

Chapter 61

Case Studies

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ABSTRACT

This chapter is taken from five illustrative case study reports resulting from doctoral research. Each case gave the researched a voice. The study selected five students at Level 1 risk of manifesting virtually all NLD assets and deficits as a consequence of shunted hydrocephalus related to spina bifida then spoke with their parents, teachers, aides and the students themselves. Each case begins with a brief description of the medical condition that predisposed each child to NLD followed by the contextual setting derived from family members. A snapshot of each student's life, classroom performance, psychological test results, teacher, aide, and parent perceptions of functional abilities, and the level of each participant's awareness of the NLD syndrome are then considered. Interpretative Discussions include teacher and aide understandings of the difficulties interspersed with those of the author. Practical help from teachers, aides, parents, and students is offered at the end of each case study. Case Studies conclude with a catalog of Key Terms and Definitions.

INTRODUCTION TO CASE STUDIES

Hydrocephalus is a major complication of spina bifida, a neural tube defect that results from failure of the spine to close properly. Spina bifida is relatively common, “occurring 10 to 20 times per 1,000 births” (Mosby, Inc., 2013, p. 1671). Today, 95% of individuals with spina bifida have hydrocephalus that is treated with a shunting procedure (Lutkenhoff & Oppenheimer, 1997). A pre-selection interview with primary caregivers and review of existing psychometric data by a developmental pediatrician and neuropsychologist identified five students with a blueprint of NLD characteristics. Participating students were aged 9-16 years and all attended mainstream Australian schools. Nineteen teachers, six teacher aides, thirteen parents, two grandparents, and five students participated in two interview phases. A total of 43 interviews were conducted. Interview transcriptions were clarified and checked through the member checking process in a fair and unbiased way. Corroboration with each informant tested the accuracy of interview transcripts and provided opportunity for expansion before the data analysis phase. On completion of interviews, a psychological test battery designed for the study was administered to determine the

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NLD status of each student. The test battery was developed by a developmental pediatrician, neuropsychologist, psychologist, and speech language pathologist. All tests were listed in the university register of approved procedures. (For more details, see Chapter entitled *The Road to Diagnosis and Post-School Life*). Test results added to the richness of case study descriptions and provided a contextual background for case study reports. This sequence allowed exploration of perceptions without influence of researcher views derived from test findings.

Author Interest in Case Studies

A 12-year journey through mainstream schooling inspired doctoral research. The author's daughter "Sally" was born with an Encephalocele, a defect included in the term spina bifida, because all share failure of the bone to fuse along the vertebral column or bones of the skull (Menkes, 1995; Sandler, 2010). Encephalocele describes protrusion or herniation of brain matter through a congenital defect in the skull. Sally's encephalocele presented as a skin-covered sac that protruded from the back of the neck in the area of the cerebellum. Approximately the size of a large orange, the sac was filled with hydrocephalus fluid. Early investigation by a neurosurgeon involved shining a light into the sac, which revealed what appeared to be brain tissue. Following extensive repair, later Magnetic Resonance Imaging (MRIs) confirmed that Sally was missing right cerebellum, which has resulted in serious balance and coordination difficulties through life. After removal of the sac and extensive repair at 10 days of age, Computerized Tomography (CT) scans were used to monitor the extent of fluid build-up in the head. By 21 days of age, a ventriculoperitoneal shunt was implanted into the third ventricle and tubing threaded under the skin to drain fluid to the abdominal cavity. During those early years of Sally's life, the words "spina bifida" or "neural tube defect" were never mentioned to the parents by any medical professional.

Early childhood years were plagued by shunt dysfunctions that each time required urgent surgical intervention, seizures, repair of alternating strabismus (squints), and constant vigilance to prevent a bump to the head. Progress was closely monitored by a team of medical professionals which comprised a neurosurgeon, pediatrician, ophthalmologist, physiotherapist and occupational therapist. Fletcher, Brookshire, Bohan, and Timothy (1995) empathize with this account when they say "parents of a child with hydrocephalus face a lifetime of monitoring the child's condition with recurrent concerns about possible relapse, shunt dysfunction and the need for additional surgery" (p. 210). As specialized care and daily physical therapies were prescribed from an early age, the mother resumed the study of music to gain credentials and build a private teaching practice. In retrospect, the study and intense practice provided a cathartic outlet from the constant monitoring of Sally.

Sally's neuropsychological assessment at age 15 years diagnosed an intellectual impairment, which was difficult to accept. No professional had ever suggested intellectual compromise. Because Sally did achieve well with individual support, the author theorized that, "if we work harder, she'll catch up". Daily therapies focused on physical and visual issues related to the problem at birth. Close liaison with pre-school and primary teachers encouraged them to make allowances for the many neurosurgeries. In-class support and provision of tuition and musical accompaniment for class and creative activities helped the author become a school "regular". With much one-on-one support, repetition and structured routines at home, in the author's eyes, Sally kept up with her peers up to Year 4. She managed the concrete tasks and predictable routines but anything new required step-by-step instruction and psychological preparation. The first "lazy" accusation was observed on a Year 5 report and such comments became frequent. Every year got harder, much harder, in every area. During one Drama class, a Year 8 peer told Sally to

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