

INSIGHTS Into Spina Bifida

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It's Back-to-School Time! Who's Teaching Whom?



Education has become more complicated for everyone—no longer do most parents simply devote a day to shopping for notebooks and pens and consider their prep work over. And for parents of students with spina bifida, and the students themselves, there are so many issues to think about: accessibility, learning disabilities, Individualized Education Programs (IEPs), cathing at school and more.

The articles in this special insert of *Insights* present advice from professionals and students with spina bifida on nonverbal learning disabilities, latex avoidance, IEPs and more. This information should be helpful to parents, students and teachers.

What may be most daunting to parents and students is the fact that they may need to educate their teachers and administrators. Many

people don't know much, if anything, about spina bifida. And nonverbal learning disabilities, which affect many children and adults with spina bifida, are still relatively unknown. Share these *Insights* articles and any others you think may be helpful with educators.

Not all children with spina bifida have learning disabilities, and your student may not need some of the supports and strategies suggested here. But if your child is struggling and the answers seem elusive, you may need a neuropsychological evaluation or other help from professionals. A good rule of thumb is that if you can't figure out a solution (or can't even identify the specific problem), it may be time to call in the experts. But don't be surprised if you have to teach them a thing or two in the process. •

Education: The Key to Opening Employment Doors

Everyone seems to agree that employment for people with disabilities is a good thing: the government, disability organizations and most people with disabilities themselves. The government is trying to help by eliminating Social Security-related disincentives and providing support services.

But a large part of the answer to the employment question is education.

Career development doesn't start with a job interview or application. It begins at school, with a good education and role models who demonstrate what's possible and how to achieve it. For people with disabilities—as for everyone else—workforce participation and achievement rise along with educational levels. Like their nondisabled counterparts, college graduates with disabilities earn more money than non-graduates. College graduates are also more likely to work fulltime and hold a management/professional position than those without degrees. But according to the National Organization on Disability (NOD), 22 percent of Americans with disabilities fail to graduate high school, compared to 9 percent of those without disabilities.

Start Early—But It's Never Too Late

In her years of providing counseling services to families living with disabilities, psychologist Kay Kriegsman, PhD, observed one characteristic that successful families seemed to share: looking ahead. She described that as the ability



to look ahead to a desirable future and work back from there. For example, imagine your 5-year-old daughter who has spina bifida as a middle-schooler. What will she need to know, what skills will she need to succeed in middle school? And what should you be teaching her now to help her prepare?

Most experts seem to agree that middle school is when parents and students should begin preparing for that critical transition to higher education, employment and independent living, by thinking about (and acquiring!) the skills they will need to succeed. Too often the individual education programs (IEPs) for students with disabilities focus exclusively on academic subjects, when actually the students also need to focus on independence, social skills,

assertiveness and other skills required to live successfully as an adult. Technical know-how is always important at work, but most jobs require many other "softer" skills, such as being on time, meeting deadlines, getting along with colleagues and self-starting.

Confidence and self-esteem are also crucial in landing and keeping a job, and these are usually acquired through achievement and practice. More high schools today require students to perform community service, which is an excellent means of acquiring valuable experience and practicing behaviors valued in the workplace. High school students with disabilities may want to think about volunteering at a local disability organization, interning at a law office or tutoring at-risk elementary students. Not only does that type of experience bode well for future employment, it's very attractive on college applications, which have become competitive.

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Nonverbal Learning Disabilities and Spina Bifida: Understanding the Challenges in School, at Home and in the Community

Recognizing patterns of behavior or symptoms is a slow process. It has taken time to link together the learning challenges now considered manifestations of nonverbal learning disability (NLD). While NLD has been studied for 20 to 30 years, it is neither widely known nor well understood. What we do know is that many people with spina bifida share a constellation of symptoms that create challenges for them academically, socially, professionally and in activities of daily living. It's important to note that although NLD is a learning disability, it affects life outside of school. Adults with NLD living on their own for the first time may have trouble finding or keeping a job, managing finances, planning healthy menus or maintaining their health.

NLD is a label, and labels provide both advantages and disadvantages. One advantage is that individual symptoms and challenges make more sense when viewed as part of a larger processing problem—the pieces finally fall into place. Another is that as we recognize patterns of processing challenges, we then devise supports and strategies to overcome these challenges, so that parents and students don't have to keep reinventing the wheel. And on a practical basis, a label can be the passport to the special education services and supports a student struggling with NLD may need.

What Is NLD?

People with NLD are not stupid, not incompetent and not lazy. They simply learn differently than most people. Unfortunately, most schools teach to the norm, which often leaves students who don't learn that way to flounder.

Basically, NLD refers to processing challenges in the areas of visualization, visual/motor coordination, motor planning and tactile facilities—being able to use touch to identify and understand things. For most people with NLD, their strengths are verbal: speech development, language processing and verbal memory. The reason so many students with NLD struggle with math is because it requires more spatial and nonverbal concepts. For example, it's difficult to understand fractions without imagining an object divided into pieces. People with NLD may experience difficulties in problem-solving and comprehension, particularly if the situation or material is new.

As children get older, it becomes more complicated. Even children who seemed to excel in elementary school may struggle with the different demands of middle and high school. At the elementary school level, teaching is primarily carried out via verbal repetition—which is very effective for students with NLDs. But in high school, students are increasingly expected to work independently, to problem solve, to apply knowledge learned in one area to another and to organize their own work—precisely the areas that many students with

For more information on nonverbal learning disabilities:

Nonverbal Learning Disabilities at School: Educating Students with Nld, Asperger Syndrome and Related Conditions by Pamela B. Tanguay, Sue Thompson, paperback, April 2002.

Nonverbal Learning Disabilities at Home: A Parents Guide by Pamela Tanguay, Byron P. Rourke, paperback, April 2001.

LD Online (ldonline.com) is a rich source of information on all types of learning disabilities, including nonverbal.

NLD find challenging. Starting in middle school and continuing through high school, college and beyond, life requires abstract thinking and inferential reasoning—reading between the lines.

As language becomes more complex, it also becomes more abstract. People and books speak with more idioms, similes, metaphors and examples—all of which may be confusing to people with NLD. Students may begin having difficulty with reading comprehension, and writing may become more challenging. Sometimes students with NLD have a hard time getting their homework done—and remembering to turn it in. Planning long-term projects, such as a term paper, may seem daunting.

It isn't easy, figuring out exactly which behaviors fit into the NLD framework, and which are typical teen, or even atypical teen but not NLD. Parents need to try to read their child. Jim Loomis, PhD, cited an example of a 15-year-old whose parents ask him to take out the trash within the next five minutes. But the teenager gets caught up in watching TV and forgets about the trash. Is it NLD or typical teen behavior? According to Dr. Loomis, if it's typical teen noncompliance and you punish him, it will usually work. If the behavior reflects a processing problem, punishing the teenager is likely to backfire—he's likely to become more oppositional, angrier and more frustrated. Parents need to make those assessments all the time—processing problem or typical kid?

It can be confusing to parents, although no more so than to students struggling with their schoolwork, and discovering that what works for other students, may not work for them. Says Dr. Loomis, "We know there is a wide range of behaviors, lots of variability. The challenge is to adapt what we know about NLD, including general strategies that may help, to individuals."

Chores at Home

Timothy Brei, MD, said, "Kids need to be doing chores, starting by elementary-school age. Learning how to perform chores, at first with help, then independently, will help hone organizational skills and prepare young students for what's to come."

To show a young child how to clean his or her room, you would begin by pre-teaching—telling the child what he or she needs to do and the desired result. For example, "We're going to clean your room because this is something we need to do every week. We're going to make your bed, pick up your toys and put your dirty clothes in the hamper. When it's done, your bed will be made and the floor will look clean."

At first, parents will have to clean along with their kids, and provide lots of review and reinforcement. Then, slowly, parents can withdraw supports, and the child should take on more of the project himself. Dr. Brei said, "Particularly at first, parents may have to provide more learning supports than feels natural to them."

Strategies for Teachers and Parents

Although there is no one-size-fits-all approach to teaching students with NLD, Drs. Brei and Loomis have several suggestions for parents and teachers.

- 1. Teach to the student's strengths.** Students with NLD learn best by rote approaches involving lots of repetition. Pre-teaching is essential—the more clearly a teacher or parent can explain what they're planning to teach and their expectations, the better prepared the students will be to learn the material.
- 2. Teach verbally.** Demonstrations are not the best way to teach students with NLDs, because they're often not very observant. Teachers should use verbal—rather than visual—instructions and cues.
- 3. Break projects into a series of smaller, simpler tasks.** People with NLD may find a complex task, such as writing a term paper, overwhelming. But dividing the work into subtasks makes the project more manageable.
- 4. Practice, practice, practice.** According to Dr. Brei, teaching difficult material once isn't enough. Students with NLDs need to practice what they've learned in order to really take it in. Multiple practice trials are a good idea.
- 5. Explain the "big picture."** For example, if students are reading a novel, it may help to explain the novel's general concepts first, so students know where to focus their attention. If you give them the framework, they can fit in the details.

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Keeping Your Child Latex-Safe at School

By Elli Meeropol, RN, MS, PNP
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Avoidance of natural latex rubber is now an accepted standard of care for people with spina bifida. In order to be effective, latex must be avoided in all spheres of life—in medical settings, at home, in school and in the community. Latex avoidance not only prevents allergic reactions in children who already have a clinical latex allergy, it also minimizes the risk of creating new sensitization in children at high risk for developing this allergy. In general, avoidance strategies in the school must balance two potentially contradictory needs: maximum inclusion of the child in school life and activities, and safety from potentially life-threatening exposure to latex. Designing an individual school latex-safety strategy for each child with spina bifida requires cooperation between the child and parents, the school nurse, teachers and administrators.

Identifying areas of potential latex exposure is crucial to designing a safe school for your child.

This article reviews four important components of this cooperative effort: working with the school, surveying the environment for potential exposures, designing emergency protocols and promoting self-care behaviors in the child. For basic information about latex allergy—what it is, how it occurs, and how to prevent it—families are referred to the SBAA *Spotlight* "Latex (Natural Rubber) Allergy in Spina Bifida" available via the SBAA website at www.sbaa.org.

Working with the School

Discussion with school staff is the first step in creating a latex-safe school environment. Articles about latex allergy have been published in the specialty health care literature and in school health journals and many schools are knowledgeable about latex avoidance. If your child is entering a school that has not had prior experience with latex allergy, it is important for the family to keep in mind how unbelievable and overwhelming this information can be at first. It may help to:

1. Begin working with the school several months before your child enters, if possible, to give school personnel time to understand and accept the new material.
2. Find an ally at the school, whether it is the school nurse, teacher, counselor or administrator. This person can help communicate both specific information about latex allergy prevention and a positive attitude about this new challenge to other school personnel.
3. Provide the school with a well-organized packet of written material about latex allergy. This packet could include:

In order to be effective, latex must be avoided in all spheres of life—in medical settings, at home, in school and in the community.

- the SBAA *Spotlight* on latex allergy
- the most recent SBAA latex list
- this SBAA *Insights* pullout
- a letter from the child's health care provider describing the allergy and the importance of avoidance, as this may increase school acceptance

If the school doesn't already have resource materials that include information on latex allergy, such as *Children and Youth Assisted by Medical Technology in Educational Settings* (from Project School Care, Children's Hospital, Boston), they may be interested in obtaining it. Latex allergy resources are also available on the web at www.sbaa.org, www.latexallergyresources.org/, latexallergylinks.tripod.com and www.execpc.com/~alert/schoolprod.html.

Identifying Potential Exposures

Identifying areas of potential latex exposure is crucial to designing a safe school for your child. This second step, best performed in cooperation with school personnel, involves becoming a latex detective. Armed with the latex list and a recent review of likely areas of exposure, the detectives look for clues in high-risk areas and activities:

- **Classroom:** Items like erasers and rubber bands, art supplies, science and lab equipment may contain latex. Many of these will cause no problem if they do not come in contact with your child.
- **Cafeteria:** Food preparation with latex gloves can cause latex-powder contamination. In addition, it is important for school personnel to understand the possible cross-sensitization between latex and certain foods such as bananas, kiwi and avocado.
- **Gym and playground:** Check for rubber mats and reconstituted tire flooring, balls and racquet handles.
- **Housekeeping supplies:** Latex gloves are often used to protect hands during cleaning and their use in hallways, classrooms or bathrooms may leave allergic powder on surfaces or in the air. Vinyl gloves can easily be substituted.
- **Nurse's office:** Take a very close look. Even if a child has a separate supply of nonlatex gloves and other first aid items, protein-laden powder from latex gloves used with other children can easily contaminate surfaces and remain airborne long enough to trigger a respiratory reaction.

- **Gloves:** These require special attention because of the powder issue. Some schools will agree to use nonlatex gloves for everything (including food preparation and housecleaning). Others may compromise by routinely using a low-protein, nonpowdered glove to eliminate the particles of latex in the air, and to reduce exposure for all children and staff. Nonlatex gloves, however, must still be used for children with latex allergy, and, in the author's opinion, for all children with spina bifida due to their high-risk status.
- **School buses:** Floor mats may be latex, and airborne natural latex rubber from tires in areas of heavy traffic may be a potential exposure. First aid kits in school busses may be pre-packaged with latex gloves.
- **Field trips** can be particularly challenging. Safety checklists for trips should include emergency medications and specify that portable first-aid kits have nonlatex gloves, tape and bandages. Parents may want to scope out field trip locations beforehand for latex safety. In evaluating lunch facilities, pay special attention to gloves used in food preparation and to balloon decorations. Parents may want to volunteer to be a chaperone and pack a picnic lunch for parent and child if there are concerns about possible latex contamination of prepared food.
- **Birthday parties** in school are also potential problems. Talk to the school about what decorations are allowed at school celebrations. Common issues arise with balloons and with cross-reactive foods such as bananas.

The social and emotional aspects of being part of the group—or of being different—may be magnified by a unusual condition like latex allergy.

Designing a latex-safe school environment can seem like an overwhelming task, and parents may experience some resentment from school personnel. It sometimes helps to point out to school staff that children with spina bifida are not the only children at risk for latex allergy. Over the past few years increased rates of latex allergy have been reported in children with asthma, with other allergies (eczema, food allergies), with cerebral palsy and with ventriculoperitoneal shunts, as well as in children who have had multiple or early surgeries. So the school is likely to have other children at risk for latex allergy.

Developing Emergency Protocols

The third step in developing a latex-safe school is developing emergency protocols. These protocols should include specific plans

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Educators, IEPs and IDEA: A View from the Inside

Public schools in the United States are governed by the Individuals with Disabilities Education Act (IDEA), which recognizes 13 disabilities under the law. Learning disabilities are defined very specifically, and must meet an aptitude/achievement discrepancy formula, meaning there must be a significant difference between a student's score on an intelligence test and on a comparable achievement test. And the difference may not be due to factors such as socioeconomic status, language, opportunities, etc.

The IEP meeting needs to consider the whole child—not just grades and academics.

IDEA does not recognize social or nonverbal deficits as learning disabilities. The law has yet to catch up to the reality lived by many students with spina bifida. According to Sunny Stephens, PhD, former Director of Special Education Services in the San Antonio Independent School District, "Regardless of whether social or nonverbal deficits are formally identified as learning disabilities under the law, they are truly debilitating and are often more incapacitating than legally recognized learning disabilities. It is incumbent upon education professionals to intervene in order to help the student succeed in life, whether he or she is a scholar or not. Education needs to address whatever a student needs to learn in order to function in his or her environment—whatever it may be."

So in today's legal environment, students with spina bifida who have nonverbal learning disability (NLD) need to start out by qualifying for special education services under another category. For most students with spina bifida, that means either "other health impaired" or "orthopedically impaired." Once a disability has been identified under any legal category, educators are legally required to address all problems interfering with the child's success. Dr. Stephens said, "Don't you dare let anyone tell you that nonverbal learning disability cannot be dealt with. You can teach organizational skills and nonverbal communication just like you teach reading or anything else."

According to Dr. Stephens, some of what looks like uncooperative behavior on the part of the school may simply reflect ignorance. NLDs are still relatively unknown and are not well understood by most educators. Dr. Stephens advises parents that the wisest course may be simply figuring out which behaviors require attention and then asking for supports in those specific areas, without focusing on the NLD label. She says, "The most successful approaches are using direct instruction to re-teach behavior, language experiences, holistic integrated instruction, task analysis and hands-on participatory activities.

Regarding the "No Child Left Behind Act," the new law requires that schools assess all children. Schools must test at least 95 percent of the various subgroups of children, includ-

ing students with disabilities. States must provide reasonable test-taking accommodations for students with disabilities.

The Role of Special Education Teachers

Special education teachers contribute important information and experience to the Individualized Education Program (IEP) process, addressing issues such as:

- how to modify the general curriculum to help the child learn
- the supplementary aids and services the child may need to succeed in the regular classroom and elsewhere
- how to modify testing so that the student can show what he or she has learned
- other aspects of individualizing instruction to meet the student's unique needs

Beyond helping to write the IEP, the special educator has responsibility for working with the student to carry out the IEP. He or she may:

- work with the student in a resource room or special class devoted to students receiving special education services
- team teach with the regular education teacher
- work with other school staff, particularly the regular education teacher, to provide expertise about addressing the child's unique needs

Special education teacher and behavior management specialist Patricia Archibold says that none of the students she works with have been labeled as having NLD. But she can see that many of them have difficulty interpreting nonverbal cues, and so she works them with on those behaviors.

For example, sometimes children with NLD unknowingly violate others' personal space, because they don't notice the nonverbal cues that discourage most people from coming closer, such as backing off slightly or flashing a warning look. So Ms. Archibold teaches that skill with an exercise, in which she separates the children into two equal groups, which stand opposite each other so that each child has a partner. One child has a stop sign. The other child walks toward his or her partner, stopping as soon as the partner holds up the

stop sign to indicate the boundary of his comfort zone. The class discusses what's happening as they make their moves and stops, and how different circumstances affect the amount of personal space they need, such as whether the approaching person is a stranger or whether it's dark outside.

Ms. Archibold said, "Eighty-five percent of communication is nonverbal. Without correctly interpreting facial expressions and other nonverbal signals, it's very difficult to understand what others are feeling—or to make yourself understood." Facial expression, voice intonation and body language actually speak much more loudly than words. For example, if you report that you're having a terrific time, but your expression is dour and your voice dull, most people will believe your nonverbal language rather than your words.

According to Ms. Archibold, kids with NLD need to learn that when we're talking about facial expressions, we're talking about emotions. And behavior specialists may need to start by building a vocabulary with emotional words, such as excited, surprised, worried and scared, and tying those words to feelings and experiences, and then, finally, to facial expressions. Ms. Archibold keeps a chart in the classroom, Feelings A-Z, that shows lots of different faces and the class works on matching emotions with faces. They also do consciousness-raising exercises, with the kids trying to express how they would feel about different events by their facial expression. They play the human mirror game, where the "mirror" must mimic the "person," with students and teacher taking turns in each role. All these sorts of activities can help children improve their focus, concentration and awareness. Research shows that socially successful children use eye contact and smiling effectively. These skills come more easily to some children than others, but all children can be taught.

Clearly, many parents have difficulty getting the services their students need from their schools. Schools work under budgetary constraints and may have limited awareness of spina bifida and NLD. Dr. Stephens and Ms. Archibold emphasized that the IEP meeting needs to consider the whole child—not just grades and academics. Parents of students with NLDs who need more services than seem forthcoming may need to insist on a functional behavior analysis performed by a neuropsychologist. The neuropsychologist should be familiar with NLD and should provide specific recommendations as well as an assessment. Once parents have those specific recommendations, it's the school's job to implement them.

A Special Education Teacher Speaks Out

Anne, who asked to remain anonymous, has been a special education teacher in the Midwest for over 18 years, at the elementary and high school levels. Her voice conveys her

For more information:

Please see the back page of *Insights* for books you can purchase from SBAA to help you through the IEP process. Both "Negotiating the Special Education Maze" and "The Complete IEP Guide: How to Advocate for Your Special Ed Child" are very helpful and thorough.

Parents with questions about the "No Child Left Behind" Act can find answers and a parents' guide on the official No Child Left Behind website at www.nclb.gov.

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Young Adults Talk about School: What Helps, What Hurts

There is a wealth of information about learning disabilities published by knowledgeable experts: psychologists, counselors, teachers and others. And their expertise is invaluable. But a perspective often left out of the story is that of students and others who live with learning disabilities.

Julia Socha is a very bright, articulate and successful 29-year-old with spina bifida. She graduated from Metropolitan State University with a BA in Human Services Administration, and now lives in a suburb of White Bear Lake, Minnesota, and works in Minneapolis. Her husband Kelly, who also has spina bifida and works in Minneapolis, attends a technical college and is working toward a degree in Human Resources. Like Julia, Kelly has been diagnosed with nonverbal learning disability (NLD).

Julia's academic and professional success did not come easily. In high school, Julia's Individualized Education Program (IEP) addressed only physical supports and some transition issues. No one knew much about NLDs, and no one—including Julia—knew why she began doing so poorly in some of her classes after 8th grade.

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being an adolescent with
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She paid attention in class and studied hard. She sat in the front of the classroom, tried asking for assistance from her guidance counselors and also asked instructors for help. When she failed a math test, the teacher returned the test along with a note accusing her of being lazy and daydreaming in class. Julia then confided her struggles to her guidance counselor, who advised her to "try harder." It's a tough row to hoe—being an adolescent with an invisible, largely unrecognized learning disability. Julia says, "I knew something was wrong, that school seemed harder for me than for other students, but I didn't know why. I just began to feel very slow and stupid. I started to believe what the math teacher said about me in his note. I feel now that my primary disability is not my physical disability but rather it is accommodating for my learning disability in daily life—employment, future college experiences, home life and daily living."

Despite feeling discouraged, Julia continued her education, first at community college, then at a technical college. After attending and completing a program at the technical college, she could afford to complete her education at Metropolitan State University. Along the way, when she was 18, an assessment by Vocational Rehabilitation identified NLD and related issues with socializing and emotional development. The assessment was unsettling, to say the least—it's not easy reading a detailed

Resources

Become Your Own Expert! Self-Advocacy Curriculum for Individuals with Learning Disabilities (A curriculum for teaching self-advocacy skills to secondary students with learning disabilities) January 1995, by Winnelle D. Carpenter, MA, Director, Cognitive Learning Consultants, Minneapolis, MN.

National Center on Educational Outcomes (<http://education.umn.edu/nceo/>)

evaluation of deficiencies you never knew you had or never could explain before. But it was a crucial first step in helping Julia figure out what she needed to succeed, academically, professionally and socially. Around the same time, Julia became friends with a woman who had also struggled with a learning disability called dysgraphia. Julia says, "Getting to know someone who had faced similar difficulties but was now doing very well taught me that people can succeed despite having learning disabilities." Armed with knowledge from her assessment and from support sessions about accommodations, and inspired by her friend's success, Julia began investigating various learning strategies. The academic supports that worked for her included note-taking help, verbal rather than written tests, tutoring and extra class and test time. Julia had to figure out what supports would help on a trial-and-error basis. There is more recognition of NLD today, but it affects different people differently, so students and teachers will still need to experiment to find strategies that work for them.

Julia advises children and adults with spina bifida—and those who love them—to learn as much as they can about hydrocephalus and other aspects of spina bifida that affect their cognitive functioning. It's not always easy acknowledging areas where you need help; in fact, it can be overwhelming. But it's an essential first step. It may be a cliché, but knowledge really is power—in this case in the form of a rock-solid foundation upon which to build progress and move confidently into the future, knowing that whatever limitations you face, there are supports that can help. Julia also advises students to recognize that NLD can affect more than academics; students may need supports in socializing, managing finances and other aspects of practical living. As Julia says, "It's challenging. Sometimes I just have to slow the world down a little to go at my speed, so that I can continue to be successful in my life."

Carrie Bloss, an intelligent and confident 20-year-old student at the University of Minnesota, tells a similar story. She was a very strong student in elementary and middle school and was in the school's gifted and talented (GT) program. But toward the end of 8th grade, she ran into trouble with math and began experiencing some NLD-related difficulties socializing with peers, too. She went to a neuropsychologist for an assessment, which uncovered various learning

difficulties but was rather inconclusive—NLD was never mentioned. The assessment also did not suggest strategies to help Carrie overcome her struggles with math and organization.

In fact, nothing much changed after the assessment. Carrie said, "I knew something was wrong but I couldn't figure out what was going on. I never thought I was stupid but I didn't really know what to think." It eventually emerged that one reason the neuropsychologist failed to diagnose Carrie's NLD was because by the time of the assessment, she had developed coping strategies that masked the underlying problems.

Since Carrie had performed so well in elementary and early middle school, she was in GT classes, including GT math, when her learning disability began to hurt her grades. Carrie's teachers were understandably confused by this GT student with no apparent learning disabilities whose grades suddenly started falling—hard. Her math teacher figured that the reason she was doing so poorly was because she wasn't doing her homework. He was right that she wasn't doing her homework, but wrong in thinking she was lazy or distracted—she simply couldn't do it.

Carrie first heard about NLD in her freshman year of high school and immediately felt that she finally had a name for what was happening to her in school.

During high school, Carrie switched to an alternative high school, where she didn't have to take advanced math to graduate. She studied consumer math instead, which focuses on practical math such as balancing a checkbook. So far, Carrie has managed to avoid math entirely in college. Organization remains a challenge. Just as the experts advise those trying to teach students with NLD to "teach to their strengths," Carrie does her best to learn to her strengths. She concentrates her efforts on subjects she can master and doesn't let herself become discouraged when she runs into problems. Carrie said, "I try to stay focused on the end result and not worry about every little difficulty along the way." Carrie is major-

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ing in elementary education with a minor in disability issues, and plans to teach inclusive classes, where kids with and without disabilities learn in the same classrooms. •

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Education Opens Employment Doors

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Technical know-how is always important at work, but most jobs require many other "softer" skills, such as being on time, meeting deadlines, getting along with colleagues and self-starting.

If you're an adult with spina bifida who didn't plan well, way back in middle school, it's not too late. Most colleges offer special programs for adults, with classes on evenings and weekends, and many schools offer online classes as well. There are also many excellent two-year programs at community colleges to help students prepare for technical careers, such as desktop publishing or becoming a medical technician.

Career Planning

Today's assistive technology is opening new doors for students with disabilities, both in terms of succeeding at school and later on the job. The technology field can be very attractive for workers with disabilities, since it offers the possibility of telecommuting, the latest in assistive technology and, generally speaking, high salaries.

But many educators believe that college counselors and disabled student services are not working together to effectively assist students with disabilities in career planning. According to disability columnist John M. Williams, "... guidance professionals need to learn about growing career options for these students. Career counselors and educators must become aware that people with disabilities are finding great jobs in information technology industries, and more jobs are being created every day."

SBAA and other advocacy organizations are working hard for more recognition of the long-term employment challenges posed by disabilities and effective solutions, but in the meantime, parents and students need to be very proactive themselves in searching out opportunities.

Higher Education

What should parents and children be doing to prepare for life after high school? For students who plan to attend college, here are some tips:

- Take as many college-prep, honors, advanced placement (AP) and other challenging courses as possible. These days, colleges look just as hard at students' coursework as at their grades.
- Think about internships, part-time jobs or volunteer work to help you develop skills that will be attractive to college admissions offices.

- If you have learning disabilities, keep records of learning accommodations and modifications that have worked for you.
- Get the highest grades that you can. Work hard!
- Start talking to colleges early. Almost all colleges these days have a disabled student services (DSS) office that can provide information on housing, assistance programs, alternative testing and other resources.
- Some colleges are more disability-friendly than others. Start your research early! If you're interested in a specific school or schools, try to talk to students with disabilities who attend and are willing to share their experiences.

Students who don't plan to go on to college should be thinking about what they would like to do and how they plan to achieve their goals,

whether via vocational education or training programs.

Summing Up

The US education system offers students with disabilities more today than ever before: the Individuals with Disabilities Act (IDEA), IEPs and new government programs to help students and workers with disabilities achieve their educational and professional goals. There has been much genuine progress and the opportunities are exciting.

But all the new laws and options can be confusing, and taking advantage of what's available often requires parents and students to be more proactive and assertive than ever. Parents and students need to think hard about their hopes and plans for the future, do the research to identify resources and possibilities and then work hard to put them to good use. •

Resources

The Association on Higher Education and Disability (AHEAD) is an international, multicultural organization of professionals committed to full participation in higher education for persons with disabilities. The association is dedicated to promoting excellence through education, communication and training.

University of Massachusetts Boston
100 Morrissey Boulevard
Boston, MA 02125-3393
(617) 287-3880

e-mail: AHEAD@umb.edu; website: www.ahead.org

The **Heath Resource Center** is the national clearinghouse on postsecondary education for individuals with disabilities. Support from the US Department of Education enables the clearinghouse to serve as an information exchange about educational support services, policies, procedures, adaptations and opportunities at American campuses, vocational-technical schools and other postsecondary training entities.

Heath Resource Center
The George Washington University
2121 K Street, NW Suite 220
Washington, DC 20037
(202) 973-0904 or (800) 544-3284

e-mail: askheath@heath.gwu.edu; website: www.heath-resource-center.org

Think College is a US Department of Education website designed to provide information on educational opportunities beyond high school for learners of all ages.

US Department of Education
Office of Postsecondary Education
Quality Improvement and Strategic Planning
1990 K Street, NW, Mail Stop 8543
Washington, DC 20006
(202) 502-7888

e-mail: ope_www@ed.gov; website: www.ed.gov/thinkcollege/

The **Transition Coalition** offers information, support and links to professionals, family members, individuals with disabilities and others interested and involved in the transition from school to adult life.

Transition Coalition
University of Kansas, Department of Special Education
Joseph R. Pearson Hall
1122 West Campus Rd., Room 521
Lawrence, KS 66045-3101
(785) 864-0686

e-mail: info@transitioncoalition.org; website: www.transitioncoalition.org

Planning Your Child's Individualized Education Program (IEP) Some Suggestions to Consider Before the IEP Team Meeting

- Consider the vision you have for your child for the future as well as for the next school year.
- List your child's strengths, needs, and interests and your major concerns about his or her education.
- Consider how your child's disability affects his or her education.
- Think about your child's educational progress. What has been working and what has not?
- Request a written copy of your child's evaluation results or a meeting with school staff to discuss the evaluation before the IEP meeting. This gives you an opportunity to understand the evaluation before the IEP team meeting for your child.
- Consider the evaluation results. Do these results fit with what you know about your child? Is the evaluation complete and accurate? If you disagree with the school's evaluation, you may request, in writing, an independent educational evaluation (IEE) at no cost to you. The school must pay for the evaluation or show the due process hearing officer that its evaluation is appropriate. The results of an IEE must be considered by the IEP team in planning your child's IEP.
- Consider a variety of ways to involve your child in developing his or her IEP, starting at a young age if appropriate. Self-advocacy skills are important to develop.
- If needed, plan to bring someone to the meeting with knowledge or special expertise regarding the child, such as a spouse, relative, friend, related service personnel or representative from a local disability organization.

The school needs to know what your child is like at home and in the community, as well as what your child's interests and activities are.

At the IEP team meeting:

The IEP meeting is very important. You, the school personnel, and other IEP team members attending the meeting will review and discuss information about your child to develop the IEP. It provides an excellent opportunity to ask questions and share important insights about your child, whom you know better than anyone else does. The school needs to know what your child is like at home and in the community, as well as what your child's interests and activities are.

- Make sure others at the IEP meeting never forget that the meeting is about a real child—your child.
- Share your visions for your child, both short-term and long-term.
- Discuss your child's strengths and needs and any concerns about your child's education.
- Remember that diagnostic tests and assessments do not present the total picture.
- When you believe that the teacher and school personnel are doing a good job, tell them so. Praise, when deserved, is a great thing.
- Be a good listener. Ask questions.

- Make sure you understand. If you don't understand something, ask to have it explained in a way that you can understand.
- Expect that what you know about your child will be used in making decisions.
- Use school data, your child's progress reports, and other information you know about your child to make decisions.
- You may not want to agree to a proposed IEP at the end of the meeting. Review the proposed IEP document at home. If you disagree with what is being proposed in the IEP document, you must notify the school as soon as possible to resolve the disagreement.

After the IEP team meeting:

- Your child's IEP must be reviewed at least once a year to determine whether the annual goals have been achieved and to revise the IEP if necessary.
- Your child's school must inform you regularly about your child's progress, at least as often as parents who have children without disabilities are informed about the progress their children are making. Schools can do this by providing periodic report cards. You will be informed about whether your child is making progress toward meeting the annual IEP goals, and whether the progress is enough to reach the goals. If your child is not making adequate progress, an IEP meeting should be held to review the IEP and make needed changes.
- You may request an IEP meeting at any time during the year if you believe it is important to consider changes in your child's IEP.

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Latex-Safe

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for recognizing and treating a reaction in each child, when to call for help and facilitating ambulance and emergency-room preparedness and latex-safety. These plans should be documented in the child's individual education/health plan and a practice drill may help parents and staff feel more secure. The *Children and Youth Assisted by Medical Technology in Educational Settings* manual referenced earlier includes suggestions for developing emergency plans. Easily accessible latex-free first aid supplies are an important part of any emergency plan.

Promoting Self-Care and Independence

The fourth step is developing each child's latex allergy knowledge, avoidance and self-

advocacy skills. While the medical aspects of latex allergy prevention are an important part of the child's individual health plan, the educational and advocacy skills should be

Making school latex-safe for the child with spina bifida takes careful preparation, patience and more than a little creativity.

written into the child's Individualized Education Program (IEP), to help him or her develop important skills and plan transition to adult responsibility.

School is, of course, about more than books and classes. The social and emotional aspects of being part of the group—or of being different—may be magnified by an unusual condition like latex allergy. An example is balloons—balloons are almost synonymous with childhood fun and parties. This is true even though latex-sensitive children cannot attend dances or proms decorated with latex balloons, and several children die each year from choking on balloons. With thoughtful planning, safer alternatives such as child-inflatable mylar balloons can provide the same fun and party atmosphere.

Making school latex-safe for the child with spina bifida takes careful preparation, patience and more than a little creativity. But the family and the school can work together to create a safe environment to maximize the child's academic and social learning.

Nonverbal Learning

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6. Provide positive reinforcement and coaching.

Let them know when they're doing it right. Students, especially those who face learning challenges, need verbal praise.

7. Use memory and scheduling aids.

Use lists, assistive technology, color-coded folders, written reminders and whatever else can help jump-start memory.

8. Don't vary the routine or details until the student really gets it.

For most students with NLD, once they know the routine, they've got it. It's processing changes and new material that may throw them.

One parent of a student with NLD shared a solution that worked for them. Their son took both regular and special education English, so he got twice the repetition he would have in only one English class. The student is now doing very well in English. Dr. Loomis said, "That's the good news about NLD. With practice, repetition and appropriate teaching, these kids can often really achieve academically even in former problem areas."

Many parents of children with NLD report that noncompliance is an issue. According to Dr. Loomis, it's not uncommon for kids with NLD

to become noncompliant at school or at home as a reaction to their struggles. For students having trouble meeting expectations—parental, academic or even their own—and feeling stressed and frustrated, defiance may be a coping mechanism. Generally speaking, kids with NLD who get the supports they need to succeed are much more compliant. According to most literature on the subject, the child with NLD loves rules—once he or she understands them—because they reduce confusion and set out a clear path.

Just as providing the necessary supports is essential, withdrawing them—by the proper degree at the proper time—is equally important. If supports are withdrawn too quickly, the child may not be able to accomplish the task and may become frustrated and oppositional.

Dr. Loomis said, "We try to identify problems early on—to eliminate or at least keep them small. If you wait, little problems become big problems, and it's tougher to carry off successful interventions."

Dr. Brei emphasized the importance of creativity. For example, in teaching a youngster to clean his room, you could tape instructions. The child could play one instruction, then turn off the tape player and carry it out, and so on. He also suggested using rewards and incentives, with rewards increasingly delayed as children get older.

Assistive technology may be helpful for organizational issues: calendars, PDAs, multiple-alarm watches. Watches with multiple alarms can help children remember to catheterize on time.

In summing up, Dr. Brei addressed forgetfulness and NLD. He said, "Most people remember by using visual images to categorize information and file it away. But if you don't have good visual/spatial skills, you're not able to make mental images and, lacking an anchor so to speak, the information may get lost."

No one yet has all the answers on NLD. Parents and students will need to experiment to discover strategies that will work for them. But research is advancing, slowly but surely, and we know a lot more today than we did 10 years ago. There is no reason for students with NLD or their parents to go it entirely alone. So keep up with the literature, seek out a neuropsychological evaluation at the first signs of trouble and teach your child's teachers how to help your student. •

This article was adapted from the 2003 SBAA Annual Conference session "Nonverbal Learning Disabilities and Spina Bifida: Understanding the Challenges in School, at Home and in the Community," presented by pediatrician Timothy Brei, MD, and psychologist Jim Loomis, PhD.

"Living with Spina Bifida: A Guide for Families and Professionals" by Adrian Sandler, MD can be purchased from SBAA at (202) 944-3285 or www.sbbaa.org.

IEP Inside View

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enthusiasm for her chosen career—although it's hard work, it's also clearly a labor of love.

Being a special education teacher is a challenge sometimes. As Anne said, "Every student is unique, and it's up to the teacher to figure out how to help each student learn best." Success requires effort, intelligence, empathy—and sometimes even intuition—to determine the correct approach for each child. Although Anne, of course, works with each child's IEP, at some point it comes down to the interaction between one student and one teacher, and at that level, she's on her own. Anne acknowledges that some special education teachers are much more gifted at the process than others. The best teachers—special ed and others—put their hearts into it.

Anne works on developing IEPs with parents and other educators, and she says that generally the process goes smoothly, despite the widespread notion that IEP meetings are always fraught with high-intensity conflict. Most of the time, she says, parents, teachers and therapists work together cooperatively to design the right IEP for each child. Anne is clearly very good at her job, so she may have a higher success rate than other special education teachers, but the high-profile battles are always more likely to make the news.

Anne recommends that all parents of students receiving special education services read the IDEA final regulations. If they don't have a copy of the regulations, the school is required to give them one. Anne says, "Parents have

more rights than they think they do, but that information isn't always explained to them. They need to know what they're entitled to."

Parents should come to the meetings prepared, bringing any relevant medical and educational records, including report cards, educational and other assessments conducted by the school and others, previous IEPs and all related school communications. In addition to formal assessments, parents should think about learning techniques that have worked well for their student and share that information with the IEP team. Before the meeting, parents should think about their goals and concerns for their child, and write down issues they want to address, so nothing important is forgotten. At the meeting, parents should ask how they can help their child meet his or her IEP goals.

When asked what's hardest about creating an IEP and meeting its goals, Anne says it's not the kids, most of whom are terrific. And it's not parents asking for more interventions or more attention for their child. The biggest problem, she says, is uninvolved parents. Anne said, "These kids need reinforcement from home. Almost half of my special education students don't get enough support from their parents." She says that many parents are not well informed about special education or the IEP process, and some parents don't even attend their student's IEP meeting.

In discussing what goes wrong in the IEP process, Anne said that some parents have unrealistic expectations for their child and the school, and become disappointed and frustrated when the school can't meet those expecta-

tions. On the other hand, says Anne, with older children, there are parents who seem to give up too easily. And a few parents blame the school for all that's not going right for their child. Anne said, "It's important for everyone involved in the IEP process to try to maintain a positive attitude. We can accomplish a lot more if everyone works together."

Like most educators, Anne believes that parents need to make reading and learning part of everyday life. Parents can read aloud to their kids, or the family can listen to books on tape in the car and at home. Discussing current events, reading newspapers, visiting the library—these are enjoyable for parents and very helpful for their kids. Anne said, "Mostly, parents just need to be involved."

Summing Up

Parents and special education teachers need to work together, as a team. It's true that schools and parents of students who need special services sometimes have competing interests. But the primary goal of schools isn't saving money or time, and the primary goal of parents isn't imposing outrageous demands on the school. The primary goal of both schools and parents is education. That's the common ground, and both parents and teachers need to find it and try to work together from there. •

This article contains excerpts from the 2003 SBAA Annual Conference session "Nonverbal Learning Disabilities: What To Do About It?" presented by special education director Sunny Stephens, PhD, and special education teacher/behavior management specialist Patricia Archibold.