

## Chapter 8

# My Journey with Sally

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### ABSTRACT

*During the past 10 years, the author has supported a young lady with hydrocephalus, spina bifida, and a nonverbal learning disability (NLD) for approximately 8 hours per week. The young lady referred to is “Sally,” who is now in her thirties. The writer’s personal interest in this chapter is to share her experiences as a support worker—both positive and negative—and by doing so, assist fellow support workers, disability assessors, teachers, and aides who work with young people like Sally. Discussion includes first impressions of Sally’s abilities, her daily life as observed during one-on-one support, and her experience with independent living. Support through several vocational training programs will be discussed as well as Sally’s diagnosis of epilepsy and the impact this has had on her life. Finally, the joys and challenges involved with experiencing local community activities, special holidays, and day trips will be shared, with relevant examples provided.*

### INTRODUCTION

For a period of 7 years, the author was employed as an assistant-in-nursing (AIN) at an aged care facility that specialized in dementia-related disorders. This was followed by a move to the disability sector and recruitment as a disability support worker, a position held for the past 10 years. During this time, clients have included individuals with Down syndrome, autism, epilepsy, obsessive compulsive disorder, vision impairment, and physical and intellectual disabilities. Insight into the problems associated with these disabilities and the effect each has had on these individuals’ and their families’ lives has greatly deepened the author’s appreciation of the challenges they face.

Over the years, Sally’s disability has presented many highs and lows. Her mother has always been keen and willing to discuss her medical and learning difficulties with the author, and when needed, provide additional reading about Sally’s severe nonverbal learning disability (NLD). The author understands that this disability becomes more obvious as the young person grows older, and the widening gap between the person’s accomplishments and those of age-peers may cause depressive symptoms if NLD indica-

tors are not recognized. Aspects of the individual with NLD's presentation that often confuse a new acquaintance are his or her fluent speech, good rote memory, and ability to talk about a range of topics of special interest. What is hidden during a casual encounter are the person's difficulties in nonverbal areas of functioning. These relate to tasks that involve fine- and gross-motor skills, manual dexterity, and visual-spatial perception (Rissman, 2007; Thompson, 1997). As well, trouble understanding daily routine tasks such as catching a bus, being punctual for an appointment, making friends, understanding social interactions, making reliable social judgments, and being able to interact with government, medical, and welfare agencies are just some of the daily challenges that may be faced by a young person with NLD.

When Sally has been unwilling to perform a simple task, an understanding of her impaired visual and spatial perception, motor skills, and manual dexterity has helped the author to realize that she is not being lazy but actually has trouble executing routine tasks. The difference between her background and that of other clients with a disability is that Sally was born with spina bifida, or a neural tube defect, and hydrocephalus, for which she had a shunt implanted when she was 21 days old. Since birth, she has had many shunt procedures, neurosurgeries, and other operations. Learning difficulties in a young person with spina bifida and hydrocephalus can be subtle and difficult to identify (Rowley-Kelly, 1993). It was not until she engaged in one-on-one interaction with Sally that the author came to realize that Sally's ability to deal with daily living tasks in no way matched her strong verbal abilities. In the early days, verbal skills actually masked her practical difficulties. Knowledge of this background has helped the author to consider the multiple skills required to carry out simple everyday tasks and the support that Sally needs to perform these on a consistent basis. It is very important for parents to have a good understanding of their family member's disability so that information and experience can be shared with the support worker and service provider.

## **BACKGROUND**

The author has drawn heavily on her progress notes, prepared as a mandatory requirement of all support workers by their employers in Queensland, Australia. This chapter will explain the author's first impressions of Sally's abilities and how, over time, some expectations have needed to be modified in order for her to achieve success. Struggles with many everyday tasks such as handling heavy saucepans, pouring liquid, cleaning a spill, and avoiding injury if glass is broken are discussed together with the physical and emotional energy required to complete routine tasks. Sally's brief experience of independent living with limited support is shared together with several vocational work experiences that have been developed around her strengths and personal interests. The profound impact of epilepsy on her daily life has resulted in extreme tiredness, memory loss, and decreased confidence due to unpredictable seizures. Although she manages to access the local community quite well, Sally's time management skills are poor. These cause her to frequently miss buses, at which times she calls her mother to collect her. If her mother is not in the local area, Sally will use the taxi vouchers allocated to her as a result of her unstable epilepsy, visual impairment, and poor balance and coordination. Finally, several holidays, day trips, and live theater productions experienced by Sally and the author will be shared with readers. The following discussion will report on the functional needs of a young person with spina bifida and shunted hydrocephalus in the hope that the needs of other young people similarly affected will be recognized so appropriate support can be provided.

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