efforts.

Individual advocacy for your own child:

1. **Get a comprehensive evaluation.** Child psychiatric disorders are complex and confusing. A full assessment will often involve several visits. Effective treatment depends on a careful and accurate diagnosis.
2. **Insist on the best.** Talk to physicians, therapists, guidance counselors and other parents. Find out who in your community has the most experience and expertise in evaluating and treating your child's particular condition. Check the clinician's credentials carefully. Are they appropriately licensed or certified in your state? If he or she is a physician, are they "Board Certified"? Push schools, insurance companies and state agencies to provide the most appropriate and best possible services, not merely services which are deemed sufficient or adequate.
3. **Ask lots of questions about any diagnosis or proposed treatment.** Encourage your child to ask any questions he or she may have, as well. Remember that no one has all the answers, and that there are few simple solutions for complex child psychiatric disorders. In addition, all treatments have both risks and benefits. Make sure you and your child understand the full range of treatment options available so you can make a truly informed decision.
4. **Insist on care which is "family centered" and which builds on your child's strengths.** Ask about specific goals and objectives. How will you know if treatment is helping? If your child's problems persist or worsen, what options and alternatives are available?

Advocating for Your Child: 25 Tips for Parents (continued)

5. **Ask about comprehensive “wrap around” or individualized services, geared specifically to the needs of your child and family.** Are such services available in your state or community? If not, why not?
6. **Be prepared.** One of the most important things you can do to help your child is to keep all information, including past consultation and treatment reports, in an organized place. Insist on receiving your own copies of all evaluations. Records can easily be misplaced, delayed or even destroyed. Maintaining your own file with all relevant information can help avoid unnecessary duplication of previous treatment efforts.
7. **Feel free to seek a second opinion.** Any responsible mental health professional will be glad to help with referrals or by sharing information. If you have any questions at all about your child’s diagnosis or the proposed course of treatment, by all means, arrange an independent consultation with another clinician.
8. **Help your child learn about their condition.** Use books, pamphlets and the Internet. Make sure the information is age-appropriate. Answer questions with honest, accurate and consistent information, but don’t overload children with more detail than they need or want.
9. **Learn the details of your insurance policy, and learn about the laws governing insurance in your state.** For example, in some states, insurance companies must provide access to a specialist, such as a child and adolescent psychiatrist, within a certain distance from your home. If no such specialist is available as part of the company’s “network”, you may be able to receive treatment from a provider of your choice, with the insurance company responsible for full payment.
10. **Work with the schools.** Insist on access to appropriate mental health consultation services. Suggest in-service training programs to enhance awareness about child psychiatric disorders. Request copies of your child’s educational records, including the results of any formal testing or other evaluations. Ask to be included in any and all school meetings held to discuss your child.
11. **Learn about the reimbursement and funding systems in your state.** The more you know, the better you can advocate on behalf of your child. How does Medicaid work? Which services are covered and which are excluded? Is there a “waiver program” which allows increased flexibility based on the specific needs of children and families? Is your child eligible? If not, why not? What other sources of funding are potentially available?

Advocating for Your Child: 25 Tips for Parents (continued)

12. **Get to know the state insurance commissioner and healthcare “ombudsperson” or consumer representative.** Ask them to attend regular meetings with parent groups. Let them know about your experiences.
13. **Use a lawyer, if necessary.** Learn about the local legal resources. Find out which lawyers in your community are familiar with educational and mental health issues. Talk to your local Protection and Advocacy agency or American Civil Liberties Union for suggestions. Call the State Bar Association. Talk to other parents who are lawyers or who have used lawyers. Consider a legal consultation to make sure you are pursuing all appropriate avenues and options regarding services for your child.

Statewide advocacy for all children, including your own:

14. **Become politically active.** Meet with state senators and representatives. Question candidates about their positions on access to necessary and appropriate mental health services for children and families. Testify at hearings on state legislation and budgets. Legislators are more likely to be influenced and persuaded by personal stories than by data, statistics or the opinions of professionals.
15. **Build coalitions and work with local advocacy and parent organizations** such as NAMI, NMHA and the Federation of Families. Develop and publicize a common “Agenda for Children’s Mental Health”.
16. **Teach children about advocacy.** Invite them to become involved in advocacy activities, where appropriate, but don’t force them to participate.
17. **Develop a legislative strategy.** If your state does not yet have parity legislation, put this at the top of the agenda. Other “family protection” initiatives include:
 - access to an independent panel to review and potentially reverse insurance company denials
 - consumer representation on community mental health center boards
 - adequate network provisions, which mandate timely and appropriate access to specialists
 - adequate funding for school and community based mental health services.

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18. **Seek bipartisan support.** Mental illness affects families of all political persuasions. Building a broad base of support has been a key to successful legislative initiatives, both at the State and Federal levels.
19. **Fight stigma.** Develop an ongoing local education campaign that reiterates the key messages:
 - child psychiatric disorders are very real illnesses
 - they effect lots of kids and adolescents
 - fortunately, they are also quite treatable, especially if treatment begins early and is individualized to the needs of each child and family.
20. **Become involved with medical education.** Meet with local medical students and residents. Sensitize them to the issues and challenges families face when caring for a child with emotional and behavioral problems.
21. **Use the media.** Write letters to the editor and/or op-ed pieces on child mental health issues. Meet with local reporters covering health care topics. Suggest story ideas to local TV stations.
22. **Work with local professional organizations.** Psychiatrists, psychologists, social workers, psychiatric nurses, and mental health counselors are natural allies with a common advocacy agenda. Coordinate efforts on issues such as parity, funding for mental health services, managed care oversight, etc. Professional organizations may also have access to resources, including funds for lobbying and/or public education initiatives, from their national associations.
23. **Talk to other parents.** Seek out and join local parent support groups. If none exist, consider starting one. Develop an email “listserv” to facilitate communication. Circulate articles, information and suggestions about local resources.
24. **Attend regional and national conferences** of parent and advocacy organizations. Such meetings provide information, ideas, camaraderie and support. Sharing experiences with other parents is both helpful and empowering.
25. **Don’t give up.** Aim for and celebrate incremental victories and accomplishments. Remember, advocacy is an ongoing process!

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There's no right or wrong way to be an advocate for your child. Advocacy efforts and initiatives should be individualized to your state, community and the particular issues, circumstances and needs within your family. Advocacy is also hard work. Even when people want to help, and are willing to listen, it takes lots of time and energy to change the system. But when it works, and it often does, the outcome is clearly worthwhile. You really can make a difference, both for your own child, and ultimately for all children who need and deserve access to appropriate and effective mental health treatment services.

Resources

The following organizations are excellent resources regarding advocacy on behalf of children's mental health:

American Academy of Child and Adolescent Psychiatry
3615 Wisconsin Avenue, NW
Washington, DC 20016
(202) 966-7300
www.aacap.org

American Psychiatric Association
Division of Public Affairs
1400 K Street, NW
Washington, DC 20005
(202) 682-6140
www.psych.org

Federation of Families for Children's Mental Health
1101 King Street, Suite 420
Alexandria, VA 22314
(703) 684-7710
www.ffcmh.org

National Alliance on Mental Illness
3803 N. Fairfax Dr. Suite 100
Arlington, VA 22203
(703) 524-7600
www.nami.org

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Resources (continued)

National Disability Rights Network (NDRN)
900 Second St. NE, Suite 211
Washington, DC 20002
(202) 408-9514
www.ndrn.org

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
1-800-969-6642
www.nmha.org

The Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202) 628-8787
www.childrensdefense.org

Bazelon Center for Mental Health Law
1101 15th Street NW, Suite 1212
Washington, DC 20005-5002
(202) 467-5730
www.bazelon.org

The Balanced Mind Foundation
1187 Wilmette Avenue
P.M.B. #331
Wilmette, IL 60091
(847) 256-8525

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
8181 Professional Place, Suite 201,
Landover, MD 20785 CHADD
1-800-233-4050
(301) 306-7070
www.chadd.org

Juvenile Bipolar Research Foundation
49 S. Quaker Road
Pawling, NY 12564
(203) 226-2216
www.bpchildresearch.org

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Resources (continued)

Depression and Bipolar Support Alliance (DBSA)
730 N. Franklin Street, Suite 501
Chicago, IL 60610
1-800-826-3632
(312) 642-0049
www.ndmda.org

Depression and Related Affective Disorders Association (DRADA)
Meyer 3-181, 600 North Wolfe Street
Baltimore, MD 21287-7381
(410) 955-4647
www.drada.org

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Fassler, D. (2003). Advocating for Your Child: 25 Tips for Parents. Retrieved from http://www.nami.org/Content/ContentGroups/CAAC/How_To_Advocate_For_Your_Child.htm