

## **Nonverbal Learning Disorders and Spina Bifida**

Over the past 10 years, we have become increasingly adept at managing the medical challenges experienced by persons living with open myelomeningocele (spina bifida). During that time, we have also become increasingly aware of the learning difficulties confronting individuals with this medical condition. Specific learning challenges, including nonverbal learning disorders (NVLD), can be attributed to brain abnormalities associated with myelomeningocele. Brain abnormalities found in this population include Chiari II malformation, hydrocephalus, and absent or partially absent corpus callosum.

### **Definition of nonverbal learning disorder**

Nonverbal learning disabilities include several specific, potentially debilitating symptoms that manifest in three major categories: neuropsychological deficits, academic deficits, and social-emotional/adaptational deficits (Rourke, 1995a). In children with a nonverbal learning disorder, there is a discrepancy between performance and verbal IQ testing scores. These children's intelligence screening tests will demonstrate a lower performance IQ score as compared with their verbal IQ score. On tests such as the Wechsler Scales, a 10-point discrepancy between performance and verbal IQ scores is considered significant.

### **Information processing deficits**

Individuals with spina bifida often have trouble processing information (for example, understanding and remembering instructions). Information processing is a key skill in academic areas such as mathematics, science, reading comprehension, and writing. The difficulty is not limited to school work, however, but also applies to processing day-to-day information from parents, siblings, and school classmates. Individuals living with spina bifida and their parents have reported problems in several areas, such as completing assignments in a timely manner, finding and getting to the classroom in the time allotted, remembering to take medication, and performing required treatments (e.g., catheterizations) at the prescribed time. In addition, some experience difficulty in making meaningful contact/friendships with peers, which may result in social isolation. Parents of children with spina bifida also report difficulty promoting independence and self-care. They may find it necessary to repeat seemingly straightforward directions over and over. **Children may present with one, two, or all of these difficulties depending on the degree of brain involvement.**

### **Cognitive challenges frequently missed**

Frequently, the challenges associated with a nonverbal learning disorder are less apparent in early childhood (i.e., age 7 and 8) and become more obvious as these youth move into early adolescence (i.e., age 10 -14 years), when academic work requires sustained attention and analytical skills. School personnel frequently miss nonverbal learning disorders because these children present as being quite verbal (this verbosity may serve a compensatory function). Parents, teachers, and health care professionals tend to overvalue the overall intelligence of youth with a nonverbal learning disorder, thereby missing the opportunity for early formal educational

intervention related to their specific deficits. This may ultimately undermine the child's ability to succeed.

### **Challenges may surface in middle school**

As these children mature in chronological age, home and school requirements become more demanding and complex. Academic requirements shift from rote memory/parroting-type activities during Kindergarten through grade 5, to more challenging assignments beginning in middle school—assignments that require self-initiation, interpretation, problem-solving, critical thinking, time management, self-reflection, and social tact/negotiation. It is during this transition from childhood into early adolescence that school problems may become more obvious and these children may begin to falter. This may present additional problems for the entire family, and frustration may mount. Of course, the individual living with the nonverbal learning disability may become the most frustrated of all.

### **Restatement of problem**

Because the nonverbal learning disability impacts not only on academic success but also the ability to plan ahead and become a self sufficient adult, the importance of identifying and developing strategies for youth with nonverbal learning disorders cannot be overstated. Overestimates of these children's abilities and unrealistic demands made by parents and teachers can be emotionally debilitating, putting them at risk for depression, withdrawal, anxiety, and even suicide. Youth with nonverbal learning disorders are often chided and punished by parents and teachers for social and academic behavior and performance that is neither their fault nor within their realm of control.

Without specific accommodations or strategies designed to address their cognitive challenges both at home and school, these children may become overwhelmed and burned out, giving up altogether. A comprehensive and detailed Individualized Educational Plan (IEP) or 504 Plan, contributed to by thoughtful parents, educators, psychologists, and health care professionals can go a long way to prevent the child from falling through the cracks and feeling hopeless.

### **Helping children with spina bifida succeed**

How can we help children with spina bifida? There are four principal advocates in these children's lives including parents, teachers, community workers, and health care providers. Later, with positive, consistent guidance and reinforcement your child will learn to advocate for him or herself. For now, you (the parent) are the child's most powerful and important advocate. Schools are obliged to listen to you. The Spina Bifida Clinic recommends that you begin to closely monitor your child's academic and social progress. If he or she demonstrates any of the above behavioral signs, we recommend that you request an Individualized Education Plan (IEP) or a 504 Plan through the school.

The first step of an IEP is assessment. The school will arrange a formal evaluation for your child, which may in some cases include formal psychoeducational testing. After the evaluation is completed, a meeting should be held at the school to discuss the results. Those in attendance should include the evaluator/assessor, the child's teachers, school administrators, and you, the parent. You have the right to present your concerns to the IEP team and to bring an advocate with you to this meeting. The

purpose of the meeting is to come up with a mutually agreed upon plan to meet your child's specific educational needs/challenges.

Sometimes parents resist the IEP process, viewing it as special treatment that only draws negative attention to their child's differences. Please remember that the school's general curriculum is not able to fully allow for children's individual differences in ability. The goal of the IEP is to eliminate what amounts to institutionalized discrimination. Your child will feel less different achieving attainable goals than struggling or failing to meet goals that are not appropriate.

### **Resources**

There are two excellent community resources for families to utilize in advocating for their child within the school district and to ensure that the child reaches their highest potential. One is the Community Alliance for Special Education (C.A.S.E.) which is located in San Francisco and serves the entire eight-county Bay Area. Their phone number is (415) 431-2285. They do charge a fee for their advocacy services, but it is based on a sliding scale and waived in special circumstances. In addition to individual advocacy services, they provide training for parents to learn how to be advocates for their children with special educational needs. The other organization is the Disability Rights Education & Defense Fund (**DREDF**). Although their main office is in Berkeley, CA, they are an international organization. Their telephone number is (510) 644-2555. They also provide training on how to be a successful parent-advocate for your child, an introduction to the IEP process, special education laws, etc. DREDF offers an IEP Handbook put out by the Northern California Coalition for \$10.00. For those families with computer access there is an excellent article called "Writing IEP's for Success" which is specifically for secondary education and beyond. This article can be found on the web at:

**[www.idonline.org/ld\\_indepth/iep/success\\_ieps.html](http://www.idonline.org/ld_indepth/iep/success_ieps.html)**.

### **Tailoring the IEP**

Every child is an individual, and the provisions of the IEP or 504 will depend on the degree of involvement and the way in which each child manifests their particular learning challenges. Therefore, a child's IEP or 504 will need to be tailored to their unique strengths and challenges. A single "standard" IEP or 504 is not adequate. While one youth's IEP/504 Plan may focus on a single accommodation needed in only one particular academic subject such as math or science, another student's IEP/504 plan may encompass his/her entire school curriculum. An IEP can be written to include direct training skills in areas such as planning, organizing, studying, writing, social cognition/skills, and/or interpersonal communication. A "504 plan" can be drawn up to outline a specific accommodation that the student may need, such as a lap top computer, note-taker, or untimed testing. Some children will require more specialized testing than the schools can provide. For example, children with a Chiari II malformation, which is present in 100% of children born with open myelomeningocele, should have neuropsychological testing completed. Ideally this testing should be done before entering middle school.

### **Modifying Homework Assignments**

Certain school assignments/homework should be modified or in some cases omitted altogether in recognition of your child's unique visual-spatial, visual-perceptual,

and/or motor challenges. Remember the processing of information in these children occurs at a much slower rate. Because of the cognitive challenges associated with spina bifida, these children will often require twice the amount of time to complete the same assignment as their non-affected peers. Therefore, their homework assignments may need to be modified accordingly. In addition, requiring these children to participate in timed testing activities is not an accurate assessment of their abilities. This also applies to long, complex homework assignments such as multi-page term papers, which will overwhelm these youth and destroy any enthusiasm they may have had for the assignment or subject matter. The purpose of homework is to consolidate the learning process and facilitate academic self-sufficiency and independent thinking—it is not meant to be punishment. Listed below are a few strategies/accommodations that can be written into your child's IEP or 504 Plan. A more comprehensive listing of modifications can be found by accessing the web at:

**[http://www.nldline.com/nld\\_sue.htm](http://www.nldline.com/nld_sue.htm)**

### **Some Suggested Strategies to Discuss with the Teacher**

1. Nightly mathematics homework should be cut in half for these children. So for example, if the class is assigned problems one through ten for homework, then your child should only be required to do the "odd numbered" or "even numbered" problems, not both. This accommodation is meant to remedy the extra time, effort, and energy it takes for him/her to complete the homework assignment in comparison to their non-disabled classmates. It is unreasonable to require these children to do the exact same work if it takes them twice as long to do it. And it does take them twice as long! In this way their workload and the time they are spending doing homework is more equitable with that of their peers and they will not become "turned off" to school.
2. This same philosophy should hold true for English papers, science projects etc. Assignments that require critical thinking skills, integration of information activities, and/or synthesis of material skills (i.e., writing concept papers) must be modified in length as well as in expectation of exacting coherence. Proposed modifications to the original assignment may include accepting a written paragraph or two instead of an entire paper, a verbally rendered story via tape-recorder rather than a written one, and/or compiling a collage of concepts specifically mined from media sources rather than hand produced materials.
3. All "timed" assignments and/or tests should be modified or eliminated altogether.
4. Paper and pencil tasks that involve copying as well as tasks involving folding, cutting with scissors, and arranging materials as in map-making, graphs, and/or mobiles should be eliminated entirely or accommodated for by providing considerable assistance.

5. Integration and coordination of time and space is extremely difficult for these youth despite their best efforts to be punctual and follow directions. Consequently, tardiness is common and should not be interpreted as willful misbehavior. These youth often require numerous verbal cues and reminders in navigating through space and time. They often get lost trying to maneuver from one place to another. Punishing these youth for being late or getting lost is neither helpful nor productive. When scheduling their classes for the year, thought should be given to clustering them together to facilitate timely movement from one class to the next, which will also help facilitate bladder and bowel elimination.
6. All children must be protected from teasing, bullying, persecution, and other sources of anxiety both in the classroom and the schoolyard. Social skill development is often lagging in these children. They are frequently socially awkward, particularly with the advent of middle school. Ongoing socialization opportunities including planned group activities and games that are inclusive for these children should be written into the IEP or 504 Plan.
7. Your child may benefit from an evaluation by his/her pediatrician and/or a psychiatrist for possible medication intervention. They may experience signs of inattention, depression, anxiety, and compulsiveness that can accompany a nonverbal learning disorder. These may be treatable with medication.

#### **In closing**

Remember that our goal for youth living with physical disability is to increase their ability while providing for full opportunity and participation. Expectations placed on these children must be attainable and worthwhile. Threatening, punishing, or taking away privileges will not fix your child's neurological disability. It may only serve to make him or her feel hopeless and depressed.