

Stories from the Spectrum: Connecting Knowledge about Children with Autism
Spectrum Disorder to Practice in Child and Youth Care

by

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B.A., 2010, The University of Western Ontario

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Abstract

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Autism Spectrum Disorder (ASD) is a complex and lifelong neurodevelopmental disorder that is widely variable in presentation and intensity of defining features. ASD affects 1 in 94 Canadians and is increasing in prevalence. The variety of professionals who work with children with ASD have an accumulation of experiences that can be instructive and inspiring for other practitioners. This study explored how their wealth of experiences might be encapsulated as short vignettes or stories that could be analyzed and used as resources for educating current and future professionals. Six stories were collected from diverse professionals, and themes were summarized in order to demonstrate the types of lessons that can be learned from a clinician's story of a significant moment or event in working with a child with ASD. The stories highlighted challenges and breakthroughs in communication and managing the child's challenging behaviours, as well as skills and techniques that professionals have found effective in practice. The study shows that clinicians' stories hold valuable information that can be shared with professionals in an interesting and memorable manner. Future research could expand on this study to build larger collections of stories with additional viewpoints and specific professional insights and experiences with a variety of children in their practice.

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Dedications

I would like to dedicate this paper to the participants to thank them for their contributions to this study. Sharing your stories has not only inspired me, but will inspire other practitioners and raise awareness about working with children with autism spectrum disorder.

Additionally, I would like to thank Jessica Ball and Doug Magnuson for their support and patience throughout this process. I am so thankful that you were both a part of my team and I am forever grateful for all of your guidance.

Chapter One: Introduction

Storytelling is a powerful tool for sharing information. People begin telling stories in childhood and they continue throughout all of their lives. It is a method of information sharing that can transcend the boundaries of gender, culture, and age. Compared to traditional teaching methods, storytelling is viewed as an effective teaching method for those working in care-based professions. Learners are able to connect new knowledge with experience in an entertaining and memorable way. In the current study, I aimed to explore how professionals who work with children with autism spectrum disorder (ASD) can capitalize on storytelling as a method of sharing information.

ASD is a neurological disorder characterized by impairments in language development, social communication, and restrictive or repetitive behaviours. The disorder looks different in each individual, as it has a wide variability in terms of presence and intensity of symptoms (Newschaffer et al., 2007; Johnson & Myers, 2007; Zwaigenbaum et al., 2005). The prevalence rate of ASD in Canada is 1 in 94 persons, making it one of the most common developmental disabilities (Coo et al., 2008). Over the years, prevalence rates have been increasing (Newschaffer et al., 2007; Johnson & Myers, 2007). It is because of the increasing commonness of ASD that professionals who work with children, especially children with developmental complexities, need to be knowledgeable about the disorder and be given the opportunity to develop their skills for working with these children and their families.

Research Inspiration

Considering how many years some professional's careers can span, I am what most would consider fairly new and inexperienced professional. My experience with

children with developmental complexities at the beginning stages of this study consisted of one year in an early intervention program, where the children had a variety of developmental diagnoses.

At the time of the conception of this study, I had just received a new job that would require me to work with children with a diagnosis of ASD. I was very nervous, as my experience working with children with ASD was limited to a couple of individual cases. As a part of the training for this new job, I was tasked with watching a video about the thought processes of children with ASD. The woman speaking in the video told of a time when she had a major realization while working with a client and how it better helped her understand not only how he his brain was working, but potentially how the minds of her other clients worked as well. When she explained what she had realized, I too felt enlightened. After days of training, this was the first time that I felt like a piece of information I was given would influence my practice. I felt a little more prepared to begin working with the children.

After this experience it occurred to me that if a variety of professionals shared stories from their many years of service with me, I would learn more than if I continued to read articles and watch presentations. If this teaching method was effective for me, it might also be effective for others. Research showed that information on this topic in the story format did not exist, and that led to the creation of this research study.

Purpose of the Study

The objective of this research is to create a knowledge mobilization piece that uses narratives from experienced ASD professionals to share information with

practitioners in the field of child and youth care (CYC) that may be relevant to their practice.

This study has three goals: first, to create a medium for professionals to share their thoughts and feelings through stories and critically reflect; second, to create collection of these stories that can be used to educate professionals in the field; and third, to attend to the gap in narrative research with respect to ASD.

Research Question

What knowledge can be found within the stories of ASD professionals that could benefit the practice of CYC practitioners?

Framework

Chapter One, the current chapter, is the introduction. Chapter Two is a review of the literature and will cover topics such as ASD, narrative research, and the training and education of child and youth care professionals. Chapter Three describes the methods of the study, including participant recruitment and data collection, while Chapter Four reviews the results according to the six phases of thematic analysis laid out by Braun & Clarke (2006). Chapter Five is a discussion of the findings, limitations, and implications of the study.

Chapter Two: Review of the Literature

This chapter focuses on research that helps develop a strong knowledge base for the concepts and ideas in the current study. First, I explain how I selected books and articles discussed in this chapter. Next, I summarize current information and recent studies about ASD addressing understandings of the etiology of ASD and how some individuals manifest it. Next there will be an explanation of the role of some of the

professionals who are involved in cases of children with ASD and how they come to learn about the disorder. Finally, the narrative research methodology will be discussed, including how narratives can be used as an educational tool.

Research Approach

The literature review was conducted using online search engines provided through the University of Victoria's library: Google Scholar and PsychINFO. The following keywords were used to search the databases:

- "Autism Spectrum Disorder"
- "Autism Spectrum Disorder" and "Canada"
- "Storytelling as a teaching method"
- "Narrative as a teaching method"
- "Narrative research"
- "Professional education" and "Autism Spectrum Disorder"
- "Professional development" and "Autism Spectrum Disorder"
- "Narratives" and "Autism Spectrum Disorder"

If any of the articles cited information that seemed relevant to the study, those articles were obtained. As well, I drew upon other resources on ASD known to me.

Autism Spectrum Disorder

ASD is a complex and lifelong neurodevelopmental disorder that has a wide variability in terms of presence and intensity of symptoms (Newschaffer et al., 2007; Johnson & Myers, 2007; Zwaigenbaum et al., 2005). This spectrum disorder refers to a series of related disorders including autism, Asperger's syndrome, and pervasive developmental disorder- not otherwise specified (PDD-NOS) (Zwaigenbaum et al., 2005;

Newschaffer et al., 2007). Severe social skills deficits and restricted, stereotyped patterns of behaviour and interests are core features of all ASD's. Significant language delays are characteristic only of autism and PDD-NOS.

The exact cause of the condition is still unknown. The history of the diagnostic category of ASD, diagnostic criteria, and key presenting features of ASD will be discussed subsequently.

History of Autism. Although individuals who meet the clinical profile for ASD can be identified in literature going back several centuries (Newschaffer et al., 2007), two men are accredited with being the first to describe disorders that reflect the basis of what we know of today as ASD. Psychiatrist Leo Kanner, in 1943, described a group of 11 children who demonstrated varying levels of intelligence, emotional disconnection, and repetitive behaviours (Kanner, 1943). Kanner claimed that these children had often been categorized as schizophrenic or feeble-minded, whereas he thought their collective characteristics formed a unique syndrome not yet identified (Kanner, 1943). Kanner described each case, including each child's family history, communication skills, intelligence, and social skills. While no two cases were alike, the children all displayed aloofness, communication deficits, and an indifference to other people (Kanner, 1943). Kanner referred to the children as having "inborn autistic disturbances of affective contact" (1943, p.250).

Shortly after, unaware of the work of Kanner, pediatrician Hans Asperger published an article describing children who showed symptoms similar to Kanner's, but with higher verbal and cognitive skills (Johnson & Myers, 2007).

From these reports, the term ‘infantile autism’ first appeared in the Diagnostic and Statistical Manual of Mental Disorders (DSM), Third Edition. It was not until the fourth edition of the DSM that Asperger’s syndrome was recognized (Johnson & Myers, 2007).

Diagnostic Criteria. No diagnostically informative biological test currently exists for ASD at this time (Newschaffer et al., 2007). Professionals must refer to the diagnostic criteria in the American Medical Associations DSM.

Since its first appearance in the DSM, the diagnostic criterion for ASD has changed significantly. Previously, autism and other related disorders were distinct diagnoses. In the newest edition of the DSM, autistic disorder, Asperger’s syndrome, and pervasive developmental disorder- not otherwise specified, are represented by one spectrum disorder known as ASD. The following is the diagnostic criteria for ASD, according to the DSM-V:

Diagnostic Criteria for 299.00 Autism Spectrum Disorder

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by:
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits

in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse

response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals, who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(APA, 2013)

Etiology. The cause of ASD is unknown. It is a complex heritable disorder that involves a great many genes and demonstrates great phenotypic variation (Johnson & Myers, 2007). Although genetics are said to play a great role in the disorder, it is believed that some environmental factors may alter the phenotypic expression.

Genetic Factors. Researchers have spent years trying to discover new genetic information that could lead to a better understanding of ASD. Studies have searched genetic information for break points, translocations, duplications, and deletions (Johnson & Myers, 2007). At least one autism-linked abnormality has been found on every chromosome. Although some sites seem to have more of an impact on the likelihood of an ASD diagnosis than others, nothing has been concretely identified (Johnson & Myers, 2007).

Some neurogenetic syndromes have been shown to play a causative role or are otherwise associated with ASD, in studies described by Johnson and Myers including: Fragile X syndrome, Neurocutaneous disorders, Phenylketonuria, Angelman syndrome, Rett syndrome, and Smith-Lemli-Opitz Syndrome (2007).

Environmental Factors. Multiple environmental factors may play a role in the presence of ASD. Advanced parental age has been shown to be associated with an increased risk of an offspring with ASD, possibly because of de novo mutations or alterations in genetic imprinting (Larsson, 2005; Croen, Najjar, Fireman, & Grether, 2007; Newschaffer et al., 2007).

During the first and second trimesters of pregnancy, a fetus is at risk of being exposed to many environmental agents that have been linked to ASD. Children who are exposed to alcohol during gestation have been shown to be at increased risk of ASD as well as other neurological disorders (Newschaffer et al., 2007; Aronson, Hagberg, & Gillberg, 1997). The child is also at a higher risk during gestation if the mother falls ill, particularly with Rubella (Newschaffer et al., 2007; Larsson, 2005).

Despite myths perpetrated by pop culture, there is no evidence of a causal association between the measles-mumps-rubella vaccine and autism. This was demonstrated by the Institute of Medicine in 2001 after a review of epidemiological studies of ASD (Newschaffer et al., 2007; Johnson & Myers, 2007).

Manifestation of features. ASD is a heterogeneous disorder and it manifests differently in each individual. Some children are significantly delayed in some areas, while being greatly advanced in others. Some children are sensitive to different sensory stimulus and some children are simultaneously hyposensitive and hypersensitive to stimuli within the same sensory modality (Johnson & Myers, 2007). Many, but not all, demonstrate atypical motor development and have co-morbid medical conditions, such as seizures, immune system dysregulation, gastrointestinal symptoms, feeding difficulties, and sleep disruption (Newschaffer et al., 2007).

There are many characteristics that are unique to ASD, ranging from who it affects and how many, to how the disorder manifests itself in different individuals. In this section the demographics of the disorder will be listed and the different ways the disorder can present itself socially, cognitively, and through behaviours will be discussed.

Demographics. The prevalence of ASD in Canada is 1 in 94 persons, making it one of the most common developmental disabilities (Coo et al., 2008). Prevalence rates have been increasing over the years and possible reasons for this trend may relate to the changing diagnostic criteria and greater public awareness (Newschaffer et al., 2007; Johnson & Myers, 2007).

One distinguishing factor of the disorder is that it affects more males than females, with ratios ranging from 2:1 to 6.5:1. The ratio is even higher for high-functioning ASD, ranging from 6:1 to as high as 15:1 (Barned, Knapp, & Neuharth-Pritchett, 2011; Newschaffer et al., 2007; Johnson & Myers, 2007).

Little information is currently available about prevalence rates according to race and ethnicity. Various studies have made claims about variances in rates, but results are inconsistent (Newschaffer et al., 2007).

Social features. Although there is no pathognomonic feature of ASD, social deficits at a young age often seem to be the first red flag reported by parents (Johnson & Myers, 2007; Williams-White, Keonig, & Scahill, 2007). Children with ASD are often described as being content spending time alone. They do not seek connections with other people, they ignore their parents bids for attention, do not display social smiling, have a lack of facial expression, make little eye contact, and show decreased orientation to faces and their names (Kanner, 1943; Zwaigenbaum et al., 2005; Johnson & Myers, 2007).

Infants with ASD show difficulty holding joint attention. They are sometimes unable to follow a point, do not respond to their name, and do not show physical signs of a desire to connect with parents (Kanner, 1943; Johnson & Myers, 2010). Kanner (1943)

described the children in his investigation as ‘robotic’, as they are were very logical and lacked empathy and understanding for others.

Due to this lack of a desire to make connections to other people, children with ASD are less likely to enter into play with peers and develop peer relationships. This often leaves them with few or no friends (Johnson & Myers, 2007; Williams-White, et al., 2007). These social skills deficits can also contribute to underachievement in school and work situations and may predict future mood and anxiety (Williams-White et al., 2007).

Communication. Communication abilities differ greatly between individuals with ASD. Some who have the disorder are non-verbal, others are verbal but lack skills in particular areas, and others have speech skills that are indistinguishable from a person without ASD. Some communication deficits seen in children with ASD include: lack of appropriate gaze, lack of expression, lack of reciprocal conversations, delayed onset of babbling in infants, decreased or absent use of pre-speech gestures, and a lack of interest (Zwaigenbam et al., 2005; Johnson & Myers, 2007). 25%-30% of children with ASD begin to say words at the developmentally appropriate time, but then stop speaking between 15-24 months (Johnson & Myers, 2007).

Children with ASD often think and speak in very logical terms and they are unable to understand and express abstract things. This makes it difficult for children with ASD to understand the feelings of others, as well as social uses of language like clichés, idioms, and hyperboles.

Children on the higher end of the spectrum are known for having better communication skills than those diagnosed on the lower portion of the spectrum. They

can be quite verbal, especially about topics that interest them, but they may be unable to find the words to express feelings and display a lack of understanding of the viewpoints of others (Newschaffer et al., 2007; Johnson & Myers, 2007).

Cognitive features. Neuroimaging of the brains of young people with ASD show several brain abnormalities including early brain overgrowth, differences in volume of grey matter, and impaired connectivity between various cortical regions (Zwaigenbaum et al., 2005; Johnson & Myers, 2007). Imaging studies also show that children with ASD use different brain areas than typical persons to process certain types of information, including face-recognition and gaze fixation (Schultz, 2005).

The intelligence level of a child with ASD often correlates with their position on the autism spectrum (Johnson & Myers, 2007). Children who are located lower on the spectrum often have delays in multiple areas that can affect their cognitive performance. These children also face co-morbid diagnoses, which affect cognition, such as global developmental delay (Johnson & Myers, 2007).

Children on the higher end of the spectrum have an intelligence level that is often developmentally typical, with marked delays in speech or social behaviour. In fact, these children can display an above-average intelligence in certain areas relating to their intense interest on particular subjects (Newschaffer et al., 2007; Johnson & Myers, 2007).

Behavioural features. Early on, behavioural abnormalities such as extremes of temperament, poor eye contact, a lack of response to parent's voices, and a lack of attempts to play and interact with others have been documented in children with ASD (Zwaigenbaum et al., 2005). As they grow older, children with ASD display unusual

attachment to objects, obsessions, compulsions, self-injurious behaviours, and stereotypies (Johnson & Myers, 2007).

Stereotypies can be self-stimulatory and include a variety of repetitive, physical motions such as hand flapping, head shaking, finger tweaking, foot stomping, and rocking (Johnson-Myers, 2007).

Behaviour abnormalities can become more problematic as a child grows and has difficulty expressing his or her emotions in an appropriate manner. Transitions, routine changes, and upsetting situations can be a difficult time for some children with ASD, which can lead to protests that may escalate to displays of aggression and self-injurious behaviours (Johnson & Myers, 2007).

Children with ASD can also display a tendency to 'elope'. This can include simply wandering to a different room when left unsupervised or leaving the building or property (Johnson & Myers, 2007). This can be extremely dangerous depending on the cognitive level of the child, as they may enter unsafe into situations or find themselves unable to locate where he or she is and how to return.

Autism Spectrum Disorder Professionals

Professions. It has been said that it takes a village to raise a child and that certainly rings true for children with ASD. Families of children with ASD often have connections with neurologists, developmental pediatricians, psychiatrists, psychologists, speech-language pathologists, occupational therapists, nurses, and social workers (Werner, 2011; Johnson & Myers, 2007). The services from this range of professionals is necessary to offer a comprehensive interprofessional assessment required to make a diagnosis and manage a treatment plan (Werner, 2011).

Education professionals play a large part in the lives of children and many hours of a child's day are spent in their care. Schools are increasingly called upon to enhance the social, communication, and motor deficits in children and adolescents with ASD (Williams-White, et al., 2007). Professionals in school settings include teachers, educational assistants, learning coaches, behavioural specialists, and counselors.

A variety of medical professionals are involved in caring for the child's and their families physical and mental well-being. For many years now, the World Health Organization has recommended that health, education, and social service professionals work collaboratively in providing services for individuals with disabilities (1988; as cited in Werner, 2011).

Specializing in developmental disorders within the health, education, or social care fields is not a popular career path. In fact, when interviewed, most graduating students in education, social work, nursing, occupational therapy, and speech therapy claimed to have no interest in working with clients with developmental disorders (Werner, 2011). Often, the reason cited for this was that working with people with ASD was difficult, challenging, and frustrating (Werner, 2011). Research has found that these misconceptions can be eliminated and positive changes can occur by enhancing university curriculum, offering practical experiences working with children with ASD, focusing on training, and promoting interprofessional collaboration (Bevan-Brown et al., 2012; Werner, 2011).

Training and education. Research has shown that professional learning and development is critical in bringing about positive changes the workplace (Bevan-Brown et al., 2012).

Barned et al., interviewed education students about their knowledge of ASD and examined the lessons on special education material (2011). The researchers found that preservice teachers and early childhood educator (ECE) students lacked knowledge and held misconceptions about children with ASD and their needs in an inclusive classroom. In fact, 93% of preservice teachers did not know that ASD was a developmental disorder (Barned et al., 2011). Knowledge about the learning needs of children with ASD that teachers did have were primarily associated with the teachers' experience teaching a specific child with a disability.

Upon examining the curriculum, Barned et al., found that on average only 8.62 hours were spent covering issues addressing special education throughout the entire post-secondary program (2011). The researchers argued that even amongst special education teachers, the level of training about ASD was significantly low. (Barned et al., 2011).

Participants also reported fear of running an inclusive classroom, using words such as "extremely disruptive", "bad situation", and "dangerous" to describe how an inclusive classroom could look (Barned et al., 2011).

Barned et al. (2011), suggest that many things need to be done to better educate teachers and school staff about ASD, as their knowledge and attitudes towards children with ASD may influence their performance as educators, the future of inclusion, and the quality of education received by children with ASD. Teachers and ECE's need more experience in inclusive classrooms, opportunities to speak with teachers who have had successes with children with ASD, professional learning about ASD, and specifically designed activities such as case studies (Barned et al., 2011).

Early professional training is necessary to provide the skills and confidence needed to work with children with ASD. Professionals who lack this knowledge may promote misconceptions or treat this population in a negative manner (Werner, 2011). One study, performed across multiple universities in Israel, concluded that graduates of caring professions are leaving university feeling unprepared to work with children with ASD and contributing to their ability to treat the population (Werner, 2011). Students in the aforementioned study identified not only a poor representation of people with disabilities in the coursework, but also identify a lack of training opportunities through practical experience and workplace placements (Werner, 2011). Werner (2011) calls for interprofessional collaboration to be integrated into school curriculum from an early stage and more information to be delivered regarding ASD. More opportunities for contact with children with ASD and other professionals should be offered through school settings. These actions can avoid the promotion of stigmas and negative attitudes and potentially increase the number of graduates interested in the specialization.

Once out of a school environment and into the workplace, it is crucial that professional development (PD) continues for professionals. In order for PD programs and training to be effective, it must be intensive, ongoing, and interconnected between pedagogy and practice (Bevan-Brown et al., 2012). Bevan-Brown et al. evaluated what ASD professionals in the field of education think make an effective PD program and they concluded that seven components were pivotal to a successful PD, these components are: cultural relevancy, expert facilitation, integration of material to practical needs of professional's clients, translation of theory into practice, provision of time for reflection, practice and action, and application of learning to authentic context (2012). Programs that

focus on these items have a positive effect on professional's self-reported levels of knowledge and changes in practice (Bevan-Brown et al., 2012).

It is unlikely that a brief training session can incorporate all seven of the components mentioned above. This may contribute to the findings of Ling and Mak (2012) that a one-time, brief staff training session has limited effectiveness. Knowledge, practical information, and emotional management are all important areas to train professionals in, and they cannot all be sufficiently covered in one session (Ling & Mak, 2012). A brief session can increase staff knowledge about ASD, but no long lasting impact was found on attributions, and emotional and behavioural management (Ling & Mak, 2012).

Continued staff training is crucial not only to update knowledge, but for improving and maintaining staff's confidence in their skills and their emotional wellness, and for improving the quality of the service being provided (Ling & Mak, 2012).

Ideally, professionals would not only be offered regular PD about ASD, they would also be offered some level of PD on each of their clients. In New Zealand, the ministry of health and education requires teacher's aides and education support workers to have PD for each child that they work with (Bevan-Brown et al, 2006). This allows for the professionals to learn the individual child's characteristics, communication skills, behaviour management techniques, and educational methods.

Dillenburger et al. (2010) state that parents desire ASD professionals to become better educated in applied behaviour analysis interventions. It is important that professionals hear these opinions as discrepant views between professionals and parents can have implications for collaborative work (Dillenburger et al., 2010).

Narratives

It seems that in recent times, educators are realizing that information can be taught to students in non-traditional ways. Alternative teaching tools can be used to foster a greater understanding and comprehension of information (Davidson, 2004). Narratives are one of these alternative teaching tools.

Methodology: The narrative approach. A narrative is a story that tells a sequence of events that are significant to the narrator and/or the audience (Moen, 2006). Stories are often reflective, creative, and value-laden. They reveal something important about the human experience (Haigh & Hardy, 2011). The oral tradition of storytelling is one of the oldest methods of communication for discoveries and developments and is used to educate and transmit knowledge and skills (Haigh & Hardy, 2011; Cox, 2001). Professionals have been using the method to teach and develop theory for over 100 years. In 1985 Freud published stories of his work with four individuals with hysteria, describing the patient's history, symptoms, and treatment (Breuer & Freud, 2004).

Narrative research is the study of how humans experience the world. Narrative researchers gather these stories to create narratives (Moen, 2006). The narrative approach is a research method used to reflect on the meaning of the experiences in narratives during the inquiry process and organize them in a meaningful way (Moen, 2006).

With narrative research, the narrative gains an importance that goes beyond the original situation and becomes applicable in other contexts. The story becomes separated from its origins and can enter into new interpretive frames, where it might take on meanings that were not intended by the persons involved in the original event (Moen,

2006). A narrative has the power to grow and affect each individual it connects with differently.

Storytelling has been used to effectively teach concepts such as ethics, caring, values, cultural norms, and differences to students (Davidson, 2004). Stories are effective as educational tools because, unlike most didactic data, they tend to be believable, memorable, engaging and entertaining (Rossiter, 2002; Fairbairn 2002). Narratives can present themselves through the use of case studies, critical incidents, role-playing, and simulations (Rossiter, 2002; Cox, 2001).

Benefits. Narratives allow audiences gain insights into specific client groups, to learn about multiple viewpoints, and to be exposed to expressions of cultural heritages. Through stories, cultural norms are shared, appreciated, and kept alive (Davidson, 2004; Haigh & Hardy, 2011).

Students seem to prefer this teaching method to traditional ways. They report that stories make information easier to process as the material is delivered on several different levels (Davidson, 2004).

Hearing information through stories can help expand the skills of professionals in many ways. Learners claim that stories allow them to visualize clinical situations in a realistic light (Davidson, 2004) and make sense of events by superimposing real life information with unknown theoretical situations (Haigh & Hardy, 2011; Cox, 2001). Interacting with stories that are real, before a person encounters similar situations in the world, can be a good way of preparing for the real thing (Fairbairn, 2002; Cox, 2001). Also, by interacting with stories that are told, learners can learn to empathize with the persons in the story (Fairbairn, 2002; Haigh & Hardy, 2011). Hearing a story allows the

audience to enter the storyteller's reality and understand how the storyteller makes sense of the events (Haigh & Hardy, 2011; Chamak, Bonniau, Jaunay, & Cohen, 2008).

Sharing stories can be a way to gain trust between the storyteller and the audience as the sharer is in a position of vulnerability and the listener is in a position of openness and understanding (Haigh & Hardy, 2011). As well, sharing stories can promote interactions between professionals. Sharing experiences with one another can reduce feelings of isolation and promote feelings of empathy and compassion (Haigh & Hardy, 2011). Stories help to form a sense of group connection and provide a non-judgmental environment for discussing taboo topics (Haigh & Hardy, 2011). Additionally, there are benefits for the people telling the stories. Storytellers report that sharing their story makes them feel empowered and satisfied that the story may help someone else (Haigh & Hardy, 2011) and they define the moment of sharing their narratives as a key moment in his or her self-construction (Chamak et al., 2008).

Limitations. One limitation of narrative research is the uncertainty of whether a story is a reflection of the facts or if it has been shaped by the storyteller (Moen, 2006; Chamak et al., 2008). Whether this becomes an issue depends on what the narratives are being used for. In some cases, the precise details will matter to the audience. In other cases, the moral of the story, or the feelings regarding the experience, will be of importance and the details may not be of significance.

Also, when stories are being shared, counter stories from listeners with opposing voices may be repressed for fear of disagreeing with the audience and entering into an unwanted confrontation or debate. The events in the story and the reaction of the audience may deter them from sharing their experiences or pressure them to become

withdrawn within the group (Haigh & Hardy, 2011). These things should be taken into consideration when performing narrative research. In this research study, the storytellers are submitting their stories privately and they will not interact with the audience or with one another. I hope this will allow the participants to share their stories freely, unhindered by the opinions of others.

Teaching with narratives. Rossiter (2002) claims that learning through narratives works because the frames of meaning from which learning occurs are constructions that grow out of human's natural tendency to tell stories of their lives. People understand the events that occur in their lives as fitting into stories; it is how we make sense of the world (Fairbairn, 2002). Therefore, the most effective way to reach learners with educational information is through these narrative constructions. Students are able to connect new knowledge with their own experiences and weave it into existing narratives of meaning (Rossiter, 2002).

Narratives offer information that the student can relate to in multiple ways. Stories enable people to engage with new knowledge and expanded possibilities because they are encountering it in the comfortable and familiar realm of human experience. The information told through stories is able to transcend cultures, ideologies, academic disciplines, and time (Rossiter, 2002). They provide students with a chance to explore the role of the characters in the story and relate the realizations to the story and to their own lives. Students can connect real life examples and their existing knowledge to concrete didactic data (Davidson, 2004; Fairbairn, 2002).

Stories offer a way of exploring the human side of information. Professionals in health care are often only offered information in ways that view the body as a

mechanism. When information is viewed from only a theoretical perspective, the learner only gets a fragment of a whole picture. Stories personify events and allow people to see the impact of illness and impairment from a social point of view (Cox, 2001).

Using narratives to teach offers the chance for the students to use the story to develop knowledge and a variety of skills. The content of the story can teach the student important practical details about real-life situations, to empathize with the characters, and the potential risks and rewards of a series of events (Cox, 2001). The skills that can come from actively listening to stories include logical deduction, decision-making, case management, and evaluating risks and rewards (Cox, 2001). As well, narratives can be an effective way for professionals to teach and communicate to one another about professional matters (Fairbairn, 2002).

Teaching about ASD. Storytelling makes up a large part of the activities done by practitioners in caring settings, such as medicine, social work, and special education (Fairbairn, 2002). Storytelling is prominent in these caring professions because the act of sharing cannot only be educational, but therapeutically valuable (Fairbairn, 2002).

Barrett (2006) suggests that the traditional ‘menu approach’ of reading about a child on paper does not help teaching professionals draw on skills and build the confidence needed to develop relationships with young people. Instead, a collaborative, conversation based approach to material can help develop understanding, empathy, and lead to practical teaching and learning outcomes for those who work with children with ASD.

One way to prompt these conversations is through the autobiographical approach. Chamak et al. stress that hearing about the personal experiences of persons with ASD

helps to develop the larger vision of autism seen by society (2008). Barrett (2006) suggests that by having a person with ASD share his or her own story with professionals, stimulating conversations between professionals could take place leading to complex sets of understanding and the ability to relate the stories to their understanding and their teaching methods.

Autobiographical experiences are invaluable because the writers are experts on their own experience with ASD. The experiences they share combine emotional and cognitive perspectives and it prevents people from seeing the ASD population as a homogenous group. For this reason, the authors should be future collaborators in shaping how the world understands autism (Barrett, 2006). Autobiographies are influential to professionals because it can allow the professionals to reconsider their own emotional responses to working with children with ASD and give them opportunities to see the world from the perspective of the child with ASD. Stories from persons with ASD are also helpful for professionals as it provides additional information about the disorder, which can lead to a better understanding. These details, potentially explaining emotions and behaviours, can influence the decisions professionals and families make relating to treatment plans and evaluation methods (Chamak et al., 2008).

Thematic Analysis

Thematic analysis is a flexible research method used for identifying, analyzing, and reporting repeated patterns or themes across a data set and allows for it to be reported in a rich and detailed account (Braun & Clarke, 2006). A theme is a concept that represents something important from the data in relation to the research question, and represents a pattern of meanings within the data set (Braun & Clarke, 2006). Generally,

there will be multiple instances of the theme within the data set. The primary researcher determines what a theme is (Braun & Clarke, 2006).

The process begins when the researcher begins to notice patterns of meanings and the endpoint is reporting the content and the meanings of the patterns. Braun and Clarke (2006) report a six-phase process for thematic analysis that will be used in this study. Phase one involves becoming familiar with the data by reading and rereading the data, moving back and forth between the content, and taking notes on any potential patterns. Phase two is generating the initial codes that appeared from the examination of the data. Phase three is searching for themes and sorting them into the initial codes and creating sub-themes if necessary. Phase four is reviewing and refining the themes so that they cohere together and there is a clear distinction between themes. Phase five involves defining and naming the final themes, and identifying the essence of what each theme is about. Finally, phase six is producing the report and providing evidence for the themes directly from the data (Braun & Clarke, 2006).

One of the useful features of thematic analysis is that it is a very flexible approach. The researcher is able to define the themes based on the need of the study and is able to pull a variety of meaningful patterns from a single data set (Braun & Clarke, 2006). Also, through thematic analysis, the researcher is able to really engage with the data set due to the recursive process of repeated readings, allowing him or her to become sensitized to the subtle features of the data (Braun & Clarke, 2006).

For the current study, a semantic approach will be taken to the thematic analysis. This means that explicit meanings will be taken from the data and the researcher will not consider any additional meaning from the information beyond what the participant has

written (Braun & Clarke, 2006). Also, a realist approach to the data will be taken, meaning that a unidirectional relationship is assumed between the experience and language (Braun & Clarke, 2006).

Chapter Three: Methods

In this chapter I focus on methods of the study, including participant recruitment and data collection. I will briefly explain how data were analyzed using thematic analysis. Finally, I discuss the ethical considerations involved in this narrative research study, including confidentiality and anonymity.

Study Design

Participant recruitment. This study utilized criterion sampling, where the researcher identified the criteria of importance that participants would be required to meet in order to participate (Patton, 1990). The criteria for a participant were that his/her job description included working directly with children with ASD and/or their families and that they were professionally situated in Canada. This population was of interest because ASD professionals are experienced in the field and are seen as having a great breadth of knowledge to share with other practitioners.

The recruitment process began after approval was received from the University of Victoria's Human Ethics Research Board. The first step of the recruitment process involved searching the Internet for publicly available contact information for ASD professionals.

The search for participants. Based on the researcher's knowledge about careers involved with ASD, various phrases related to professions were entered into the search engine Google with the hopes of gathering a diverse group of professionals from within

Canada. The following phrases are a few examples of what was used to search for participants:

- “Developmental Pediatrician Canada”
- “Behavioural Specialist Autism Canada”
- “Special Education Teachers Alberta”
- “Autism Researcher Canada”

From these searches, various types of WebPages showed up and through some navigating, individuals and their contact information were able to be located.

In one instance, a newspaper article on the current status of autism in Canada listed several professionals and the organizations they were affiliated with. By looking for these people on the organizations online directory, their e-mail addresses were discovered.

Another search turned up a reference page for parents of children with ASD, listing registered professionals in the province of British Columbia who specialized with children with ASD, organized by profession. This website lead to contact information for a number of occupational therapists, physiotherapists, and speech and language pathologists.

To gain the perspective of special education teachers, a search was done for teachers in Alberta. Alberta was specified as the location because from the results of the previous searches there was not yet any representation from this province. This query led to a school that listed its faculty and their qualifications. The teachers who had been educated and trained in special education were contacted.

Finally, when browsing a scientific publication about autism, the name and contact information of an individual who had spent many years researching the biological side of ASD in children was discovered and they too were asked to participate in the current study.

Contacting prospective participants. Once e-mail addresses for ASD professionals had been discovered, the individuals were sent an introductory e-mail by the primary researcher inviting them to participate in the study (See Appendix A) and a letter of implied consent (See Appendix B). E-mails were sent to 57 prospective participants. It was hoped that 6-8 professionals would respond. Professionals, who wished to participate in the study, completed the required tasks, which will be discussed subsequently, and sent the material back to the researcher via e-mail.

Data Collection

The participants were sent both tasks via e-mail in the form of a Microsoft Word document (See Appendix C). The first task that was asked of the participants was to document a true story, based on their professional experiences, which illustrated something that a lesser-experienced practitioner could learn from. It was asked that the story be kept between 500-1500 words. The participants were reminded to use professional judgment and to reflect on their code of conduct when reporting the story. It was requested that any identifying information be altered or removed from the story to ensure the anonymity of the parties involved.

The second task involved completing a five-item questionnaire. At the beginning of the questionnaire, participants were reminded that if they did not feel comfortable with any of the questions, they were welcome to skip those items. The questionnaire was

designed by the researcher to better understand the perspective of the participant and why he/she chose the narrative he/she did. The items asked about the participant's role in the story and some of the professional strategies that the story highlighted.

Given that the participants e-mail addresses were found on professional websites, it was likely that the correspondence arrived to their workplace e-mail account, meaning it was probable that they completed the tasks in their place of work. It was noted that although they were free to take part in the study whenever and from wherever they pleased, the researcher did not condone using office hours for the tasks if the participant felt like his/her employer would frown upon doing so.

Between the narrative and the questionnaire, it was expected that participants would spend between 30-40 minutes to complete the study. When the tasks were completed and e-mailed back to the researcher, the participants were sent a follow-up e-mail (See Appendix D) thanking them for their time and letting them know they would be sent a copy of the final report upon the study's completion. This follow-up e-mail also reminded participants that should they choose to withdraw from the study, they could do so in the upcoming months and all of their data would be securely destroyed. No incentives were offered to participants.

Participant demographics. Six responses were received from participants. Participants were male and female. Responses were received from a behavioural specialist, teachers trained in special education, a child support worker, an educational assistant, and a speech and language pathologist. Two responses came from professionals in British Columbia, two responses came from professionals Ontario, and two responses were received from professionals in Alberta.

Data Analysis

The information in the stories was analyzed according to the six phases of thematic analysis proposed by Braun and Clarke (2006):

1. Familiarize yourself with the data
2. Generate the initial codes
3. Search for themes
4. Review themes
5. Define and name themes
6. Produce the report

After reading each story submission, attention was given to each step of the process with the information from that particular story in mind. For phase one, Braun and Clarke (2006) suggest becoming familiar with the data by reading and rereading the information and noting any potential patterns. After a story was received, it was read three times over before any notes were recorded. After becoming familiar with the story, the information was summarized in point form and potential patterns were noted. For phase two, interesting or prominent features of the data were extracted and codes were created based on the information. Data relevant to each code was organized together in a chart. For example, if a data extraction spoke about aggression, the codes might include causes of aggression, acts of aggression, and feelings related to aggression. All data extracts relating to aggression were grouped together. For phase three, potential themes were generated and codes from phase two were sorted into each theme as potential sub-themes. Phase four involved reviewing and refining themes so that they were cohesive, yet distinct. Themes were mapped out from the information from phase three in order to

have a visual representation of how themes and sub-themes from each story were organized. As an example, Figure 1 shows the phase four concept map for story one.

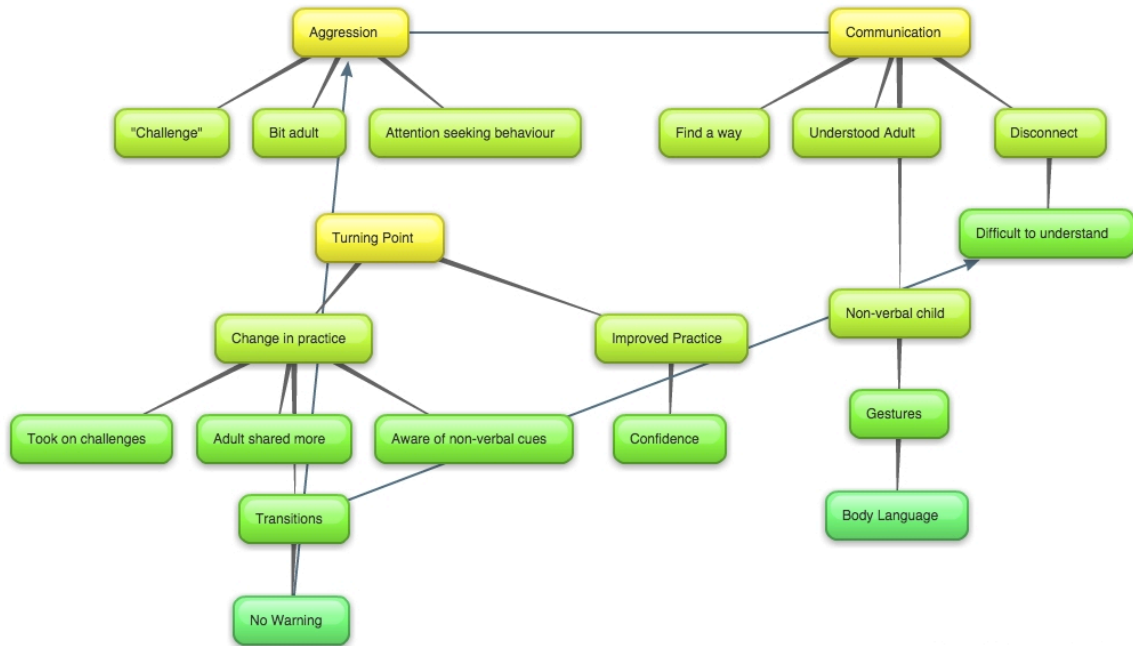


Figure 1. An example of the phase four concept mapping process, illustrated with reference to Story One: Summer Camp Conundrum.

It displays three themes drawn from the story: aggression, communication, and a turning point. The sub-themes presented were created from codes extracted from the data in phase two and three. Lines can be seen between two concepts, which the story implied were related in some way. For example, there is a line connecting the sub-theme “transitions” to the theme of “aggression” because the author mentions how if the client in the story was not made aware of upcoming transitions, he would react with physical aggression. Phase five directed the analysis to a place of perfecting and finalizing to ensure that the themes were clear and explicit. The specifics of each theme were refined

and the purpose of the theme was evident. For this step, clearer and more concise concept maps were created as seen in Figure 2.

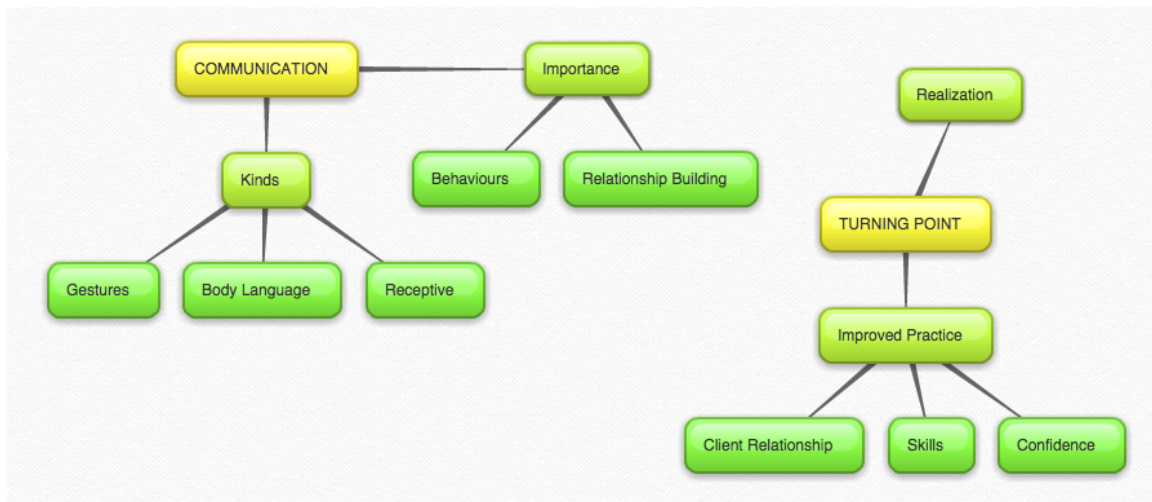


Figure 2. An example of the phase five concept mapping process, illustrated with reference to Story One: Summer Camp Conundrum.

Themes that did not have a clear link to the lessons that the researcher thought the story was trying to convey did not become a final theme in phase five. These themes were highlighted because they directly related to practice and contained information that could be helpful to future practitioners. In the visual, the size of the word corresponds to the frequency that a theme appeared in phase five of the analyses of the stories.

“Communication” showed up most often between stories, followed by “Aggression”, and the remaining themes each appeared only once. Finally, for phase six, this report was produced describing the themes, presenting the extracts, and discussing the results.

Ethical Considerations

Approval of this study was granted from the University of Victoria’s Human Research Ethics Board before the study commenced. This approval acknowledges that

the rights of the participants were respected. Following is a discussion of consent, confidentiality, and anonymity.

Implied consent. In order to have a diverse population of participants, professionals from across Canada were asked to participate. Due to the distance between the researcher and the participants, the study required web-based tasks. Since the participants and the researcher never had face-to-face contact, letters of implied consent were used, as it was not feasible to collect signatures. The letter of implied consent stated that if the participant understood the letter of information and had the opportunity to have questions answered by the researcher, then by submitting the story and the questionnaire their free and informed consent was implied.

Confidentiality. To ensure that information gathered from participants remained private and secure, certain provisions were put in place as follows: (1) The researcher was the only one with access to the data during the study. The data was stored in a password-protected computer in a secure location; (2) The data will remain stored here for two years, accessible only by the researcher, at which point it will be electronically destroyed; (3) The research results will only be shared with the university for thesis-related purposes and with the participants; and (4) all identifying information was removed from original data records, which will be discussed in more detail in the following section.

Anonymity. In order to share stories about people and places, all identifying information had to be removed from the data so that these people and places would not be recognized. Before writing their story, participants were asked to refrain from documenting all identifiable information. Examples of this type of information were

provided, such as names, ages, organizations, and cities. It was suggested that this could be done by using pseudonyms, using broad and generic details, or withholding information.

Once the information was submitted, the researcher checked it for a final time for any identifiable information. Participants were informed that should the researcher find any information that could identify parties, it would be altered or removed before the data could be considered viable. In the event that a participant disclosed information about the harm or neglect of a minor in his/her story, the researcher was obligated to report this information to the Ministry of Child and Family Development of B.C. This was stated to the participants in the letter of informed consent.

Chapter Four: Findings

This chapter presents stories generated by participants and responses from the questionnaires. I discuss excerpts from the stories and how they relate to the lessons that the author wanted to convey to the readers. In addition, I will identify if key themes that emerged in the data reflect concepts from the ASD literature described above. After offering an analysis of each narrative, commonalities and differences between the themes evoked by each narrative will be presented. With the exception of minor editing in order to ensure anonymity, the stories below are presented verbatim from participants' submissions.

For the analysis of the stories, not all information presented in the story was included. I focused on drawing out and examining the main lessons that the storyteller wanted to convey that would be educational to future practitioners. Comments or ideas presented in the stories that did not have a clear link to a lesson were not included. For

example, in the first story the majority of the information revolves around an incident between a practitioner and a child and how communication was the key to deterring the child's aggressive behaviours. There was an additional part to the story where the practitioner told of how this child also needed warning about upcoming transitions. I felt that this portion of the story did not hold enough information to teach future practitioners about how some children with ASD deal with transitions. Rather, this information seemed like it was added to support the storyteller's initial thoughts on communication, so rather than having "transitions" as a stand-alone theme, it was integrated as a sub-theme into the 'turning point' theme.

Story one: Summer Camp Conundrum

A practitioner who once worked at a summer camp for children with various developmental complexities submitted the following story.

I worked in a summer camp which would run 2-week programs for children with different types of exceptionalities. Because of the short nature of the camp, I was challenged to try and get to know and understand my campers in little time. Often I would volunteer to work with the more challenging students at camp as some of them could be difficult to manage physically. One of the campers I worked with was non-verbal and had a tendency to try to physically escape and also lash out at surrounding people. Due to the inability to verbally communicate, I was finding it difficult to gain an understanding of what the camper was feeling or their mood until physical communication made it apparent that he was upset. One instance I was holding his hand to take him to the washroom and he bit my wrist to the point where there were visible bite marks that lasted for a few days. The following day the camper, while we were heading to an activity and holding hands again, pointed to my wrist in a manner that suggested he was asking what happened. I then explained to him that those were the marks left from him biting me. While I was telling the camper the story and explaining that he had hurt me, I could see his body language changed to be remorseful and apologetic. This was when I realized that although he was not able to produce any spoken language, he still understood almost everything I was communicating with him. I did not realize that the camper was resorting to physical communication, through biting or pinching, as last resort to try to get my attention.

From that point on when I was telling him anything I was very conscious as to how his body language and facial expressions changed to the information I was giving him. Although we still had a few instances where I did not understand how the camper was feeling, I was much more capable of working with him from that point on.

Another point I took away from this camper was the importance of communication and transitions when working with children with ASD. Throughout the 2-weeks, I noticed that if I was not clear with the student as to what activity was happening next and did not give timely cues that we would be transitioning to a new activity, then it would heighten his anxiety and would often lead to him lashing out. In the beginning I was thinking that this was due to him not wanting to do the next task, but I realized, as I tried different strategies, that he transitioned into other tasks with ease if there was clear communication. I would prompt the camper a few minutes prior to switching tasks what was going to happen, then I would I would give periodic prompts (~30sec.) until it was time to make the actual transition. I found that this would greatly alleviate the anxiety and stress of switching tasks and resulted in fewer physical confrontations and a much happier camper!

Themes. Several concepts seemed significant in reading this story. The analysis process identified two prominent themes: communication and professional realizations. Both of these themes are discussed below.

Communication. This story demonstrated the variety of types of communication that children with ASD can demonstrate: receptive language, nonverbal communication, and compensatory efforts (Johnson & Myers, 2007). The boy in the story was able to point as a way of communicating with the professional. This was a successful effort as the professional interpreted this action and responded. Following his response, the storyteller describes how the child's "body language changed to be remorseful and apologetic". Although the professional does not explain what about the child's body language gave him this impression, he does seem to feel like the boy conveyed those emotions through his body. This event led the professional to come to the conclusion that the boy might understand spoken language.

With all of this new information about the child's communication styles, the professional adjusted his practice so that he could better serve the child. He claims to have been more attentive to the boy's nonverbal cues from that point on.

This was an important lesson for the professional because being able to communicate with a child with ASD opens so many doors for the adult and the child. After finding a way to communicate with the child, he was able to develop a positive relationship with him and the frequency of the child's aggressive behaviours reduced. This may be an illustration of how being able to communicate thoughts and feelings reduces the frequency of negative emotions like anger and frustration that come with not being able to express one's wants and needs. The professional figured out the link between communication and happiness: "...it was always my self-challenge to try and determine how I can communicate with ASD campers so that I could make their experience at our camp that much better."

Professional realizations. Interestingly, there is a clear turning point in this story when the professional had an epiphany and he subsequently adjusted his practice methods. The professional marks this moment by saying things like "That was when I realized..." and "From that point on..." Before this point, the professional describes the challenges associated with working with the child in his story. After this point he was able to attend to the issues with a new mindset and that improved his practice and his client's experience working with him. The positive changes that he perceived in his practice included having more confidence, better relationship building skills, and a better understanding of communication strategies.

From a storytelling point of view, a professional realization is an important moment to identify in a story because the reader can readily identify the issue, the cause, and methods for solution. Often, the lesson that the storyteller is trying to convey is related to this pivotal moment. The storyteller in this case said that the lesson that he would like to convey is that “no matter the range, there is always a way to communicate with [people with ASD]”. The moment of his realization was when he spoke to the child and saw a clear response that fit with the context of his speech. He realized that despite this boy being nonverbal, there was a way to communicate with him.

Links to the literature. The story above identifies a pattern of behaviour commonly seen from children with ASD; vigorous protesting to transitions (Johnson & Myers, 2007). Children with ASD find comfort in the consistency of routines because the expectations and upcoming events are known. When these routines are disrupted, it can frustrate, confuse, or anger the child, leading to protests. The boy in the foregoing story was reported to have trouble transitioning from one activity to the other and often “lashed out” during these times. The professional in the story discovered that by making the upcoming events known with verbal prompting, the child was much less anxious about the shifts in his routine.

Werner (2011) found that health and social professionals who worked with children with ASD perceived the work as difficult, challenging and frustrating, yet rewarding, important, and an opportunity for growth. The professional in this story reflects this idea. Right away, he admits to taking on clients that were perceived as “challenging”. He implies at various points that between the child’s inability to communicate and aggressive behaviours that his work could be frustrating. Yet, in his

questionnaire response, the practitioner says, “I loved taking on some of the more difficult campers and doing my best to gain an understanding with them.” He goes on to say “I was able to start developing a friendship with him, which turned into a camper I will never forget because he taught me so much.” Not only did the practitioner develop a positive relationship with the child, but he was also inspired by his interactions with the camper in this story to take on other professional challenges.

Story Two: Speaking Surprise!

A practitioner, new to the field of speech and language pathology, working at a school with a child with ASD submitted the following story.

It was my first year out of graduate school and I was working with a child with autism spectrum disorder. He was non-verbal, did not read or write, and did not show any signs of understanding numbers. He enjoyed swinging, spinning objects, cutting with scissors, and iPad games. The school had been using visual aids with him for years to try and develop his communication skills but he'd never really taken to the system.

Fast-forward a few months into working with this child. I had become more familiar with his communication methods—pointing, stomping, laughing, etc... We still felt as though he was capable of more so we had jumped through all of the hoops necessary to obtain an iPad app for him that would turn the iPad into a communication device. We chose this method because of his interest in technology. We were beginning to use the app with him at school—exploring it, modeling it, trying to help make the connections between the buttons and the objects. He showed signs of understanding the function of the app, but this was restricted to his meal times. He was able to request a food item from his lunch kit by pressing a button of a photo of the item.

One day he was following his classroom routine as normal, when he suddenly vomited. Immediately afterwards he walked straight to his iPad, opened the app, navigated through the folders and pressed the “sick, sick, sick, stomach ache, sick” buttons. These were buttons of abstract concepts that he'd never used before! He essentially got up and talked to us after years of silence!

It was in this moment that I realized that I had been operating, for months, under the assumption that this boy was not what many professionals would consider very ‘high functioning.’ I knew I must have been thinking this way because of my shocked reaction to his demonstration of knowledge. His actions in this moment proved me wrong. In an instant I completely reevaluated my entire practice.

With children that are non-verbal I find that sometimes you must operate under assumptions and educated guesses. In this case I was operating under the wrong assumption—I assumed less of the child rather than more and that was a mistake.

Themes. Following analysis, the two most prominent themes in the story above were communication and assumptions. Both of these themes are discussed below.

Communication. This story revolved around trying to help a boy with ASD find his voice. The author speaks to the topic of communication in multiple ways. Different communication systems that are available to nonverbal children are described. The storyteller mentions visual aids but claims that the boy had “never really taken to the system”. Visual aids often include communication books, picture communication exchange systems, and first/then schedules.

The author then mentions a more modern tool, the iPad. Applications exist for the iPad that turn the tablet into a communication device. The child is able to interact with the tablet and have it speak for him/her. In the story the boy seems to demonstrate an understanding of how to use his iPad to communicate. This might relate to his interest in using an iPad, as the author mentions at the beginning of the story. A child will be more motivated to use a system that he/she is interested in.

In the story there is also a discernible point of professional realization. This point can be identified by the author stating, “It was in this moment that I realized...” The storyteller’s realization was that she had assumed that the child could not demonstrate expressive communication and it appeared that that may have been an incorrect assumption.

Assumptions. As mentioned earlier, when there is a turning point in a story one can often use it to identify the problem, the lesson, and the outcome of the event. The problem in this case was that the professional seems to feel like she made an incorrect assumption about her client. When asked what she wanted the lesson of her story to be

she replied, “do not make assumptions about a child’s functioning. Their actions do not dictate the be all and end all of their skills and knowledge...If you assume they are functioning at a lower level than what they are you risk treating them in an immature of condescending manner”. Unfortunately the storyteller did not continue on to describe the events that followed her realization.

The professional does describe the dangers of making assumptions about children with ASD. She fears that assumptions can negatively impact the care that a child receives. She explains on the questionnaire an example of the negative impacts of her assumption: “I’m sure that because of these assumptions [that the child did not understand how to communicate] I have given the child a task that was below their intelligence level, or spoke around him about his case or other professional matters, or spoke to him like a toddler rather than a boy approaching his teen years.”

These words clearly heed a warning to other professionals and one can sense the regret that this storyteller conveys: “These are things that I’m not proud of, but I’m sure that they happened and had he been a verbal child those things might not have occurred.” In this story it seems that not only did the author learn from her mistakes, but she is using this as an opportunity to share her mistakes so that others can learn from hers.

Story Three: Routines, Rituals, & Rewards

A child support worker shared the following story about a child she worked with in a group home.

I am a CSW and have always worked in group care settings—group homes where children with developmental issues can stay for a period of time with 24 hour care. I have worked with children with many diagnoses, but only a couple who have had autism. One boy always sticks out for me when I hear ‘autism’ because I worked with him for a long time, and he wasn’t what I would consider my easiest client. He was very aggressive and had a lot of behavior issues, such as hitting, biting, and pinching. He would act out towards his family, staff, and his peers.

There were many days when I'd go home with minor injuries that were a result of his actions. We realized over time that certain techniques and motivational tools seemed to work for him and resulted in him showing less aggression. Some things that worked with him were keeping with his routine, daily schedules, first/then charts, and rewards. For example, getting him ready in the morning was always a challenge. He always protested doing his hygiene routine. To make this time easier for everyone, the staff all followed the same routine. We would tell him that he had to get ready before being able to watch TV. Then, for each step of getting ready, we used a first/then chart—we would say "ok *client* First brush teeth then bath." Then we would say "First bath, then dress." Finally "first dress, then tv." The FIRST AND THEN method really worked. We found breaking everything into steps worked well because giving too much information at once would lead to an inappropriate behavior then it would usually spiral into a bad day. Rewards would be given if he completed simple tasks such as riding the bus quietly or using his communication cards when he needed to address a difficult situation. Rewards would be a trip to McDonalds or a special treat. Routine, structure, and gentle guidance really helped keep any individual at ease.

Themes. For this story, three themes were identified and it is interesting because it was noticed that the themes are closely linked to one and other.

Aggression. This story makes clear the possibility that children with ASD can become aggressive towards themselves or others. The child in this story acts out physically towards staff by hitting, biting, and pinching.

The story also illustrates the importance of trying to find the function or cause of the aggressive behaviours. It is hard for professionals to do their work and build relationships with a child who is aggressive. Finding the function or cause of the behaviours can give information about how to prevent or eliminate the behaviour.

In this story the professional and her team discovered that certain strategies were effective in reducing the child's inappropriate behaviours. By sticking to routine, following schedules, and offering rewards, the boy showed less aggression. The professional attributes this pattern to the idea that giving the client small pieces of

information let him know what was going on, which reduced his anxiety, while at the same time did not overwhelm him with information.

Techniques. As mentioned, the professional listed different techniques that she and her team used with the child to reduce his aggression. She explains how they made use of a first/then chart to get him through his morning hygiene routine, how all staff were consistent with routines, and how rewards were given for completing tasks. The storyteller says “I find working with children with autism, that routines are very important. They can take a while to put in place but they are good for the child and the staff because expectations are clearly laid out and habits can be formed.”

Persistence. This story is a good example of how persistence is an important quality for ASD professionals to have. The professional says, “I was able to move past the bad things about working with him and focus on the good. By working through the tough situations and the negative feelings, I was able to keep him happy, which kept me happy, and I was able to see who he really was and develop a relationship.”

It is important that professionals are aware that progress is not immediate and change can happen. She acknowledges, “Working with special needs children can be challenging because everything takes a little extra time and results don’t happen immediately.”

The link between these themes is how they interact with one another. The professional’s persistence led to discovering what techniques worked with the child and implementing those techniques led to a reduction in the frequency of aggressive behaviour.

Links to literature. The story above illustrates how some children with ASD need structure and routine to complete tasks in a calm and content manner. As mentioned earlier, Johnson and Myers (2007) list a behavioural characteristic of some children with ASD as protesting to transitions and routine changes. These protests can escalate to intense emotional episodes characterized by aggression and self-injurious behaviour (Johnson & Myers, 2007).

The story from the professional illustrates how a client very much relied on schedules and routines in order to refrain from becoming anxious, frustrated, and acting “very aggressive and [displaying] a lot of behaviour issues”. The professional implies that she believed that the client being overwhelmed with information might have caused the violent outbursts. By breaking this client’s routine down into manageable steps, he was able to process the information, which kept him regulated and led to a good day in her care.

This story also showed how, despite a practitioner feeling challenged by a child with ASD, they still feel their work is rewarding, an experience that Werner (2011) claims other professionals report as well. In the story above, the client demonstrated aggressive behaviours and at times had even injured the professional who was working with him. Despite this, the professional shared in her questionnaire responses that “[she] was able to move past the bad things about working with him and focus on the good...I was able to see who he really was and develop a relationship. We ended up having so many good times with one another!”

Story Four: Motivational Music

A special needs teaching assistant shared the following story about a child who responded very well to music.

Several years ago I worked with one individual who was high functioning but was never able to channel his abilities into school tasks. He was verbal, but did not speak often. Most of his talking was one or two word phrases and he'd never look at you while he spoke. He could read, write, and do math but asking him to sit in class and do these things seemed like we were asking him to do the impossible. He would just sit and daydream or put his head down and roll it back and forth on the desk and it was very frustrating for me as his assistant to know he could easily do the work, yet have him be so unmotivated.

I tried a reward system—extra recess, computer time, free time—but that didn't work. I tried to give him space to think and I tried to sit near and motivate, but neither option worked.

One morning, there was a school concert being held for all the students with a band from the local high school. I accompanied him to the concert and immediately saw the change in his behaviour. When the music started playing, he started smiling and swaying. His attention was glued to the band. I'd seen him in music class lots before, but his reaction was never like this! I don't know whether it was the songs, the sight, the sheer volume, or a particular instrument that he liked, but something about this live band music clicked with him!

I started to use this newfound interest of his to motivate him to do his class work. At first this happened by accident--That afternoon after the band had played we were in class following our routine. He had an assignment to do—I don't remember what it was—and as usual, he wasn't doing it. So off the top of my head I just said "If you finish this then I'll find you videos of bands to watch" and he finished his work really quickly! That moment inspired me. I thought, "I can use this..."

So, I downloaded music like the band had played and put it on an ipod. I got permission from the teacher to allow him to play it in class during work periods. As long as he was doing the task, he could listen to the music with headphones on. At the end of the week if he'd done a good job following the class routine and completing all of his work, I would download new music for him to listen to the next week.

This interest stemmed into other activities too. During computer time he's research bands and in the library we found him books about instruments. We kept up with this motivation theme for the rest of the school year.

Themes. The most prominent theme in this story is music. There is also something to be learned from this story about how to modify programming for a child with ASD.

Music. This is an interesting story because it shows how children with ASD can develop very strong fascinations with objects and interests (Johnson & Myers, 2007). In this case, the child grew to love music played by instrumental bands. It sounds like it was a positive interest for the boy to develop since it was reported that the music made him happy and attentive.

The story demonstrates how the interests of a child with ASD can be very specific. The child in this story was not just interested in any kind of music—he responded to instruments playing music. The professional even mentioned that she’d seen him and music class before and his reaction had been totally different. His interest was specific to this new genre of music.

When a child has a strong interest in something, it is an intelligent strategy to use this interest to help the child grow and develop. The professional was able to apply this child’s interest to his schoolwork, which was designed to help him grow academically.

Modified programming. It is interesting in this story to read how the professional used this child’s interest to modify his schoolwork. She tailored so many aspects of his classroom activities to his interest. She used his new love of music to create different rewards that motivated him to do his work. The professional said that her lesson from the story is to “Find a way. There is a solution to every problem, sometimes they are just hard to find.” This relates to her stumbling upon a way to help the boy remain in his inclusive setting while receiving modified programming and still doing the required work.

Modifying the programming to suit the child’s likes and interests is a way to please all parties involved with the child’s care. The child is interested and pleased with

the theme of the task and the professional, and presumably the teacher, are happy to have the child complete the task. This story is a great one for professionals because it illustrates practical examples of how to work with a child in a school setting.

Story Five: Tricky Transition

An elementary school teacher shared the following story about a new child to her class.

I am an elementary school teacher based in a special education program. My story is around a young child that was placed in my classroom in the middle of the year after relocating to live with new family members. This child was diagnosed with severe autism and had recently undergone and a traumatic family event. We knew little to nothing about this child and their background and it was our job to get to know them while maintaining the order and routine of the classroom with the 12 other students.

When they first came into our classroom, I noticed the typical challenges associated with autism such as an inability to socially interact with other students, little communication skills and difficulty focusing on a task. Some of these characteristics may have been worsened by the child's disrupted home life and transition to a new school. This child was young and quite severe in terms of disability and it became quickly apparent that they did not know how to express what they were feeling inside. They would interfere with other kids activities; they would have a number of meltdowns and engage in physical altercations with staff as well as other students. We knew we needed to intervene and spend more time with this child to truly understand and teach them how to behave in our classroom so that we could get things in the program back on track.

One of the behaviours that I noticed was that if they didn't want to participate in an activity they would throw anything they could get their hands on. If we sensed any anxiety welling up we would first ensure that this child was far away from anything that could harm another student. I thought I would try a PECS book so that the child could point to the picture that corresponded to how they were feeling or a picture of the activity that they would like to do, as these are successful with other students in the classroom. But a lot of the time these books would end up being thrown or what they were feeling was not illustrated in the book. I needed something else.

By looking through online forums, I researched more into using sign language as an alternative and decided to incorporate pictures of myself and the teaching assistants signing more relevant things to this student such as 'pet' with a picture of the classroom guinea pig or 'food' with a picture of their lunchbox. Over time, we started to see small improvements and advances in their signing. This particular student loved cookies and we would keep a pack or two in the classroom for special snack times. We used cookies as one of signing tests and they picked up on it right away. We then expanded this to include the standard 'yes', 'no' and 'more' commands. That took more time but this child learned them and was making visible progress in the right direction.

As the school year progressed, this child's understanding of sign language excelled. I shared this new tool with this child's new guardians to help them work with them at home. In the classroom we continued to develop our signing skills to be able to continue to teach the child new skills. By giving this child the outlet to communicate in a way that they were comfortable has decreased the number of outbursts and allowed them to feel confident to complete their day-to-day tasks.

Themes. The story above involved a complicated scenario but contained valuable information for professionals.

Communication. This story offers examples of clinical tools that some children with ASD use to communicate. The professional mentions using PECS (picture exchange communication system) with the child and implied that he did not take to that method, even though others in the class used it. She mentions that his communication book often ended up being thrown across the room. This is an important lesson for practitioners because it illustrates that just because a tool works for one child it does not mean that it will work with another.

The failure of the PECS motivated the teacher to try a new method: sign language. It sounds like it took time, but the child began to demonstrate knowledge of the system. Another lesson for professionals is that when one is at a loss for a solution to a problem, do as this teacher did, research and ask for help or suggestions from others.

In the questionnaire responses, the professional in this story makes clear that she thinks communication is a very important tool for a child. She says, “Although children with ASD have difficulty communicating they still have a voice and valuable thoughts and opinions.” She also states that the lesson she wants people to take away from her story is that “we need to be patient with each child to begin to understand them.”

School. This story illustrates the role that schools have in the life of a child with ASD. The storyteller mentions multiple times that helping this child to settle into the classroom routine was important to restore order and “get things back on track.” This urgency could be for multiple reasons. Perhaps she understands the importance of routine. Perhaps she wants to create a safe environment for this boy and the other children and

this is dependent on his comfortableness in the classroom. Also, she could have been taking into consideration the recent disruptions in the boy's home life. A child spends a lot of time in a day at school so it is important that he or she feels safe and welcome.

Furthermore, school is the location of many of the professionals who will be working with a child with ASD. The storyteller takes ownership of the importance of her role as a teacher and her role in the child's life; "it is my responsibility as someone who cares for them to take the extra time and be more patient to understand how they are trying to communicate." She is aware that she has the potential to help this boy grow and develop. Not only does she know the influence that she can have, but the influence that her staff can have as well. She ensures they are growing professionally in order to better serve the child. She explains that her coworkers are developing their alternative communication skills so that they can continue to support the boy's development by learning sign language.

It is important for other professionals to see how significant they are in a child's life and to see other passionate professionals, who might inspire them to do more, be better, or see things in a different light.

Aggression. This story, like others, involves a child who can act physically aggressive. He gets in physical altercations with staff and students and throws objects. While this could be a result of his recent traumatic home experience, the professional suggests that these behaviours could be occurring because the boy "did not know how to express what he was feeling inside." As with previous stories, the inability to communicate can lead to emotions of frustration and anger and those feelings can lead a child to act out aggressively.

Story Six: Unwilling Walker

A practitioner tells the following story about working closely with a mother to develop strategies for her child with ASD.

In my current position, much of the work I do involves coaching parents of children who have recently been diagnosed with ASD to use strategies throughout their daily routines to support their child's development of skills and independence. Often, when I first begin working with a child and their parents, the parents will identify various challenging behaviours (e.g., hitting, biting or kicking other, flopping to the floor, bolting or running away, and screaming and crying) which arise throughout their day, and they want to know how to respond to those behaviours. In many cases, the parents are concerned that they should be responding to the behaviour by implementing a particular consequence, and they are expecting that I will tell them exactly what to do each time the specified behaviour occurs. But, there is no "one size fits all" answer to managing challenging behaviours, and many parents are confused to hear me say that I do not have the solution, but that we can work together to figure out strategies that will help to reduce the challenging behaviour. I once worked with a mother and her non-verbal preschool aged daughter who was diagnosed with ASD about one year prior to me meeting the family. When I met the family the mother was very concerned that her daughter had recently started showing signs of extreme dysregulation (i.e., screaming, crying, flopping to the floor and attempting to climb up the mother's body) whenever they left their house to go for a walk. The little girl had been walking independently for some time and the mother was concerned about how she should be responding, and whether carrying her daughter, or skipping daily walks altogether would be rewarding the challenging behaviours. The mother expressed that daily walks had always been a part of their morning routine and that she could not understand what had changed. At times when the little girl became upset leaving the house for a walk and the mother did carry her she would calm a little bit, but continue to show signs that she was upset (e.g., crying and whining). Before going on a walk with the mother and her daughter to observe and identify potential functions for the change in the little girl's behaviour I spent some time talking to the mom about their usual "going for a walk" routine and encouraged her to think about what might be different about the routine from her daughter's perspective. We talked about how walking was going in other environments. The mom explained that walking at the park, and into shopping malls typically went smoothly, and that on occasion the girl was calm when leaving the house to go for a walk in their neighborhood, but most of the time it was difficult for the mom to support her daughter to get past the end of the driveway. At some point in the conversation the mom realized that their "going for a walk routine" had recently changed. The weather had become warmer and the little girl was walking independently with more ease, so the mom had started to introduce "walks" which

involved her daughter walking beside her mom, instead of riding in her stroller. The mom realized that she had been using the same phrase, “let’s go for a walk” to describe both activities (i.e., walking and stroller rides). At that point, we talked about how we could change the routine to support the little girl to be calm and have more success while walking with her mom. In the end we created a plan for adults to be more specific with the use of their language to communicate expectations about leaving the house to the little girl. The mom decided that she wanted to use the word “walk” to refer to times that her daughter would walk, and “stroller ride” to refer to times that she would be pushed in the stroller. We also decided to use visuals with picture of the little girl in her stroller and walking beside her mom to support her understanding of what we were trying to communicate. These visuals were especially helpful for the mom in the beginning, because she was working on teaching her daughter that walk did not mean the same thing as stroller ride, which is the activity her daughter had learned to expect when she heard walk. Thinking about ways to help make going for a walk more motivating for the little girl, and gradually fading out stroller rides and increasing the distance she would walk with her mom were also part of the plan we created to help the “walk routine” go more smoothly. A few weeks later, when I saw the family again, the mom took out their visuals and showed the little girl the picture of “walk”, the little girl went independently to the door to get her shoes and brought them to her mom. After getting her shoes on the girl took her mom’s hand and walked out the front door and down the street with her. The mother reported that short walks were going really well and she now wanted to learn how to teach her daughter to appropriately request to be carried, so that she would not need to try to climb up her mom’s body when she felt tired on longer walks.

Themes. A behaviour specialist submitted this story and her skills and knowledge on behaviours is apparent in the themes of the story.

Behaviour. This story drives home two very important points for other professionals to know: behaviours have a function and behaviours can be changed. As the author says “all behaviours have a function—an unmet underlying need.” She teaches that by understanding the function that a behaviour serves we can give children the information they desire and teach them skills to meet their needs in a socially appropriate fashion. In the story above, the function of the behaviour appears to be to express confusion and frustration about a misunderstanding that stemmed from the language used to communicate.

To teach the child the skills to meet their needs and give up their inappropriate behaviour, the professionals should develop a plan. By working out a plan with the people involved in the child's life, in this case the mother, information can be shared and the big picture can be seen. In this story by talking things out with the child's mother, she and the professional realized that there had been a change in the routine. Through this conversation they discovered that they had been using the wrong words to communicate with the child which led to her confused emotions and challenging behaviours. The professional and the mother came up with a practical plan that could be implemented in order to extinguish the behaviour and please all of the parties involved.

Communication. As in other stories, this one drives home the fact to other professionals that communication is very important to a child with ASD and it can often impact other areas of his/her life if there are problems. In this story there was a simple confusion with the language being used and it led to an issue so disruptive that the mother sought assistance from a professional. By communicating with the child in a way she understood, the child was able to understand the events and expectations and behave in a socially acceptable manner.

Links to the literature. The professional who shared this story stressed the importance of working closely with the child's mother to develop strategies to work with the child on the issue of refusing to go for a walk. She revealed in her questionnaire responses, "Parents know their children and their daily routines the best and will be the most consistent source of support in their child's life. Therefore, they should be included in decisions about strategies that are being recommended regarding their child." She also goes on to say how important working as a team is and how events in this story helped

her to develop a working relationship with the child's mother, "Working together with parents to help them identify the functions of a behaviour and supporting them to come up with strategies they believe will support their child's learning and development is empowering for parents. Having this experience with this family helped to establish a relationship in which we work together."

The idea about positive relationships with children's parents as described in this story is reinforced by Dillenburger and colleagues (2010) who found that effective communication and collaboration between parents, teachers, and other professionals is increasingly viewed as an important factor in the treatment of children with ASD.

Overall Findings

An interesting observation about the children described in the stories above, is that their described gender was male more often than female; four individuals were male, one was female, and one was unidentified. This is comparable to the prevalence rates of males diagnosed with ASD compared to females; with ratios ranging from 2:1 to 6.5:1 (Johnson & Myers, 2007).

Commonalities. Some themes appeared multiple times between the stories collected. A visual arrangement of the frequency of final themes from all six stories can be seen in Figure 3. The larger the word, the more often it appeared as a major theme between the stories. As illustrated, the theme of communication appeared most often, the theme of aggression was the second most common, and all other themes appeared only once.



Figure 3. A visual illustrating the frequency of the major themes across all six stories. The size of the word corresponds to the frequency that the theme appeared in the data.

Communication was a theme that was very prominent in many of the stories. This is theoretically understandable as communication and social deficits are key features of ASD (Johnson & Myers, 2007). The fact that this showed up so strongly and so often shows that communication is so important in the life of a child with ASD and the professionals. The stories taught us when a child with ASD is not able to communicate they can become anxious, frustrated, and angry and this can lead to physical aggression. In many of the stories it seemed like the key to decreasing the aggressive behaviours was to find a way to communicate with the child. This allowed the professionals to discover their needs and attend to them. Also, finding a way to communicate with one and other

opened the door to being able to form a relationship, another important factor when working with a child with ASD.

Aggression was another topic that appeared in several of the stories presented above. Although an inability to communicate can be a cause of this, it is not the only cause and professionals need to work to discover the cause of the aggression. It is important to note that although aggression was a strong theme within these stories, not all children with ASD are aggressive. This is a misconception held by society that promotes the stigma of the children. The storytellers said themselves that the aggression stemmed from another underlying issue and once they were able to move past that the child stopped the behaviour and they were able to form bonds with the child.

In order for staff to address these behaviours promptly so that they can move past them and begin bonding with the child, staff training is crucial for maintaining their knowledge and confidence in dealing with challenging behaviours (Ling & Mak, 2012).

A final interesting observation about the stories was being able to identify the moment in when the professional realized how to turn the situation into a learning opportunity. By recognizing one's own faults in practice, by applying knowledge to a new situation in a novel way, or through sheer luck, a professional can have an epiphany that will forever change their practice for the better. These are the moments that are worth sharing with other practitioners, as there is often a lesson that coincides with these realizations—a lesson that made a person better at what they do.

Differences. An unexpected finding was that most of the stories did not mention the presence of other co-workers or a larger team. In most of the stories the professional focused on their lone relationship with the child. Often a child with ASD has an entire

team of professionals that work together to assist the child in different areas of their expertise. None of the stories above focused on interprofessional relationships or how a team can work together to provide child-centered care. Most stories also failed to mention the role of the child's family. Only one story described a strong role of a family member of a child with ASD. The notion that the professional's stories did not describe the role of others does not necessarily imply that a team was not involved in the child's care; rather in that particular story their role was not influential enough to be mentioned. In future research, it would be useful to obtain stories about working as a team so that professionals can learn positive ways to work with one and other and across disciplines.

Another difference among the stories was the location of the described events. The children were described at school, walking in their neighbourhoods, at summer camp, at concerts, and in group care. Professionals and society in general should have basic knowledge about children with ASD because they are active members of our communities and they deserve to be welcomed and understood as they interact in a wide variety of public and private spaces.

Chapter Five: Discussion and Implications

Each of the foregoing stories described an issue that was faced by a practitioner working with a child with ASD. The professionals wrote about strategies they used and the outcomes of the described events. The information that they shared can be used to educate other professionals about situations they might encounter, possible courses of action to take in those situations, and about the different personalities of children with ASD.

Practical Implications

Taking into account the limited amount of time professionals spend learning about ASD (Barned et al., 2011), I would like to see collections of stories about working with children with ASD used as education and training materials for future and current professionals. Bevan-Brown et al., (2012) state that professionals view communication amongst participants and opportunities to learn from others during training sessions important for professional development and education (Bevan-Brown et al., 2012). Sharing and discussing stories is a way to initiate professional conversations and learn from others.

A successful professional development session on ASD is said to require team interaction, cultural relevancy, expert facilitation, reflection time, and authentic context (Bevan-Brown et al., 2012). A presentation based upon the real-life experiences of a diverse group of professionals, shared in the form of stories, is a way to incorporate all of the components listed above. Stories, told by experts, could be shared as a group, discussed in small groups, and reflected on individually.

Not only are stories good to use as training material for professionals within a specific field, but also good way to for professionals to communicate between disciplines (Fairbairn, 2002). Children with ASD often have a multi-disciplinary team of professionals working with them and it would be beneficial for the professionals on that team to share information between one and other to ensure that there is consistency between the services provided. Sharing stories with one another about the client is one way to pass along information that would offer the professionals memorable information that they can draw upon in the future.

A benefit of using stories to educate is that the different experiences and viewpoints shared in stories works against the problem of seeing children with ASD as a homogenous group (Barrett, 2006). Every story is personal and shares the characteristics of different individuals and the audience can understand that each child with ASD is unique. Even in the small sample of stories in this study, there was a child that showed sympathy and understanding, there were children who were learning to communicate in different ways, and there was a child that discovered a love of music. The format of using stories to educate can implicitly break down the stigma of ASD and revise expectations of what these young people can do and how relationships with them can be formed.

The education system is one context where it would be beneficial to use stories to create training and education programs relating to ASD. Williams-White et al., (2007) state that with the increase in the prevalence of ASD, schools will be called upon more than ever to enhance the learning of children and adolescents with ASD. Williams-White and colleagues (2007) found that students in teaching college lacked knowledge about ASD and believed many popular misconceptions about working with a child with ASD. They suggest that more information about working with children with ASD is needed including case studies and interaction with professionals who have had successes in an inclusive classroom (Williams-White et al., 2007; Werner, 2011). Stories can contribute to this endeavor.

Future projects that create story collections could also act as a platform for people and professionals to have their stories heard. It is likely that there are many people who have information, quandaries, or insights they would like to share, but they do not have the platform to do so. A book can be this platform for people to have a voice. Haigh and

Hardy (2011) state that a benefit of storytelling is that the people who have shared the stories feel empowered and satisfied that their story may help someone else.

Limitations of Study

Although this study has implications for practitioners working with children with ASD, there are clear limitations. First, the sample size of this study was small. To better support the themes constructed to represent the stories, and to gain additional viewpoints on important moments in working with children with ASD, more stories are needed from a variety of professionals, including occupational therapists, developmental pediatricians, and physical therapists. — In a more confirmatory study, it would be important to establish whether two or more data analysts would construct the same themes to represent the most illuminating aspects of the stories obtained. Including and perhaps comparing and contrasting the analytic results of readers with different professional backgrounds would be interesting in itself (perhaps revealing different professional lenses on narratives) and could establish the salience of recurrent themes seen in professionals' narratives.

Suggestions for Future Research

This study is the starting point for further explorations the narrative approach to inter-professional learning. In this exploration of a shared story-telling medium, the research question in this study was quite broad. The study establishes that professionals are willing to share stories and that their stories can be instructive and illuminating. Future research using shared story-telling could focus on more specific questions, for example, asking about the prominent themes discerned in the stories collected for this study.

What stories would come from asking participants to share a story about communication and ASD? What could we learn from come from asking participants to share stories about working with a child with ASD who showed aggressive behaviours? If multiple practitioners from the small group of participants all shared information on this topic, then perhaps these are areas of importance in the field of ASD that are worth exploring further. Particular professions could find material related to their practice by asking for stories related to that specific field and use them to create a shared repertoire of knowledge and experience to use as a communal resource within a community of practice (Werner, 2009). For instance, speech and language pathologists could ask professionals to submit stories about methods they used to teach children with ASD to speak or to tell stories of using assistive technology with a client.

Another direction would be to use the methods from this study, but expand the criteria for participants to include other people knowledgeable in the field of ASD, in addition to professionals who work with children with the diagnosis, such as parents of children with ASD and people who are diagnosed with ASD.

Concluding Remarks

With the prevalence rates of ASD increasing (Johnson & Myers, 2007), research on ASD and the people who are affected by it will strengthen professional awareness, education, and development. The more information that we can make accessible and memorable to professionals, the better the influence we can have on their knowledge and practice, which in turn improves the quality of care that they provide to the children.

Stories are a way to deliver this information in a way that is interesting, memorable, and

universal. The stories in this study provide rich examples of how children with ASD can impact our lives and how we can have an influence on theirs.

The aim of this research was to create a medium for professionals to share their stories about working with children with ASD, to demonstrate a knowledge mobilization approach that uses narratives to inspire and share information among practitioners, and to contribute to ASD research using narratives. These goals were achieved and the study has created a foundation upon which further research can expand and develop.

The ASD community is growing. The stories shared and themes elucidated in this study, and similar such story-sharing projects, can help practitioners working with children affected by ASD to be inspired, connect, share, and learn together.

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Appendix A
E-mail Greeting Script

Hello,

My name is Amy Bishop and I am a graduate student with the department of child and youth care at The University of Victoria. I am conducting a study as part of my course requirements entitled, Stories from the Spectrum: Connecting Knowledge about Children with Autism Spectrum Disorder to Practice in Child and Youth Care.

I am looking for professionals who work or have worked with children with Autism Spectrum Disorder (ASD) to participate in the study and found your information during my online searches. To qualify as a participant, your job description must involve working with children who have been diagnosed with ASD and/or their families.

I have attached a letter detailing the study, including what would be required of you should you choose to participate. Your role would consist of submitting a short story and a completing brief questionnaire via e-mail.

Please read through the letter of information and do not hesitate to let me know if you have any questions or comments. I can be reached at this e-mail or by calling 1-519-494-0936.

Thank you for considering assisting me with my research. Your time is greatly appreciated.

Sincerely,

Amy Bishop

Appendix B
Letter of Information and Implied Consent

Stories from the Spectrum: Connecting Knowledge about Children with Autism Spectrum Disorder to Practice in Child and Youth Care

You are invited to participate in a study entitled *Stories from the Spectrum: Connecting Knowledge about Children with Autism Spectrum Disorder to Practice in Child and Youth Care* that is being conducted by Amy Bishop. I am a graduate student in the department of Child and Youth Care at the University of Victoria and you may contact me if you have further questions by the contact information located at the bottom of this letter.

As a graduate student, I am required to conduct research as part of the requirements for a master's degree in child and youth care. It is being conducted under the supervision of Dr. Jessica Ball. You may contact my supervisor at 1-(250)-472-4128 or by e-mail at jball@uvic.ca.

Purpose and Objectives

Compared to traditional teaching methods, storytelling is viewed as an effective teaching method for those working in a care-based profession. Learners are able to connect new knowledge with experience in an entertaining and memorable way through the use of narratives.

The purpose of this research project is to create a report based on narratives about working with children with Autism Spectrum Disorder (ASD) that is targeted towards child and youth professionals that have little or no experience working with this population.

Stories from ASD professionals will be gathered and analyzed by the researcher. These stories and their analyses will be presented in a report and it is hoped that practitioners working in the field of child and youth care, who have little or no experience working with children with ASD, may find the information influential and beneficial to their practice.

You are being asked to participate in this study because you are an experienced practitioner who works with children with ASD.

What is involved?

If you consent to voluntarily participate in this research, your participation will include submitting a short story (between 500-1500 words) of a case or scenario that is significant to you in relation to your practice with children with ASD. Following this you will be asked to complete a short questionnaire about the story you have provided.

The form to submit your story and the accompanying questionnaire has been attached in this e-mail. Should you choose to participate it is asked that you complete the documents and return them via e-mail. It is expected that completing these two tasks will take approximately 30-40 minutes. Although this study relates to your professional endeavors, please do not complete the tasks during business hours if doing so would interfere with your organizational duties.

Once the data has been received, the researcher will analyze the stories and the questionnaires for various themes and lessons and present a report discussing how the

information in the narratives can influence the practice of child and youth care practitioners.

Risks & Benefits

There are no known or anticipated risks to you by participating in this research.

Research of this type is important because it contributes to existing knowledge of ASD and is presented in such a way that it aims to teach others practicing in the field of child and youth care. It is hoped that by educating practitioners in a meaningful way, it will influence their practice and benefit the children and families that they work with.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation until July 1, 2015. If you do withdraw from the study your data will securely destroyed and not used in the study. Beyond August 31, 2015, the study that will have been submitted to The University of Victoria and the data will no longer be able to be removed.

If you do not feel comfortable sharing information that is asked of you on any of the questionnaire items, you are encouraged to skip those questions and only share information that you feel comfortable disclosing.

Anonymity

All people involved in the data collection and final thesis report will be anonymous, including you and any people that are involved in your story.

When writing your story, please remove ALL identifying information that would identify you or any persons and/or organizations in your story. This includes names of people, businesses, and organizations, numerical ages, cities, specifics of diagnoses, etc... You are welcome to use pseudonyms in your writing or broader substitutions (Saying 'a teenager' instead of 'a 14 year old').

Once you have submitted your story, the researcher will check the submission for any remaining identifying information and edit it as necessary as an additional measure in ensuring confidentiality.

Even with identifying information removed, there may be a possibility that the uniqueness of the features of the data may make parties recognizable. After submission, the researcher will look at the data and alter any unique and identifying features as a final confidentiality measure.

No names or distinguishing features shall appear in the final data and any written reports.

In the event that you disclose information about the harm or neglect of a minor in your story, the researcher is obligated to report this information to the Ministry of Child and Family Development of B.C.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by securely storing the data in protected files, which will be in possession of the primary researcher. Only I, and

my thesis supervisors listed below will have access to the data. 2 years after the final submission of the thesis project to The University of Victoria, the data will be disposed of securely through digital shredding.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways:

- Thesis submission to the University of Victoria
- Thesis presentation to the project committee
- Submission to the graduate studies theses collection in the University of Victoria library
- A copy of the final report will be sent via e-mail back to participants

Contacts

Individuals that may be contacted regarding this study include:

Amy Bishop, Primary Researcher
E-mail: abisho@uvic.ca
Telephone: (519)-494-0936

Dr. Jessica Ball, Primary Research Supervisor
1-(250)-472-4128
jball@uvic.ca

Dr. Douglas Magnuson, Secondary Research Supervisor
E-mail: dougm@uvic.ca

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

By completing and submitting your story and the questionnaire, **YOUR FREE AND INFORMED CONSENT IS IMPLIED** and indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

Thank you for considering this opportunity.

Please retain a copy of this letter for your reference.

Appendix C
Questionnaire

Stories from the Spectrum: Connecting Knowledge about Children with Autism Spectrum Disorder to Practice in Child and Youth Care

Please write down a true story, based on your professional experience, which illustrates something that lesser experienced practitioners could benefit from. This story can be about you, a client, a client's family, your education, or your workplace. The story should be between 500-1500 words.

Reflect on your code of conduct and use your professional judgment when documenting your story. Refrain from reporting any information that could identify a person, city, or organization. Information that you feel is necessary to your story that could identify a client, family, or colleague, should be altered accordingly.

Please complete the following questions. If you do not feel comfortable sharing information that is asked of you on any of the questionnaire items, you are encouraged to skip those questions and only share information that you feel comfortable disclosing.

1. What are the key themes or 'lessons' that you hope to have conveyed through your story?

2. How was your practice affected after the events that you described in your story occurred?

3. Based on your role in the story you provided, would you have done anything differently?

4. What do you think went well in the story you described?

5. What techniques/strategies were used, if any, during the events you described?

Appendix D
E-mail Thank You Script

Hello,

I have received the data that you submitted for your participation in the study entitled, Stories from the Spectrum: Connecting Knowledge about Children with Autism Spectrum Disorder to Practice in Child and Youth Care.

I'd like to thank you for participating in this research. The time and effort that you put into participating is greatly appreciated. It is hoped that the report that comes from this data will be used to assist lesser-experienced professionals in their work with children with ASD.

When all of the data is received and analyzed, you will be e-mailed a copy of the study's final report.

If you would like to withdraw from this study and have your data destroyed, please let me know no later than July 1, 2015.

If you have any questions please do not hesitate to contact me at this email or by phone at 1-519-494-0936.

Thank you again.

Sincerely,

Amy Bishop