Preface

The inception of this book is attributed to many years of disquiet and a search for answers. Through scholarly devotion to subject matter and concern for those affected by a nonverbal learning disability (NLD), the authors who contributed to this text have embodied a conviction of purpose and displayed a united effort, culminating in the publication of this essential resource.

The book draws upon my doctoral research that explored educator, parent, and student perceptions of the learning experiences of students with spina bifida and hydrocephalus in Australian schools (Rissman, 2007). Such children are believed to be at Level 1 risk of manifesting virtually all assets and deficits of an NLD, one of the only disorders for which the neurobehavioral characteristics have been thoroughly investigated (Fletcher, Brookshire, Bohan, & Timothy, 1995). Personal interest in the study was driven by a 12-year journey through mainstream schooling with a daughter born with an encephalocele, a defect included in the term spina bifida because both involve failure of the bone to fuse along the vertebral column or bones of the skull (Menkes, 1995; Sandler, 2010). Encephalocele refers to protrusion or herniation of brain matter through a congenital defect in the skull. Following extensive early repair of my daughter’s encephalocele, a ventriculoperitoneal shunt was implanted to drain hydrocephalic fluid from the head to the abdomen. The early childhood years were plagued by shunt dysfunctions, each requiring urgent surgical intervention, seizures, repair of alternating strabismus (causing squinting), and constant vigilance to prevent a bump to the head. Progress was closely monitored by a team of medical professionals comprised of a neurosurgeon, pediatrician, ophthalmologist, physiotherapist, speech therapist, and occupational therapist. A neuropsychological assessment conducted at age 15 years indicated an NLD.

A review of the literature suggested a need to raise educator awareness about the subtle but increasingly disabling nature of an NLD (Rissman, 2007). While abundant literature and reports of teacher misunderstanding emanated from the United States and Canada, there was no reason to assume the learning experiences of Australian children who displayed the NLD profile were the same. My study probed assertions by Roman (1998), Rourke (1989), Rourke (1995), Rourke, van der Vlugt, & Rourke (2002), Russell (2004), Tanguay (2002), and Thompson (1997) that educators were unfamiliar with the NLD syndrome. It explored the perceptions of teachers, aides, and parents involved with five students with shunted hydrocephalus and spina bifida who displayed hallmark signs of an NLD, the aim being to engage individuals who contributed to the whole context of the child’s life (Parlett & Hamilton, 1972). The theoretical foundation rested on understanding that a student’s learning experiences were influenced by past and present school experiences, the attitudes of peers, and parental expectations. The intention was to gather multiple perspectives from stakeholders about the educational experiences of these five students. By undertaking this research, I sought to fill a void in the literature by investigating contentions that educators were unfamiliar with this learning disability. As an insider of the NLD world then,
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I was attuned to what people were saying during the study’s recruitment phase, and lived experience enhanced sensitivity to the plight of parents, teachers, teacher aides, and students. In the context of five families and schools in Queensland, Australia, this study “gave voice” to forty-three teachers, aides, students, and parents or caregivers.

Families were expected to offer history of educational experiences and how they believed their child was perceived at school. Since nonverbal deficits become more noticeable with age, it was thought that a greater emphasis on challenges regarding life skills, friendships, and social isolation may emerge from families of older students. The project probed understanding of students’ impaired ability to perform many daily tasks that teachers, aides, parents, and even physicians are often at a loss to explain. The ultimate goal was to foster increased understanding that would “be noticeable to a variety of audiences” (Lincoln & Guba, 1985, p. 225) including teachers, psychologists, and school counselors so that early identification and intervention may generate appropriate expectations before educational and social difficulties lead to anxiety or worse. As a result, the significance of verbal and nonverbal abilities required for academic, social, and emotional functioning might gain ascendency in the minds of professionals and parents. A confirmed need for this learning among educators may stimulate inclusion of NLD information in teacher training programs.

The openness of the naturalistic inquiry approach allowed people to tell important stories in their lives—in their own language and in their natural setting. A three-tiered selection process involved five primary selection criteria, a 15-point parent questionnaire that probed key indicators of an NLD, and existing psychometric test data that was examined by experts in the field of NLD. All parents or caregivers believed their young person had good verbal skills but experienced trouble with mathematics and handwriting. The final study group consisted of five students aged 9 to 16 years—all attending mainstream schools—who displayed hallmark signs of an NLD and therefore had a greater than chance probability of obtaining an NLD diagnosis. Forty-three interviews with teachers, aides, parents, and students were conducted, and a psychological test battery designed for the study was administered by a psychologist and speech therapist. The test battery assessed each student’s intelligence and NLD status.

All students were found to be severely learning disabled and high on the NLD parameter. Educators revealed a lack of understanding of the NLD syndrome, posing questions such as “Nonverbal, what is it? . . . so is it a visual problem?” Some teachers devised innovative strategies to help the student in class, while others expressed frustration and questioned if the traditional instruction “doesn’t work either, what does?” What stood out was an absence of understanding about the significance of nonverbal skills for daily life. Teachers expressed frustration over poor organization, decision making, task completion, and problem solving, and a mixture of concern and criticism was leveled at the students’ social incompetence. Students who could not work independently were perceived as “lazy” or “molly-coddled,” and problems with everyday living skills were often blamed on the family. Findings revealed a compelling need to raise awareness about NLD among those well-placed to shape the child’s development (Rissman, 2007). When a child is deficient in nonverbal learning and cannot learn from experience, “he indeed has a serious learning disability” (Myklebust, 1978, p. 85).

In 2008, Tsatsanis and Rourke stated, “NLD is considered a learning disability in the fullest sense” (p. 181), while Ris and Nortz (2008) claimed, “There is clearly increased interest in and acceptance of the diagnostic entity of NLD” (p. 357). Impairments are lifelong, and most individuals come to the attention of psychologists or neuropsychologists in the middle to late childhood years or during young adulthood (Casey, 2012; Rourke, 1989).
As mentioned earlier, research has found that hydrocephalus related to spina bifida predisposes an individual to NLD. Liptak, Garver and Dosa (2013) reported that brain and brainstem abnormalities are associated with a “nonverbal learning disability, problems with memory, attention-deficit disorder, and problems with executive function” (p. 207). Sensory and motor functions below the spinal cord defect are usually impaired (p. 209). If coupled with an NLD diagnosis, the complex issues faced by young people with spina bifida, hydrocephalus, and NLD unsurprisingly deserve urgent attention by those who are in a position to recommend and advocate for help.

To an observer, a talkative and pleasant personality can disguise the quality-of-life issues confronting a person with NLD. Early identification of the NLD by pediatricians, psychiatrists, speech and occupational therapists, neuropsychologists, psychologists, teachers, aides, school counselors, and disability service providers is critical to gaining the right support to avert mental health issues. A key message delivered in this book is that a person who speaks, reads, and spells well can still have a serious disability. It is essential that educational, medical, and allied health professionals, along with disability service providers, understand the importance of intact nonverbal skills for individuals to function effectively in home, learning, and community environments on a daily basis.

If teachers and career advisors do not understand the seriousness of deficits in the nonverbal areas of functioning, how can they offer reliable guidance and plan meaningful training programs for these young adults? Teachers and school counselors tend to guide academically challenged students toward vocational fields such as hospitality, construction, auto mechanics, tourism, retail, hairdressing, or horticulture. These fields require fine- and gross-motor, visual, spatial, tactile, planning, organizational, and problem-solving abilities. Vocational subjects can be problematic for students with NLD which begs the question “What happens post-school when students seek work in a competitive workforce?” Students with NLD appear bright, but they have trouble coping with simple everyday tasks, and they do not quite fit in with peers. The post-school period is when functional and social problems magnify as teacher aide support evaporates and the young person wants to pursue work initiatives introduced through school. The individual has likely been involved with career development programs and engaged in vocational training programs.

These young adults are at risk of falling through the cracks. If difficulties are not identified and addressed so career guidance can be couched within a realistic framework, depression can set in as the young person grows older and compares his or her real prospects with those of age-peers. As peers forge ahead vocationally and socially, families struggle to make life productive for their young adult with spina bifida, hydrocephalus, and NLD. The young person may be trusting and impeccably honest, which makes them an easy target for predators as well as physical, emotional, and financial exploitation in adulthood.

The most serious crises seem to occur at the point when [students] leave school and attempt to enter the competitive work force. It is at this juncture that they begin to experience the most devastating effects of their deficits. (Rourke, 1989, p. 145)

THE SEARCH FOR ANSWERS

This book is a practical resource for teaching, medical, and allied health professionals whose roles might include identifying NLD and advocating for those affected. Target audiences include
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- Tertiary educators; undergraduate and postgraduate students in education, psychology, and nursing disciplines; and individuals pursuing certificate courses in disability services;
- Independent practitioners including psychologists, neuropsychologists, physicians, speech and language pathologists, and occupational therapists;
- Associations for spina bifida and hydrocephalus, closed head injury, Asperger syndrome, Williams syndrome, Turner syndrome, de Lange syndrome, velocardiofacial syndrome, Sotos syndrome, fragile X syndrome, multiple sclerosis, and congenital hypothyroidism; and
- Government disability services and community housing personnel including medical officers, assessors, psychologists, and occupational therapists.

Authors explain common NLD indicators, their manifestation over time, and the dilemmas faced by families and professionals addressing the needs of children and young adults with this profile. The book offers evidence- and research-based accounts drawn from scholarly endeavors, academic literature, and my 33 years of experience gained from rearing a child with severe NLD. I come to this task as an educator who seeks to help these children by furthering the knowledge of others.

Medical and Educational Perspectives on Nonverbal Learning Disability in Children and Young Adults is based on the premise that NLD exists as a clinical entity. There is no intention to minimize the impact of neuronal abnormalities associated with spina bifida and hydrocephalus on physical, cognitive, social, and emotional functioning. Rather, an important goal here is to name and explain the neurobehavioral consequences that face children, young adults, parents, and professionals on a daily basis and that cause frequent misunderstanding. The book is organized into 11 chapters as follows:

Chapter 1 seeks to engage the reader with what is an enigma for some—the NLD profile. Discussion includes the origin of the disability, the physical presentation, differences between NLD and other commonly diagnosed learning disabilities, and possible consequences if the NLD is not identified early and managed. A significant goal of this chapter is to inform practitioners in the teaching, medical, and allied health professions about the complex and serious nature of an NLD so that early identification and intervention may prevent mental health issues from arising.

Chapter 2 focuses on specific conditions that research has found predetermine an NLD. This chapter provides a three-level hierarchy of disorders, first addressing those associated with a level 1 risk of manifesting an NLD most clearly, and then moving to levels 2 and 3 where signs and symptoms are less obvious. Objectives are to inform educators, medical and allied health professionals, and government disability service providers about the behavioral characteristics associated with predisposing conditions so that features presented in class and consultation rooms may lead to prompter identification, assessment, and intervention.

Chapter 3 reviews the scientific literature that has given rise to our current conceptualization of NLD. Clinical practice considerations are discussed and illustrated by a case study, which is followed by discussions of issues in need of further research. Also addressed are the benefits of considering NLD in the context of the World Health Organization’s classification system for describing health and health-related conditions. The chapter ends with a proposed definition of NLD and a list of resources.

Chapter 4 presents a framework for parents and educators to conceptualize the profile of neurocognitive strengths and weaknesses in individuals with NLD across different stages of development and in the context of environmental demands. The author describes how a comprehensive neuropsychological assessment can clarify an individual’s unique learning profile and guide intervention. It emphasizes the importance of early identification and an integrated, collaborative approach to intervention.
Chapter 5 is inspired by the parable of six blind men and an elephant. The authors have long been
struck by the number of specialists who come into contact with children with NVLD (another commonly
used acronym for nonverbal learning disability). Each profession may emphasize and name a particular
aspect of NVLD. This chapter offers a developmental perspective of NVLD across the lifespan, identi-
fies a subtype model for NVLD, and addresses ways in which parents and other family members can
organize and manage teams of treating specialists from hospital, school, and family perspectives.

Chapter 6 discusses the challenges involved with transition planning and post-high school life for
young adults, especially individuals with NLD, and emphasizes that careful planning can lead to suc-
cess. Review of NLD characteristics, effects on learning, non-awareness and misconceptions of NLD,
and effective supports for individuals with NLD are illustrated via the example of one young college
student with NLD and spina bifida. Research-based strategies for transition planning as well as methods
to promote self-advocacy are illustrated.

Chapter 7 is based on five illustrative case studies that resulted from doctoral research conducted in
Australia. The study involved the selection of five students at Level 1 risk of manifesting virtually all
NLD assets and deficits as a consequence of shunted hydrocephalus related to spina bifida, followed
by interviews with their parents, teachers, aides, and the students themselves. Each case begins with a
description of the medical condition that predisposed the child to NLD and is followed by a snapshot of
the student’s life, classroom performance, and psychological testing, as well as participants’ perceptions
of the student’s functional abilities and their level of awareness of the NLD syndrome. Practical help
from participants is offered at the end of each case study.

Chapter 8 is written from the perspective of a support worker who has provided individual support
to a young adult with shunted hydrocephalus, spina bifida, and NLD over a 11-year period. The purpose
of sharing this experience is to assist fellow support workers, disability assessors, teachers, and aides
who interact with similarly affected young people to better understand their complex needs in home,
learning, and social environments. Discussion includes first impressions of the young person’s abilities,
daily life, and independent living. Support through several vocational training programs is discussed in
light of NLD strengths, challenges, and complicating medical factors.

Chapter 9 explores data-driven hypotheses concerning language, cognition, and social communication
in adults aged 19 to 44 years who have NLD and autism spectrum disorder (ASD). Research findings
include strengths in vocabulary breadth, weaknesses in semantic precision and integration, and responses
to adult autism screening surveys that are above diagnostic thresholds for both clinical groups. Trends
in the data point to difficulties with gestalt formation that are amenable to intervention.

Chapter 10 addresses challenges faced by individuals with NLD in understanding and using language
in social contexts due to their struggle to interpret nonverbal communication and nonliteral language.
Assessing and understanding these challenges is critical to the design of targeted intervention. While
individuals with NLD rely heavily on their auditory skills, it is imperative that they learn social-prag-
matic and language skills in order to function in dynamically changing social exchanges. This chapter
provides information regarding assessment and intervention practices related to social interactions for
individuals with NLD.

Chapter 11 is written in two sections. The first section provides an overview of the diagnostic process
used in one Australian research study and the role of the psychologist and neuropsychologist in diagnos-
ing NLD. Also discussed is the burgeoning global interest in recognizing NLD in a formal classification
system. The second section discusses realistic issues that may be experienced by those who live with, teach, care for, guide, and advocate for an individual with shunted hydrocephalus, spina bifida, and NLD. This section reports, as impartially as possible, some of the author’s lived experience.

NOTE: Some names and identifying details have been changed to protect the privacy of individuals. “Nonverbal learning disorder” and “Nonverbal learning disability” will be used interchangeably throughout the book, as both are commonly used terms.

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REFERENCES


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Teachers said verbal skills were "excellent," "very well-developed," and "really, quite, quite, outstanding." They remarked that she "can talk about anything, has no trouble...tells lots of stories," "[is] a good little talker," "speaks very eloquently," and "[is] fine in that area." One said,"Her forte is going to be the verbal...I could see her as a radio announcer."

[ Year 10 English teacher ]

"As soon as you said, 'Pick up a pencil,' he would talk about it, he would discuss it, he would happily draw it, he would act it out, but writing about it, he just couldn't think of how to start a sentence. He would be stuck. He had no hope of being able to."

[ Year 5 Class teacher ]

Teachers know that kids with short attention spans and behavioural difficulties learn a certain way. "I know what those ways are. I learned at Uni how I can teach students like this, but I don't know anything about what I can do to get her learning. What do you do if the traditional instruction doesn't work with her, and the more visual hands-on work and using multiple intelligences...If that doesn't work either, what does? What is it and why won't anyone acknowledge there is something?"

[ Year 9 Maths teacher ]

"But we would expect her to be able to make a decision: 'Do you want this green thing or do you want this red thing?' and we think that's an easy decision to make. There's no right or wrong answer...and maybe we don't understand."

[ Year 9 Teacher aide ]

"She's the one we're always telling to do things...remind her to brush her teeth, get dressed, and when she is with Grandma, she must be reminded to do her bed, her room, have breakfast. Then after breakfast, 'Now go and do your teeth.' When she is finished one task, she must be moved on to the next."

[ Parent of year 5 student ]