

Understanding Nonverbal Learning Disorders in Children With Spina Bifida

Carol L. Russell

Kayla, a fifth-grader with curly, dark brown hair and dark eyes, glares at her mother as she rolls her wheelchair in the front door. She and her mom exchange hugs, then Kayla explodes into tears as she describes her day. She had a different paraeducator that day, the schedule was rearranged since they had a concert practice, she missed some of her favorite class—art, her dad was a few minutes late to pick her up, and she had math homework to do, which she didn't understand.

Kayla continues to go over these things and gets even more upset. Her mother knows that her daughter will continue until she gags and throws-up if she doesn't intervene, so her mother gets out bubbles and has Kayla blow them with her, knowing that if Kayla's blowing, she can't be throwing up. Kayla's mother listens to her, then tries to move on to the "what's for dinner" and "let's look at the mail" topics. Kayla calms down, but continues to bring up each of the things that were different than her normal routine throughout the evening. Kayla expresses feelings of confusion and being overwhelmed by her day. Kayla's mother listens but is careful not to let Kayla get too upset and intervenes with bubbles or controlled breathing (Lamaze type) as needed. She

continues with the evening routine, knowing that this is what Kayla needs most.

At bedtime, Kayla reviews her frustrating day, and the tears start again. Her mom listens, reassures, and reminds Kayla that things should be better tomorrow. With a kiss and a wish for sweet dreams from her mom, Kayla soon falls asleep, exhausted.

Coping for Children With Nonverbal Learning Disorders

Changes are easier for some than for others. These things that were out of routine for Kayla might frustrate any child during the day. They may come home and share, perhaps get upset. But the need for understanding and appropriate response differs for children with nonverbal learning disorders. Kayla's response was much more intense and lasted longer than that of a child who is typically developing. She could not "let it go." Kayla thrives on routine, and new and novel things can be overwhelming, even exhausting.

One of her doctors put it best by saying that Kayla uses full energy—physically, neurologically, and emotionally—to just get through her day, and she can be exhausted by evening, even when there are few changes during the day. When the routine changes, she

Energy and Spina Bifida

Response to change can be much longer and more intense for a child who has NLD and spina bifida. Routine is essential. Full mental and physical energy is needed to just get through the day. The child can be exhausted by evening—even when there are few changes in the day.

may be able to "hold it in" (which takes energy) for the day, but the emotional explosion occurs once she's home.

This article provides information regarding nonverbal learning disorders (NLD) and NLD specific to children with spina bifida. Teachers, therapists, and other professionals including administrators and family members of children with spina bifida will benefit from learning about this disorder and using the resources referenced throughout. This article defines NLD and describes its characteristics and its general effect on the child's learning is discussed. Discussion includes who should diagnose NLD and the important role of intervention. NLD specific to children with spina bifida is described and how it influences their learning is discussed. This article also presents effective support for the child with spina bifida and

NLD, including available resources. Teachers, family members, therapists, and other professionals must recognize the nonverbal learning needs that are neurologically based in children with spina bifida and appropriately support them in the learning environment to truly offer them success in school and in life.

What Is a Nonverbal Learning Disorder?

Nonverbal learning disorders were first noticed in the early 1970s as researchers noted the large discrepancies between the verbal and performance IQ scores of some children with learning disabilities (Myklebust, 1975). Unfortunately, 30 years later most professionals and educators in general have not heard of NLD (Thompson, 1997). "Current evidence and theories suggest destruction, disorder or dysfunction of the white matter (long myelinated fibers in the brain) in the right hemisphere could be the cause for nonverbal learning disorders" (Thompson, 1997, p. 11). According to Thompson, researchers have observed NLD in individuals with neurological insults such as

- Moderate to severe head injuries.
- Repeated radiation treatments.
- Congenital absence of the corpus callosum.
- Treatment for hydrocephalus.
- Removal of brain tissue from the right hemisphere.

What Are Some Characteristics of NLD?

Thompson (1997) described three categories of dysfunction that are evident in children with NLD:

1. **Motoric:** lack of coordination in both fine and gross motor skills; may have severe balance problems, difficulty with fine motor tasks.
2. **Visual-spatial-organizational:** lack of image; difficulty with visual recall, spatial perception, and spatial relations.
3. **Social:** lack of ability to comprehend nonverbal communication; difficulty adjusting to transitions and novel situations; significant challenges with social judgment and interactions (Little, 1993).

A comprehensive checklist for each of these areas is included in Thompson's (1997), *The Source for Nonverbal Learning Disorders*, pp. 40-42.

How Does This Effect the Child's Learning?

Neuropsychological testing is used to identify difficulty in the following areas:

- Impulsivity
- Attention to tasks
- Memory
- Sequencing
- Organization
- Higher reasoning
- Visual-perceptual skills

People with spina bifida often have difficulty with higher order conceptual reasoning abilities such as

- Efficiency of processing
- Mental flexibility
- Conceptualization
- Problem-solving abilities (Sandler, 1997; Rowley-Kelly & Reigel, 1993).

The learning needs of children with spina bifida have often led to a diagnosis of attention deficit disorder (ADD) or attention deficit/hyperactivity disorder (ADHD). Thompson offers a detailed comparison of ADD/ADHD and NLD that is helpful in differentiating the two (Thompson, 1997, p. 54). Examples include

ADD/ADHD	NLD
<ul style="list-style-type: none"> • Difficulty following through. • Easily distracted. • Difficulty playing quietly • Does not seem to listen. • Manipulates situations. • Seeks out novelty, surprise, and newness. 	<ul style="list-style-type: none"> • Slow or arduous performance of tasks. • Faulty spatial perceptions. • Talks through all activities. • Misreads nonverbal communication. • Can't comprehend personal manipulation or deception. • Avoids novelty.

Who Should Diagnose NLD?

"It takes an experienced professional to pick the child with NLD out of the lineup!" (Thompson, 1997). Proper diagnosis is important but can take some time because NLD can seem invisible to the casual observer. An interdisciplinary team, including parents, should conduct the assessment. The team should be knowledgeable of NLD and how to distinguish it from other disorders (Brumback, 1996).

Thompson (1997, p. 45) included a helpful chart of comparisons of various syndromes with social incompetencies, including Williams syndrome, autism, Asperger's syndrome, pervasive developmental disorder, hyperlexia, and nonverbal learning disabilities. This chart clearly differentiates these various syndromes, looking at areas of speech, IQ, motor, and behavior domains. The diagnosis should lead to recommendations for supporting the child with NLD. In Thompson's (1997), *The Source for Nonverbal Learning Disorders*, these supports were referred to as compensations, accommodations, modifications, and strategies.

Identification and support services for children with NLD are urgent due to the risk of depression, withdrawal, panic attacks, anxiety, and even possible suicide (Thompson, 1997).

How Important is Intervention?

Literature suggests that it is possible to help children with NLD compensate for their neuropsychological deficits, and we can teach problem-solving, memory strategies, and coping techniques. The urgency of identifying and giving support services to children with NLD is "especially acute" due to the risk of depression, withdrawal, panic attacks, anxiety, and even possible suicide (Thompson, 1997). When we overestimate the child's abilities or put unrealistic demands on the child, ongoing emotional problems can result (Fletcher, 1989; Kowalchuk & King, 1989).

How Is NLD Specific to Children With Spina Bifida, and How Does It Affect Their Learning?

Most children with spina bifida who have lesions (openings on the spine) above the sacral area are born with abnormalities of the brain structure, called Arnold Chiari II malformation (brain stem elongation). Most (90%-95%) have hydrocephalus (too much cerebral spinal fluid in the ventricles), which requires a shunt—a tube to help drain the fluid into the stomach. The shunt is usually placed in the right side of the brain. In addition, many children with spina bifida are born with little corpus colosum, which is a wide band of neural fibers interconnecting the two cerebral hemispheres of the brain (Rowley-Kelly & Reigel, 1993; Sandler, 1997). All these factors contribute to NLD in children with spina bifida.

Children with spina bifida and NLD generally find early success in preschool years, with strengths in language development and remarkable verbal expression. The preschooler may have poor fine-motor coordination, demonstrate spatial confusion, have difficulty with self-help skills, prefer routine, have difficulty with transitions, and over-focus on tasks. Children with spina bifida demonstrate good performance in early elementary years in areas of spelling, math facts, and reading. The student in elementary school may

- Work slowly and have difficulty completing tasks on time or handing in finished work.
- Exhibit more pronounced large- and fine-motor challenges.
- Have visual-spatial-organizational difficulties.
- Talk continuously.
- Continue to have difficulty with fine-motor, writing, and copying skills.
- Take things literally, trust naively, and misinterpret.
- Have difficulty with change (e.g., substitute teachers).

The incredible rote memory that helps the child in early grades fails the child when the academic demands are more complex (Thompson). These challenges increase in middle school, and in many cases, the child is first diagnosed with NLD during adolescence

(Thompson, 1997). NLD does not go away; one does not "grow out of it."

How Can We Best Support the Child With Spina Bifida and NLD?

As stated previously, learning by observing is difficult to impossible for a child with NLD. Interestingly, the former title of *The Source for Nonverbal Learning Disorders*, by Thompson (1997) was *I Shouldn't Have to Tell You*. In this book Thompson stated,

If a child is constantly being admonished with the words, "I shouldn't have to tell you this!" it should alert everyone that something is awry, because you DO have to tell him everything....Such a child will cope by relying upon language as his principal means of social reasoning, information gathering and relief from anxiety. As a result, he is constantly being told, "You talk too much!" (p. 13)

We, as professionals and family members, DO need to tell them everything. We must do this with a positive attitude without demeaning or laughing at them because they don't "get it." There's no humor in continually "not getting it." We must try to explain and break down the subtleties, inferences, and nonverbal communication in life. We must also break down assignments, the plot of a movie, or the social response (or nonresponse) of a friend.

The effects of NLD in children with spina bifida permeates all areas of their lives, such as

- Self-care: remembering to do self-care and the sequences of self-care tasks, importance of catheterization on time and understanding realistic consequences if not done, importance of checking for and prevention of pressure sores.
- Cognitive: understanding concepts, homework expectations, memory challenges, difficulty remembering sequences, challenges with tasks that require visual-spatial skills.
- Physical: difficulty with handwriting and copying, motor planning, and sequences.

- Social: problems making and keeping friends, lacking an understanding of inferences and subtleties, failing to get jokes, needing an explanation to understand a movie plot.

- General life skills: organization of time, money, and relationships.

Dysfunctions with NLD intensify as individuals get older; they are not outgrown (Thompson, 1997).

Spinabilities: A Young Person's Guide to Spina Bifida, edited by Lutkenhoff and Oppenheimer (1997), has wonderful tools to assist young people with spina bifida and NLD. The authors break down materials and make them easy to read and understand. Tools are included, such as self-care charts for monitoring skin care and hygiene, tips for organizing school life, writing tips, checklist for work readiness, and many other helpful suggestions.

We can learn best from observing and listening to our children. The following list of needs is shared, by permission, from Mikaella, an eighth grader who has NLD and spina bifida. Although a few items may look similar to the suggestions from Kayla's list (see box, "Recommendations for Kayla"), this list is stated in Mikaella's own words, illustrating her awareness of her individual needs and challenges. Mikaella writes:

Please

- Explain things in detail and break them down for me.
- Help me to remember. (If I know today, I may not remember tomorrow.)
- Write it down or draw it out for me.
- Help me with organization. I struggle with sequences, outlining, space and time, money, scheduled events, etc.
- Provide a structured routine for me. Please schedule related services as early at the beginning of the year as possible, and tell me to put it on my calendar.
- Know that it really helps me when I have the same teacher for my first and my last class. That way I am in the same place at the beginning and end of the day. This helps me get

Examples of NLD Dysfunction

Thompson's (1997) three categories of NLD dysfunction are illustrated by examples specific to children with spina bifida:

1. **Motoric:** Although it varies, depending on the level of the child's lesion on the spine, children with spina bifida have some paralysis (the higher the lesion, the higher the paralysis), and gross motor skills involving the lower body will be affected (Rowley-Kelly & Reigel, 1993; Sandler, 1997); yet, balance, even trunk balance, can be difficult. Fine motor and self-help skills such as scissor cutting, handwriting, shoe tying, buttoning, or peeling an orange may come slowly, and perhaps with frustration (Lutkenhoff & Oppenheimer, 1997; Rowley-Kelly & Reigel, 1993; Sandler, 1997). According to Thompson, a young child with NLD is hesitant about motorically exploring the environment due to kinesthetic processing and spatial perception challenges (1997). When this is combined with paralysis and perhaps nonaccessible environments and barriers, motorical exploration is lacking.

2. **Visual-spatial-organizational:** Children with NLD have difficulty creating a visual image, so coming up with an idea and putting it on paper is a challenge. They have difficulty with visual recall. Seeing what is on the board or in the text and copying it is strenuous because they may forget it by the time they get to their paper. Handwriting can be laborious at first, remembering how letters are formed—how many loops, bumps, etc. Handwritten spelling tests require not only the memory of how to spell the word, but how to form the letters. Some children know well how to spell the words, but cannot accurately write the words. Difficulties with spatial perception and spatial relations can make maps, graphs, tables, and so on difficult to understand or produce. It is difficult to change from one activity to another. The child with NLD may use all his or her concentration and attention just to make it through the day or even through a crowded room (Thompson, 1997). Again, add to that the wheelchair or walker that a child with spina bifida may need to maneuver, and it's even more of a challenge. On top of that, if there is a new or complicated situation, or a change in schedule, then imagine the frustration for this child.

Organization is a challenge for the child with NLD and spina bifida. Children with organizational problems often have difficulty with remembering to hand in completed homework, knowing what is relevant information and what is not, and prioritizing tasks. The whole concept of time and money can be overwhelming. They survive the changes in routine only if prepared and repeatedly rehearsed. The need for organization permeates all the child's life; therefore, supports are needed in all environments.

3. **Social:** Children with NLD find it challenging to comprehend nonverbal communication. Body language or tone of voice can be misinterpreted. Students with social problems often have difficulty with the idea of personal space, facial expressions of others, and nonverbal signals of pleasure or displeasure (e.g., something has gone far enough). Verbal processing may be efficient, but receiving and understanding nonverbal communication can be difficult, if not impossible (Thompson, 1997).

Children with spina bifida often develop proficient language skills at an early age. This can mask the true understanding of communication. On the surface, children with NLD seem to understand and are very social; however, social interactions that require higher order reasoning can cause these children to struggle.

Communication that includes inferences or subtleties is confusing. Deceit and manipulation are not understood. Children with NLD may naively trust and therefore can be taken advantaged of. Due to their difficulty adjusting to transitions and novel situations, many social situations are challenging and these children may avoid them. Significant challenges with social judgment and interactions can cause life-long problems for individuals with NLD.

Visual-spatial-organizational challenges result in difficulty with

- Creating a visual image
- Visual recall (like copying)
- Handwriting
- Spatial perception and spatial relations (maps, graphs, tables)
- Transitions

Recommendations for Kayla

The following is a general list of recommendations for Kayla, who has NLD and spina bifida, compiled by her individualized education program (IEP) team over several years:

- Provide extra time for in-class tests and assignments.
- Provide extra assistance with understanding material (break it down, assist with highlighting, note general area and page numbers to assist with referencing, alphabet grid on desk to use as a quick reference for writing).
- Provide enough time to respond to compensate for processing speed, both verbally and in writing. It is not uncommon for children to want to say something socially, or raise their hands to give an answer, but forget what they were going to say once it's their turn.
- Provide help with note taking to compensate for the decrease in mental processing speed and decreased memory.
- Modify assignments that have copying as the main component.
- Keep requirements for written output to a minimum. Try not to let motor deficits block learning and academic success.
- Preview material and use supplemental aids, such as outlines, study guides, and highlighting, to allow the child to benefit from instruction.
- Specifically teach study skill techniques.
- Use organizational techniques for keeping track of material. A daily system of monitoring organization must be in place on a daily basis.
- Use verbal strengths to help with organization, problem-solving, and learning (such as self-talk).
- Encourage learning and using memory enhancement techniques.
- Provide a structured, predictable environment.
- Specifically discuss and prepare the child for transition and changes. It is often helpful to write out changes in the schedule so the child can refer to this when there is a question. This aids independence (because the child can refer to the schedule on his or her own) and also saves the teacher or parent from repeating the plan again and again.
- Accommodations for testing:
 - Minimize visual confusion on tests and answer sheets. (e.g., remove decorative graphics and nonrelevant visuals).
 - Use verbal testing as needed.
 - Modify or eliminate timed tests.
 - Eliminate or break down word problems and abstract essay questions to a concrete level with extraneous information eliminated.
- Provide encouragement to participate in structured extracurricular peer groups.
- Verbally teach the child things that other students learn intuitively or from observing.
- Provide verbal interpretation of visual cues to help the child understand social situations. Movies can offer good practice for this. (Tyler et al., 2001)

organized and ready at the beginning of the day and together at the end of the day, getting ready for the next day.

- Keep things concrete. I get confused with multiple meanings.
- Be aware that I do better in the morning than in the afternoon, when I'm more tired.
- Be patient with my medical needs. With my meds, I can sometimes become overheated and flushed. I will let you know if I need medical attention.

- Know that I do need support from my paraeducator, not all the time, but many times.
- Respect my desire to be fully included in the general education classroom and activities. Since the age of 2, I have been with my friends and I like being with them. My parents have always tried to make sure I was fully included.
- Know that I may be absent due to medical appointments.
- Know that I need pathways throughout the classroom.
- Know that I will need help catching up on material I may

have missed if absent or out for self-care needs.

- Help me remember to drink the fluids that I need each day and to do my push-ups to relieve pressure and prevent pressure sores, even though I don't like to.
- Review with me classroom emergency procedures. Let me retell you so you know that I understand (Tyler et al., 2001).

Mikaella also illustrated NLD clearly, as she stated after seeing the Harry Potter movie while in the process of reading the book,

The early development of language skills can mask the true understanding of communication in children with NLD and spina bifida. They appear to understand and may be very social; however, social interactions requiring higher-order reasoning (e.g., inferences and subtleties) cause struggle and frustration.

"You know how everyone is saying that you need to read the Harry Potter book first, and then see the movie? Well, I think I needed to see the movie first, to picture it, and then read the book. It makes a lot more sense to me that way." She articulately expressed her need to see the image first so that she could picture it in her mind and that she could make more sense of it all after seeing the movie first.

What Are the Best Resources Available to Get More Information About NLD and Children With Spina Bifida?

An increasing number of helpful resources are available to better understand NLD and children with spina bifida, including the resources referenced in this article. Of particular help is *The Source for Nonverbal Learning Disorders* by Thompson (1997), which has been repeatedly cited. As stated earlier, Thompson lists specific supports, referred to as compensations, accommodations, modifications, and strategies (pp. 109-122). She also lists strategies specific to curriculum areas (pp. 93-98).

Another excellent resource is the SANDI Project (Spina Bifida Assessment of Neurobehavioral Development,

International), which can be located on the Internet at: <http://ped1.med.uth.tmc.edu/spinabifida>. This project is a collaborative effort between various educational and medical institutions. An additional resource is, *Helping Your Child with Spina Bifida Learn: A Manual for Parents and Teachers* by Lloyd (1999).

Your best resource is the child and the child's family. Listen to them. Learn from them. Being a parent of a child with spina bifida and an educator of early childhood special education in higher education, I know that this information is more than valuable—it has changed my family's life. As a parent, this information has shed new light for my husband and me so we more fully understand our daughter's learning needs. With the understanding of nonverbal learning disorder, we have changed our whole outlook and response with our daughter, who is now age 14 and in the 8th grade.

As an educator, I am compelled to share this information with other professionals and parents. It helps us to make sense of what doesn't make sense to our children with spina bifida and NLD. We need to validate and respond to the nonverbal learning needs of children with spina bifida. We must recognize the nonverbal learning needs that are neurologically based in children with spina bifida and appropriately support them in the learning environment to truly offer them success in school and in life.

References

- Brumbach, R. A. (1996). Nonverbal learning disabilities, Aspergers syndrome, pervasive developmental disorder—Should we care? *Journal of Child Neurology*, *11*, 427-429.
- Fletcher, J. M. (1989). Nonverbal learning disabilities and suicide: Classification leads to prevention. *Journal of Learning Disabilities*, *22*, 176-179.
- Kowalchuk, B., & King, J. D. (1989). Adult suicide versus coping with nonverbal learning disorder. *Journal of Learning Disabilities*, *22*(3), 177-179.
- Little, S. S. (1993). Nonverbal learning disabilities and socioemotional functioning: A review of recent literature. *Journal of Learning Disabilities*, *26*, 653-665.
- Lloyd, A. (1999). *Helping your child with spina bifida learn. A manual for parents*

- and teachers*. National Institute of Health and Human Development, Grant #PO1 HD35946: SANDI Project, Houston, TX.
- Lutkenhoff, M., & Oppenheimer, S. G. (Eds). (1997). *Spinabilities: A young person's guide to spina bifida*. Bethesda, MD: Woodbine House.
- Myklebust, H. R. (1975). Nonverbal learning disabilities: Assessment and intervention. *Progress in Learning Disabilities*, *3*, 85-121.
- Rowley-Kelly, F. L., & Reigel, D. H. (1993). *Teaching the student with spina bifida*. Baltimore: Brookes.
- Sandler, A. (1997). *Living with spina bifida: A guide for families and professionals*. Chapel Hill: The University of North Carolina Press.
- Thompson, S. (1997). *The source for nonverbal learning disorders*. East Moline, IL: LinguSystems.
- Tyler, J., Russell, C. L., Kessler, B., Zapeda, M., Russell, F. L., & Russell, T. (2001, September). Powerpoint inservice presented to Emporia Middle School, Emporia, KS.

Carol L. Russell, Associate Professor of Early Childhood, Elementary Teacher Education, Emporia State University, Emporia, Kansas.

Address correspondence to Dr. Carol L. Russell, Elementary Teacher Education, Box 4037, Emporia State University, Emporia, KS 66801.

TEACHING Exceptional Children, Vol. 36, No. 4, pp. 8-13.

Copyright 2004 CEC.