

Chapter 2

History of the Concept of NVLD

The National Center for Education Statistics estimates that 20–25% of children will have learning disabilities (1998). “Specific learning disability” (SLD) is the most prevalent eligibility category in special education. SLD is a disorder in one or more of the central nervous system processes involved in perceiving, understanding, and/or using concepts through verbal (spoken or written) language or nonverbal means. The term does not include learning problems that are primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage (Federal guidelines 34 CFR 300.7).

SLD manifests itself with a deficit in one or more of the following areas: attention, reasoning, processing, memory, communication, reading, writing, spelling, calculation, coordination, social competence, and emotional maturity. Clinically children with SLD might have problems with *input*, or how they take in information through perception: auditory, visual, and tactile. Additionally the students might have difficulties with *integration*, or how they use new information, to understand novel concepts and to link new with extant ideas. They might find it difficult to understand an idea, start with small details and work up throughout every step, and combine multiple ideas. Lastly one might see problems with *output*, which is where a child shows what he or she has learned. Successful output includes not only oral and written expression, but also the ability to prepare information for output by ordering and organizing thoughts for cohesive communication of ideas.

Disorders often mentioned in this category include:

- *Dyslexia*. A language-based disability in which a person has trouble understanding written words. It may also be referred to as reading disability or reading disorder.
- *Dyscalculia*. A mathematical disability in which a person has a difficult time solving arithmetic problems and grasping math concepts.
- *Dysgraphia*. A writing disability in which a person finds it hard to form letters or write within a defined space.
- *Auditory and visual processing disorders*. Sensory disabilities in which a person has difficulty understanding language despite normal hearing and vision.
- *Nonverbal learning disabilities*. Problems with visual-spatial, intuitive, organizational, evaluative and holistic processing functions, and social/emotional issues.

Given this complexity, it is incumbent upon school psychologists and other support personnel, for example, resource teachers, speech and language therapists, school counselors, and occupational therapists (OTs), to know about *all of the subtypes* of learning disabilities. This is necessary so that we can identify, diagnose, understand, and intervene in the lives of these students to increase their chances of success in their school age and adult lives. While we currently know the most about dyslexia and ADHD, our understanding of nonverbal learning disability (NVLD) is considerably less well developed. Estimates vary about how prevalent NVLD is, but the most cited estimate is that 10–15% of all learning disabled students have a nonverbal learning disorder (Ozols & Rourke, 1988). It is imperative that practitioners know how to identify students who are at risk for, and manifest, this disorder. Although data have been accumulating since as far back as Johnson and Myklebust's (1967) classic work, *Learning Disabilities: Educational Principles and Practices*, nonverbal learning disabilities are still the least known and the least understood subtype. Although there has been increased interest in this disorder in the 1980s and 1990s, researchers and practitioners have not even been able to agree whether nonverbal learning disabilities should be abbreviated as NLD (mostly used on the West Coast) or NVLD (preferred by East Coast clinicians), nor have they arrived at an accepted definition, although Rourke's definition is the most noted (Pelletier, Ahmad, & Rourke, 2001). We have chosen to use the abbreviation NVLD for the purposes of this book.

Without knowledge or understanding, we run the risk of intervening in ways that are not helpful, or possibly even harmful to our students. As the reader will see over the course of this book there are many more associated features and symptoms of NVLD which need to be accounted for than in its language-based counterpart, dyslexia. Treatment is made even more complicated by the variety and number of different professionals who come into contact with children with NVLD.

For instance, the authors initiated a study in an urban hospital setting where we were trying to look at the effects of a particular intervention on spatial processing for students who met our study criteria for NVLD. This intervention was conducted in the child development unit and was primarily provided by occupational therapists. These occupational therapists more often than not referred to potential students with NVLD as children with "sensory integration" problems (Humphries, Krekewich, & Snider, 1996). The hospital also had a speech and language clinic that provided language and social skills interventions for children it tended to diagnose as experiencing "semantic/pragmatic" disorders (Volden, 2004). Likewise, there was a psychiatry department where students were being treated in groups for social skills deficits. The departments did not communicate across disciplines about these students, all of whom might have met our criteria for NVLD. This greatly inhibited our ability to find subjects, resulting in the termination of the research project. Our belief is that these same issues are also common to most schools and/or school districts, resulting in poor continuity of care for students with NVLD. This is similar, as the reader will see, to the old adage about the blind men all touching different parts of the same elephant and calling them by different names, resulting in inconsistent and incomplete treatment.

To help readers develop a “feeling” for this disorder, let us review a clinician’s concept of the child with NVLD. Judy Lewis’ overview on the website NLDline.com, which is based on educator Sue Thompson’s (1997) groundbreaking work, *The Source for Nonverbal Learning Disorders*, is a useful reference. Lewis lists early speech and vocabulary development, remarkable rote memory, strong auditory retention, attention to detail, at times good early reading skills, and excellent spelling skills as among the assets of some children with NVLD. Five major categories of deficits and dysfunction are identified: motor, visual-spatial, organizational, social, and sensory. Motor deficits include poor coordination, severe balance problems, and difficulties with graphomotor skills. Visual-spatial/organizational deficits reflect a lack of image formation, poor visual recall, faulty spatial perceptions, and difficulties with executive functions. These executive functioning difficulties include decision making, planning, initiative, assigning priority, sequencing, motor control, emotional regulation, problem solving, planning, impulse control, establishing goals, monitoring results of action, self-correcting, and problems with spatial relations. Social deficits include difficulties comprehending nonverbal communication, adjusting to transitions and novel situations, along with deficits in social judgment and social interaction. The last category refers to sensitivity in any of the sensory modes: visual, auditory, tactile, taste, or olfactory.

Defining NVLD

As implied above, how NVLD is defined is crucial to how we assess, understand, and intervene for it. In contrast to dyslexia, NVLD is not currently in any formal eligibility or diagnostic codes such as the Diagnostic and Statistical Manual of Mental Disorders – IV-TR (2000) Or ICD-9 (2008). Some researchers do not view NVLD as a specific learning syndrome and argue against it even being considered as an “official” diagnosis (Pennington, 2009), while others argue that creating a formal diagnostic code will aid in the research and treatment of NVLD and for insurance reimbursement for services. At this point it does not seem likely that NVLD will be considered for DSM-V, which is in the planning stages for 2012 (Semrud-Clikeman, personal communication, 2009).

We assert that NVLD should be formalized, not only to aid research, but also to make it easier for parents to be able to receive benefits for intervention for the disorder. In addition, we believe that having a formalized diagnostic category will be a useful heuristic tool for guiding assessment and intervention. But let us begin with an historical perspective for how our understanding of the syndrome of NVLD has progressed over time.

Josef Gerstmann, an Austrian born neurologist, who fled Nazi Europe to the United States in the late 1930s, wrote the first published article on a syndrome

consisting of symptoms very similar to what we now call nonverbal learning disorders. This syndrome, that eventually took his name, became the Gerstmann Syndrome (1940). He noted that this syndrome consisted of difficulties in the areas of finger agnosia (difficulty with information getting from and to the fingers), right–left orientation (confusion between right and left), agraphia (handwriting difficulties), and acalculia (math difficulties). He linked these nonverbal issues to problems in math and writing, but his primary focus was on sensorimotor and fine motor issues. Although NVLD is now more recently thought of as a right-hemisphere issue (Gross-Tsur, Shalev, Manor, & Amir, 1995; Semrud-Clikeman & Hynd, 1990), Gerstmann wrote that “the localizing value of the syndrome is significantly emphasized by the fact that the syndrome of finger angosia is represented in the brain unilaterally, and that (as in aphasia and apraxia) it is associated with a correspondingly located lesion in the dominant side of the brain, that is, the left-hemisphere in right-handed persons” (p. 405).

Johnson & Myklebust (1967) significantly furthered our thinking about NVLD in their book, *Learning Disabilities: Educational Principles and Practices*. In this work they described their version of the syndrome of nonverbal learning disorders. Whereas Gerstmann (1940) had noted fine motor difficulties and difficulties with math and writing, Johnson and Myklebust (1967) observed additional difficulties in visual-spatial processing and something they called “social perception.” They suggested that children with these issues had difficulties in the following areas: understanding gesture, nonverbal motor learning, body image, spatial orientation, right–left orientation, and social perception. Additionally, these children also demonstrated distractibility, perseveration, and disinhibition. Later work has also found overlap with ADHD and executive function issues (Landau, Gross-Tsur, Auerback, Van der Meere, & Shalev, 1999). Johnson and Mykelbust’s vision generally holds true to current thinking about NVLD.

The next major advances in research and thinking about NVLD were made by Byron Rourke and his many colleagues. He is the leading exponent of the dominant model and/or definition of NVLD today. After decades of research and two seminal books, *Neuropsychology of Learning Disabilities: Essentials of Subtype Analysis* (1985) and *Syndrome of Nonverbal Learning Disabilities: Neurodevelopmental Manifestations* (1995), Rourke has left a significant mark on the field both by trying to establish a diagnostic set of criteria for NVLD and offering a theory for the cause of the disorder.

Rourke’s diagnostic criteria have remained fairly stable over time. Most recently, Rourke and his colleagues (Pelletier et al., 2001) have stated that the following criteria have to be met to determine NVLD:

1. Target test at least 1 SD below the mean.
2. No, or very minimal, simple tactile imperception and suppression versus very poor finger agnosia and/or finger dysgraphesthesia.
3. The highest scores on two subtests of the Verbal Scale of the Wechsler Intelligence Scale for Children-III (WISC-III): Vocabulary, Similarities, or Information.
4. Two of the subtests from the WISC-III nonverbal subtests of Block Design, Object Assembly, or Coding fall among the lowest scores of the Performance scale.

5. Wide Range Achievement Test–Revised (WRAT–R) standard score for Reading is at least 8 points higher than Arithmetic.
6. Tactual Performance Test, right, left, and both hand times become progressively worse vis-à-vis the norms.
7. Normal to superior grip strength versus mildly to moderately impaired Grooved Pegboard.
8. WISC-III: VIQ exceeds PIQ by at least 10 points.

The following conditions meet Rourke’s criteria for a “diagnosis” of NVLD:

- Children presenting with the first six criteria would definitely be diagnosed with NVLD.
- Seven or eight of the features present would constitute a positive diagnosis.
- Five or six criteria suggest probable NVLD.
- Three or four criteria suggest questionable NVLD.
- One or two criteria suggest low probability of NVLD.

Those of us who do assessments will find problems with Rourke’s algorithm. First, all of the instruments would be considered outdated today. Second, although many newer, better standardized tests are available, none have been utilized to update the definition. These are things that the authors will take up in later chapters.

A Developmental Orientation

In this section we offer a look at how a child with NVLD might manifest at different developmental stages. We briefly address signs of NVLD in early (preschool) development, early schooling, later elementary and middle school, and high school. It is important to note that the presenting symptoms change across development and are often difficult to identify.

Early Developmental Signs of NVLD

Piaget (Inhelder & Piaget, 1964) refers to his first stage of development as the sensorimotor stage, whereby much of learning is about the child’s interactions with his/her environment and a sensory level. However, this is less likely for an NVLD child. As Rourke (1995) notes, others noted that the first developmental stage is sensorimotor. In describing NVLD children, “these children remain essentially sedentary, exploring the world not through vision or locomotion, but rather through receiving verbal answers to questions posed about the immediate environment” (p. 8). The disparity between precocious language development, especially vocabulary, and the delays in motor development in the child is most notable in the early years.

Anecdotal reports from parents of children with NVLD often state that their children would sit and point at an object, saying what they wanted rather than crawling toward it. In anticipation of normal exploration, one parent spoke of how she “baby-proofed” her house to protect her child, yet her child never crawled to or tried to open anything. Many of these children do not use typical toddler toys or enjoy coloring or drawing. They are usually disinterested in or unable to put puzzles together (Johnson, 1987a). Parents are often confused when their extremely verbal child is not developing consistently across developmental lines. They may create unwarranted and inaccurate expectations, based upon inappropriate assumptions about their child’s superior language development. Problems for the child can become exacerbated when poor motor and spatial development can disappoint and confound the parents.

Early sensorimotor exploration is important in the child’s development, since learning depends upon the interaction of the child with the environment (Piaget, 1972). The brain develops secondary to its interactions with the environment developing neural networks that then create efficiency. Although NVLD children are interacting with their environment, it is often more verbal and observational and less motoric and spatial, which alters development of the neural networking. As the old saying goes, “neurons that fire together wire together.” It is likely that less interaction and practice exploring the environment with the body may lead to less efficiency in motor skills compared to children with many more hours of practice. In turn, as they grow older, children with less confidence in their motor skills may be less inclined to engage in activities demanding it, further reducing their skill growth and development.

When clumsiness is deemed significant by a parent or a preschool teacher, consultation with a pediatrician or physical therapist may be recommended.

Early Schooling

Kindergarten teachers may notice problems in fine motor skills that have not been noted earlier in a child with NVLD. The child may struggle more than his or her peers with items such as scissors, crayons, or pencils. As demands for writing and drawing increase, the teacher may notice immaturity in the child with NVLD compared to typically developing peers.

The teacher may turn to an occupational therapist (OT) for consultation and guidance. After observing the child, the OT might provide an evaluation or offer treatment. Sensory Integration Therapy (Ayres, 1994) might be offered to treat what the OT views as a sensory integration disorder. If the child’s issues are in the mild to moderate range, this may be all that is offered.

Sometimes children with NVLD may be referred for help with non-phonological reading difficulties (Pennington, 1991), but intervention may be premature.

Rourke (1995) notes that these difficulties may well be developmental for children with NVLD, and most children with NVLD develop basic reading skills without intervention. However, David Gresham (Griffin & Gresham, 2002) theorizes that these reading problems are often associated with difficulties in visual processing problems, like tracking. Tracking refers to the ability of the child to stay on the correct line of reading or math without veering off course creating confusion and extra time for the student to reorient oneself. Gresham suggests that these problems are due to visual-spatial processing difficulties. He claims that NVLD children frequently require tracking training, and that 30% of NVLD children need to be retrained to read fluently. He suggests performing a thorough optometric examination that includes an assessment of visual tracking.

Often, children with NVLD develop early math difficulties, although some use their verbal memory strengths to help them compensate through third grade, and occasionally beyond. If not earlier, during this period concerns begin to develop about social perception and pragmatic language development. Further, boys and girls with NVLD can present with clinical signs of anxiety, depression, attention problems, obsessional preoccupations, and self-esteem problems (Palombo & Berenberg, 1999). It remains unclear whether children with NVLD experience difficulties with peers because of processing issues, for example, difficulty processing facial expressions and social signals, executive function difficulties, novel problem solving, or due to another reason. They might even result from reduced interaction with peers due to their sensorimotor issues (Hale & Fiorello, 2004). Clearly further research is required to evaluate these hypotheses.

With difficulties in the social area, especially with pragmatic language problems, the next professional to become involved is most often a speech and language therapist. During earlier stages these children might have been seen for articulation issues connected with poor oromotor functions, while in early elementary school they are more likely seen for pragmatic language difficulties in social discourse. Children with NVLD often do not use appropriate vocal intonations. They might speak in a flat monotone or with a sing-song voice. It can be difficult to read their mood from their facial expressions and they may seem wooden and constricted (Palombo & Berenberg, 1999). In speech and language nomenclature these issues are often called “semantic-pragmatic” disorders (Volden, 2004). It is believed to bode well for youngsters if these issues are identified early and intervention begins before the child falls behind allowing secondary features, especially anxiety, to develop (Palombo & Berenberg, 1999).

Even though children may struggle and become frustrated by math and written expression, they tend not to be referred to special educators because they perform “well enough.” Their superior verbal skills often cause educators and parents to assume that their difficulties arise from insufficient effort, or difficulty paying attention. Rourke (1995) wrote that young children with these symptoms are often misdiagnosed with ADHD. Unfortunately such misdiagnoses can lead to a host of self-esteem problems and psychological issues, particularly when appropriate interventions are withheld.

Later Elementary and Middle School Signs

As academic subjects become more abstract, and more independent work is expected, NVLD children often begin to experience greater difficulties. Executive function problems increase. At the same time more demands are placed on social skills creating significant additional stress and frustration that can elevate anxiety and which also makes academic progress difficult.

At this point academically oriented professionals often become involved in the lives of NVLD children. Teachers become alarmed and mention their concerns at parent conferences. Parents ask for help for their children and wheels are set in motion. In either case, some variation of a Student Study Team (SST) is requested. School staff and sometimes parents gather to problem solve new ways of working with the child. These discussions can result in recommendations and/or interventions within the classroom. In public schools these concerns can also lead to a psychoeducational evaluation of the child. If testing reveals that the child is eligible for other special services, either under IDEA-04 or Section 504 of the Rehabilitation Act of 1973, an Individualized Education Plan (IEP) or Section 504 Plan could be developed to detail more specific ways of working with the child based on the available data (see Chapter 7 for more details) (Hale & Fiorello, 2004; Telzrow & Bonar, 2002).

Providing the best assistance for the student can become problematic because so much depends upon who gets involved and what they already know. The child's parents also need to educate themselves to become more knowledgeable as they will become increasingly involved in their child's treatment team. Helpful books for parents include: Sue Thompson's *The Source for Nonverbal Learning Disorders* (1997), Pamela Tanguay's *Nonverbal Learning Disorders at Home* (2001) or *Nonverbal Learning Disorders at School* (2002), Kathy Allen's *Star Shaped Pegs, Square Holes: Nonverbal Learning Disorders and the Growing Up Years* (1998), and Rondalyn Whitney's *The Nonverbal Learning Disorder Guide for Teachers, Parents, Employers, and Therapists* (2000). The SST or IEP team could advise them to join the Nonverbal Learning Disorders Association (<http://www.nlda.org>) or to become familiar with websites such as Judy Lewis's <http://www.nldline.com>, Pam Tanguay's <http://www.NLDontheweb.org>, or Charles Schwab's website, <http://www.schwablearning.org>. More information related to working with the families will be provided in a later chapter.

High School Signs

If the child with NVLD has managed to navigate the comprehensive middle school environment, the high school experience becomes the next challenge. During high school, social skills can become a source of even greater concern, as social stresses, such as the demands of dating, are increased. Advanced math and sciences will also be more challenging. Increased demands on executive functioning, as in written

expression and advanced reading skills, can present severe challenges. Research is mixed regarding whether students with NVLD are more at risk for psychiatric disorders, like depression with some finding increased levels of depression (Brumbach, 1985; Fletcher, 1989; Rourke, Young, & Leenaars, 1989) and other not finding that children with NVLD are at increased risk for psychiatric disorders (Mokros, Poznanski, & Merrick, 1989). It is possible that these contradictory findings are due to the significant differences in age groups, race, and income among the different studies (or differing definitions for diagnosis given the wide range of diagnostic criteria used in research on NVLD). However, with interventions, accommodations, and modifications students with NVLD are often able to tap into their skill sets and experience success as emphasized by Brooks (1991) and his concept of “islands of competence.” By this he is referring to the fact that learning-disabled students have relative strengths and weaknesses and that it is at least equally important that the student’s strengths get recognized and enhanced as it is to remediate any relative weaknesses or deficits. Skill sets might include acquisition of a second language, drama, certain aspects of the arts, language arts, and some of the language-based sciences.

Generally the support team continues to be involved in the student’s program, if not via the IEP process then sometimes utilizing the Section 504 laws. Transition planning becomes essential and decisions about further education need to be made. In our experience, students who have not become too demotivated, depressed, or demoralized can move on to successful adulthood if they, with the help of their parents and coaches, choose wisely with special regard for their strengths. Students with NVLD often interact better with adults than with their peers. Personal accounts written by people with NVLD suggest that adulthood may bring more successful interactions and relationships. Debbie Green, for example, in *Growing up with NLD* (1999) writes of her joys as a teacher. Laurie E. Reed talks of her career as an occupational therapist in *Unaware: Living with Non-verbal Learning Disabilities* (2001). These authors emphasize that early accurate diagnosis and appropriate intervention are crucial to the well-being of the person with NVLD.

Summary

In this chapter we have offered an overview of the history of the development and understanding of nonverbal learning disorders. The most commonly used definition has been reviewed and we have considered how the child with NVLD might appear at different developmental stages. Next in Chapter 3 we will discuss advances in our current thinking about NVLD and the possibility that NVLD is not one disorder but rather has subtypes.

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