

Chapter 11

The Road to Diagnosis and Post–School Life

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ABSTRACT

This chapter is written in two sections, each with its own introduction and background. “The Road to Diagnosis” is not intended to be exhaustive. Discussion touches on the role of the psychologist and neuropsychologist in the NLD diagnostic process in light of considered views of experts offered in earlier chapters. The critical need to assess executive functions (EFs) as a core component of an NLD is raised as well as the need to include NLD in a formal classification system. Formal inclusion of NLD in an organized structure not only has potential to transform lives on an international scale, but it would acknowledge accumulated scientific research findings, and persistent advocacy of investigators. The “Post-School Life” 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.

INTRODUCTION

A clear differential diagnosis is critical to gaining funded support for individuals in school and post-school environments. Many psychologists are unfamiliar with NLD. They need to recognize this disability for what it is—not as a behavioral disorder, as it was previously conceptualized by psychologists. This section discusses the role of the neuropsychologist in diagnosing NLD, the need to assess executive functions and adaptive behaviors, and the diagnosis of NLD in one Australian study. The potential roles of the International Classification of Functioning (ICF) and the umbrella organization, the International Classification of Disease (ICD), in having NLD recognized in a formal classification system are discussed in view of increasing global interest.

DOI: 10.4018/978-1-4666-9539-9.ch011

Although NLD is not formally identified in any current classification system, the findings from several hundred peer-reviewed journal articles, the publication of dozens of books and book chapters, and the creation of a half-dozen or so websites dedicated to this disorder have revealed the clinical features that characterize this disorder and provide compelling evidence supporting its validity. (Casey, 2012, p. 37)

BACKGROUND

All learning involves verbal and nonverbal processes. In an educational setting, psychological testing that is limited to intelligence and academic functioning typically excludes principle NLD characteristics. This model of assessment has been found to be an inadequate method to render an accurate NLD diagnosis. Multidimensional neuropsychological testing, which provides insight into brain-behavior relationships, is essential. Psychometric testing of individuals with suspected NLD should include assessment of visual, spatial, and tactile perceptions; fine- and gross-motor skills; and manual dexterity; as well as assessment of cognition, adaptive behaviors, and executive functions (EFs). An important objective of this chapter is to highlight the need to assess the verbal *and* nonverbal abilities needed to function effectively in home, school, and post-school environments. This is particularly important for those already living with comorbid conditions such as hydrocephalus and spina bifida. Comprehensive neuropsychological and occupational assessments play an influential role in providing reliable career guidance and vocational placements and in designing appropriate support packages so individuals can develop functional competencies relative to their needs.

Box 1.

THROUGH THE AUTHOR'S EYES

The author's interest in raising awareness about NLD is driven by quality of life issues and need for a secure infrastructure that takes parental demise into account. Without persistent advocacy, her daughter Sally's security and quality of life would be severely compromised due to unawareness about NLD in the disability sector. Sally lives with spina bifida, shunted hydrocephalus, and a nonverbal learning disability (NLD). Independent living is a hot topic for parents of a young person with spina bifida and hydrocephalus who wants to transition from home, because support funding is usually needed. Cognitive difficulties including "a nonverbal learning disorder, poor executive skills, attention deficits, and memory problems" might delay maturation and "impede his or her ability to acquire the skills needed to live independently, which in turn affects family members" (Holmbeck et al., 2003, p. 1650). Sally experiences all of the aforementioned difficulties, which are well-documented in her assessment data. For some time, she has wanted to try independent living. She needs substantial funded support that is clearly recommended by well-certified assessors. The author has experienced many difficulties securing appropriate funding to allow this transition to occur.

The biggest problems have involved funding bodies and service providers whose assumptions of Sally's needs appear to overrule professional recommendations. These assumptions may be based on Sally's presentation. She presents as an articulate young lady with the ability to converse on a range of special-interest topics. Her presentation might appear to contradict assessment data. As expressed by an occupational therapist, "To the lay observer, [Sally] presents as functioning at a higher level than she actually is. [She] is socially trained by her mother's constant reinforcement over the years. She is not, however, socially skilled and has a child-like interpretation of the nuances of interpersonal relationships." Magnetic resonance imaging (MRI) has revealed multiple malformations of the brain associated with the occipital encephalocele at birth and its repair. Multiple malformations have manifested in a range of nonverbal deficits including poor balance, right-sided weakness, epilepsy, and visual, visuospatial, and intellectual impairment. Her presentation could be attributed to relatively intact left hemisphere skills, evidenced by verbal fluency, sound vocabulary, and strong rote-learning ability. Thirty-three years of care, teaching, ongoing therapies, and numerous extracurricular activities with high levels of support have no doubt played a complementary role.

As noted, over the years, particular problems with support workers have included preconceived ideas of Sally's abilities based on her presentation. It may also be the case that some service providers compare her to other clients whose disabilities are more visible. In the past, difficulties with everyday tasks have been attributed to lack of motivation. One government bureaucrat claimed she did not agree with Sally's ICAP (Inventory for Client and Agency Planning) assessment. This assessment revealed a score of 47/100, with a concluding comment that Sally "requires extensive personal care and constant supervision."

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