“It is a Price we all Pay”: Parents’ Perspective on Addressing the Needs of Children with Autism with Self-Injurious Behaviour

by

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A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF EDUCATION IN SPECIAL EDUCATION

Faculty of Education

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Vancouver Island University

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We accept this Thesis as conforming to the required standard.
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Abstract

One of the most damaging and profound behaviours of people with autism spectrum disorder (ASD) and other related developmental disabilities is self-injurious behaviour (SIB). This study examines the experiences and perspectives of families on raising children with autism who exhibit such behavior. A qualitative research methodology was employed that used semi-structured interviews as the data collection instrument. The interviews aimed to answer two questions: 1) What are the experiences of families and students with autism who exhibit self-injurious behaviour? 2) What practices and supports do families hope schools could provide to support the needs of their children with SIB? Overall, the stories shared in this narrative inquiry illuminate the human impact of SIB and the challenges parents face to find answers for their children. Additionally, the results of this study highlight the disillusionment of families in schools’ ability to adequately and inclusively support the complex needs of their children. The four conceptual themes were revealed through data analysis. Theme 1, *effects of SIB on families*, explores the challenges of raising children with this condition. Theme 2, *schools are ill prepared for complex learners*, details the shortfalls of schools at addressing the needs of these students. Theme 3, *parents’ perspectives on treatment*, discusses different treatment options to address SIB. Lastly, theme 4, *what parents want from schools*, discusses specific recommendations parents would like see adopted to improve service delivery and outcomes for their children who self-injure.

*Keywords: self-injurious behavior, self-injury, autism spectrum disorder*
Acknowledgements

I would like to express my sincere gratitude to the families that participated in this study; without your willingness to share your stories and experiences this study would have not been possible. I am forever grateful for your contributions and I commend you all for your strength and unwavering commitment to your unique and wonderful children.

Embarking on my first narrative inquiry was an exciting yet daunting task and without the calm and reassuring approach of Dr. Mary Ann Richards I don’t think I could have made it this far. Mary Ann, your guidance and encouragement throughout this process were instrumental in the creation of the final product. Thank you for helping me fulfill this life-long personal goal.

Lastly, to my Mother, though we don’t always see eye to eye, I know that our love for each other cannot be disputed. We have been through so much together and in the words of Willy Nelson, “Like a band of gypsies we go down the highway. We’re the best of friends…” I love you Mum!
Dedication

This thesis is dedicated to the shy little girl who would wake up early every morning eagerly awaiting her ride to school; to learn all she could about the world and about herself.

This thesis is dedicated to the little girl’s mother, grandmother and uncle who would take her to school each day saying how proud they were of her.

This thesis is dedicated to the power of education.
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Chapter 1

Introduction

Self-injurious behaviour (SIB) is a complex phenomenon that has been described as one of the most devastating and challenging-to-treat behaviours of people with autism spectrum disorder (ASD) and other related developmental disabilities (Edelson & Botsford Johnson, 2016). Carr, (1977), a researcher and pioneer in understanding and treating self-injury claimed, “Self-injurious behavior is perhaps the most dramatic and extreme form of chronic human psychopathology” (p. 800). Forty years later, despite a policy of full inclusion for all learners, little success has been made in finding inclusive solutions for many students who engage in this behavior and how to best support them in school settings.

Definition of SIB

Self-injurious behavior can be described as “a class of behaviors, which the individual inflicts upon his/herself that have the potential to result in physical injury, more specifically tissue damage” (Schroeder, Oster-Granite, & Thompson, 2002, p. 1). Additionally, SIB in this context should occur without an apparent intent of willful self-harm and is not intentional such as in suicide (Weiss, 2013).

Self-injury is on a continuum and ranges from severe, life-threatening injuries to less directly damaging cases (Weiss, 2013). Common manifestations of SIB include head banging, self-biting, self-scratching, eye poking, hair pulling, hand mouthing and skin picking (Rojahn, 1994). SIB has also been described as transitory or episodic in duration or can persist for months or years (Minshawi et al., 2014).
Risk Factors

Research has identified risk factors for SIB among children with autism spectrum disorder. Baghadadli, Pascal, Grisis and Aussilloux (2003) in a study of 222 young children with autism examined variables such as chronological age, sex, adaptive skills, speech level, associated medical condition, degree of autism and parental social class. These authors found higher rates of SIB in children with a high degree of autism and a significant delay in daily living skills. Another study, however, by Duerden et al. (2012) found that abnormal sensory processing was the strongest predictor of self-injury followed by sameness and social functioning.

Prevalence

In a literature review, Kahng, Iwata and Lewin (2002) surveyed the treatment of SIB from 1964 to 2000 and referenced rates of SIB in children with developmental disabilities and ASD between 7% and 23%. However, a recent clinical-based study by Soke et al. (2016) calculated a prevalence rate of SIB in children with ASD at 27.7%. Research suggests that the general long-term course of SIB can first manifest in childhood then progress into adolescence and increase in prevalence and persist well into adulthood. For example, a cohort study by Taylor et al. (2011) found that of 49 adults diagnosed with ID, many with comorbid ASD and SIB, 84% continued to exhibit SIB 20 years later.

The Complexity of SIB

Among the research there is considerable discussion and debate over the etiology, functions and treatment of SIB. Compounding the complexity of SIB in the ASD population, as noted by Minishawi et al. (2014), is the etiological origin is unlikely to
involve a simple determinant. These authors stated, “There appears to be multiple and often co-occurring processes involved in the emergence, presence and maintenance of SIB” (p. 127). Additionally, Casanova and Casanova (2016) reiterated this and asserted, “The heterogeneous nature of aggression and SIB is the result of multiple causations, which provides difficulties in classification” (p. 41).

Theoretical Overview of Functions and Etiological Theories of SIB

Several etiological theories attempting to explain SIB have been published in the literature. In 1977 Carr presented five hypotheses attempting to explain SIB in autism. These included: 1) SIB learned operant maintained by positive social reinforcement (positive reinforcement hypothesis), 2) SIB learned operant maintained by the termination of an aversive stimulus (negative reinforcement hypothesis), 3) Self-injurious behavior as a means of providing sensory stimulation (self-stimulation hypothesis), 4) Self-injurious behavior is the product of aberrant physiological process (organic hypothesis), 5) Self-injurious behavior is an attempt to establish ego boundaries or to reduce guilt (psycho-dynamic hypothesis).

Since then other theories have emerged largely of a medical and biological in nature.

Treatment Methods for SIB – Brief Overview

Many divergent theories exist regarding how to treat self-injurious behavior with children with autism spectrum disorder. These include behavioral, sensory, pharmacological and medical treatments. Edelson and Botsford Johnson (2016) stated the treatment strategies for SIB usually align with the type of training a practitioner has received: “a physician is likely to prescribe medications, a psychologist is more likely to administer a behaviour-modification program, an occupational therapist will probably
apply a sensory-intervention technique… .” (p.11). A more detailed description of the treatment methods will be presented in the literature review in chapter two of this paper.

**Research Questions**

The intent of this study was to better understand parents’ perspectives and experiences on raising children with autism who self-injure. A second objective is to see how these experiences can inform decision-making and improve the educational outcomes for these students. The two questions are:

1) What are the experiences of families and students with autism who exhibit self-injurious behaviour?

2) What practices and supports do families hope schools could provide to support the needs of their children with SIB?

**Value and Limitations**

SIB impacts all areas of a person’s life (Boesch, Taber-Doughty, Wendt, & Smalts, 2015). The most dangerous aspects of SIB are the health risks. These risks include: lacerations, fractures, recurrent infections, physical malformations, detached retinas/blindness and in extreme cases death (Minshawi et al. 2014). Mandell (2008) reported SIB is one of the main causes of hospitalization in children with autism spectrum disorder. Other compelling evidence that SIB has a negative impact on quality of life include: “restricted educational and vocational opportunities, increased social isolation, limited access to community-based activities, costly medical and residential care and of course restrictive treatment practices (eg, protective equipment, physical holds, seclusion/time-out, loss of personal property)” (Minshawi et al., 2014, p. 126).
As SIB is associated with a wide range of detrimental consequences that compromise quality of life it is imperative research is sustained to find and or develop successful interventions and practices that reduce or alleviate SIB and promote the meaningful inclusion of students with significant challenges.

In 2016 the British Columbia Ministry of Education released the Special Education Policy Manual that defined and explained the service delivery model and best practices for students with special needs. The overriding theme in this policy is the promotion of an inclusive education system where students with special needs are viewed as fully participating and valued members of a community of learners. The policy states “all students should have equitable access to learning, opportunities for achievement, and the pursuit of excellence in all aspects of their educational programs” (p. 2).

Contradictory to this policy a recent report titled, *Stop Hurting our Kids 2*, released by Inclusion BC in May 2018, showed “… seclusion [is] still being routinely used instead of positive behaviour support programs in too many schools” (p. 4). The survey involved one hundred and seventy parents and guardians and 89 percent reported seclusion concerns. These parents described the negative effects of this practice on their child’s self-esteem and mental health. In this report Inclusion BC urged immediate action from BC’s Education Minister to rectify this situation and protect children from this outdated and aversive practice.

This research could contribute to the potential for better school-family connection and awareness building. The value of this research lies in contributing the parent voice; which to date has largely been left out of the research arena in this field.
Limitations of the study include a small sample size of participants. This restricted sample might not generalize to other populations. It is not my intention however to generalize these findings and “… it must be noted that the goal of qualitative research is never to generalize findings to other individuals but rather to represent the “voices” of those being interviewed … .” (Fletcher, 2012, p. 68).
Chapter Two

Literature Review

Introduction

First this chapter briefly discusses the theoretical framework from which the study is based. It then breaks down the body of SIB treatment knowledge into the primary disciplines of behavioral, biological/medical and pharmacological and finally sensory. A greater emphasis is placed on describing treatment options that are within educational purviews such as the behavioral and sensory treatments. Then a review of caregiver stress related to SIB is presented. Next, the chapter examines the current research with a focus on several new studies using sensory integration therapy (SIT) to reduce SIB. Finally, the chapter addresses the gap in research and the paucity of studies conducted in school settings. Additionally, the scare use of narrative inquiry to acquire knowledge and insight about families’ experiences raising children who self-injure is documented.

Theoretical Framework

This study employs Bronfenbrenner’s (1979) Ecological Systems Theory (EST) perspective. The core tenet of this theory is the interrelated nature of contexts. EST proposes that individuals exist within four concentric systems. The first system starts at the individual level (microsystem), and extends outward to include family and school (mesosystem), then society (exosystem), and finally cultural values and customs (macrosystem). Each level is interconnected and Bronfenbrenner (1986) contested that to understand a child properly each level needs to be carefully examined.

Understanding why a child self-injures is a complex phenomenon that has continued to challenge parents, educators, service providers and researchers. A common
theme throughout the literature is the discipline-oriented nature of the field. Some researchers believe this may be a barrier to creating effective treatment approaches. For example, Minshawi et al. (2015) argued that the psychological and biological theories and treatment approaches are complementary, however, “in clinical practice and research treatment trials, experts in behavioral, medical, and pharmacological approaches to the assessment and treatment of SIB rarely function as a multidisciplinary team” (p. 1559). I believe efforts to advance the field and alleviate or minimize the suffering of children and their families with this condition will be most effective when a more holistic perspective of SIB, such as that encapsulated by EST, is adopted. Moreover, schools need to promote and purposively work to developing collaborative partnerships between families and other professionals involved in the care of these children. It is an oversight to focus solely on the individual who self-injures without considering the influence of other contexts that may impact a child such as family and school. Burns, Warmbold–Brann and Zaslofsky (2015) stated that taking an ecological systems approach has fostered a better understanding of many phenomena at the school level, such as school bullying and physical inactivity, this exemplifies that it could also be successfully applied to SIB.

**Treatments for SIB**

An extensive amount of research has been generated in the development of treatment options for SIB. With many divergent theories regarding how to treat self-injurious behavior with children with autism spectrum disorder the field is complex and forms a continuum of treatment options based on specific disciplines.
**Behavioral treatments**

Intervention based on the principles of applied behavior analysis (ABA) has been effective in reducing and sometimes eliminating SIB (Minshawi et al., 2014). Behavioral theories suggest that SIB can be maintained by reinforcement (positive or negative), making these behaviors resistant to change unless the environmental factors surrounding the behaviors are sufficiently altered or manipulated (Minishawi et al., 2014). Minishawi et al. (2014) believed SIB can be viewed as a learned mechanism whereby an individual is responding to environmental or internal stimuli in order to obtain reinforcement.

An important practice developed using the principles of ABA is the functional behavioral assessment (FBA) or functional analysis (FA). This process has made it possible to identify environmental influences on SIB and formulate individualized treatment plans (Gresham, Watson & Skinner, 2001). A vast amount of research highlighting its usefulness has been conducted (Gresham, Watson & Skinner, 2001; Pelios, Morren, Tesch & Axelrod, 2013).

The FBA is built on the principle that behaviors serve a function for an individual. In an FBA information is gathered about the antecedents, behaviors, and consequences surrounding a specific behavior in order to hypothesize the function of that behavior for the individual. The results of the functional behavior assessment should then guide and inform the intervention(s) (Mahatmya et al., 2008; Pelios, Morren, Tesch & Axelrod, 2013).

The most common communicative functions of SIB described in the literature by Carr and LeBlanc (2003) and Iwata et al. (1994) and are:
(1) to gain social attention from others
(2) to obtain access to items in the environment
(3) to escape or avoid from demands; and
(4) to obtain automatic or sensory stimulation

Depending on the function of the behavior examples of interventions include:

- reinforcement of incompatible of behaviors (Azrin, Gottlieb, Huhart, Wesolowski & Rahn, 1975: Banda, McFee & Hart, 2012, use of choice and schedules to engage students (O’Reilly, Sigafoos, & Edrisinha, 2005), providing communication systems (Braithwaite & Richdale, 2000; Durand & Merges, 2001), and decreasing academic demands (Reed, Luiselli, Morizio and Child, 2010)

Matson and LoVullo (2008) reported that more contemporary approaches have developed over the years to treat SIB that emphasize positive behaviour change rather than punishment strategies. Aversive treatments used in the 1960s and 1970s included: response-contingent electric shock (Tate & Baroff, 1966), aromatic ammonia as the aversive stimulus (Tanner & Zeiler, 1975), and punishment with citric acid (Mayhew & Harris, 1979). These treatments are now considered inhumane and unethical.

**Pharmacological treatments.**

There is a rapidly expanding body of literature examining the use of medications to treat SIB (Coury et al. 2012; Doyle & McDougle, 2012; Symons, Thompson & Rodriguez, 2004). A breakdown of the classes of psychotropic drugs (and their shelf names) commonly used to treat children with autism who self-injure is provided by Mahatmya, Zobel and Valdovinos (2008).
• Selective serotonin reuptake inhibitors – commonly referred to as antidepressants:
  Prozac, Luvox and Zoloft

• Antipsychotics – Haloperidol and atypical antipsychotics – Risperidone

• Opioid antagonists - Naltrezone

While medications are commonly used to treat self-injurious behaviour these medications “often produce difficulties in the form of adverse side effects (Bleiweiss, 2016, p. 68). These side effects include: fatigue, gastrointestinal pain, appetite changes and heightened anxiety. Bleiweiss (2016) raised an interesting argument when he said, “it is plausible that medication side effects may function as a setting events, paradoxically exacerbating the very behaviour the medication intends to treat” (p. 68).

**Medical/Biological Treatments**

Research into medical and biological factors that cause SIB has increased over the last few decades (Edelson and Botsford Johnson, 2016). Many studies detail various neurochemical transmitter systems that have been implicated the pathophysiology of SIB. These include dopamine (DA), glutamate, opioid, gamma-aminobutyric acid (GABA), serotonin (5-HT) systems and adrenergic systems (Symons, Thompson & Rodriguez, 2004; Buitelaar, 1993). In addition, Minshawi et al. (2015) presented an exhaustive list of medical conditions that may underlie the presentation of SIB. These include: pain (headaches/migraines, infections, dental issues), seizure activity, gastrointestinal factors, sleep deprivation and dietary deficiencies. Other theories developed include hormonal dysfunction (Carr et. al, 2003) and the impact of allergic diseases (Jyonouchi, 2016).

The medical advances demonstrate the complexity of SIB and the need to view the phenomenon from many perspectives.
SIB and Caregiver Stress

A common theme in the literature focuses on the stress experienced by parents of children with autism spectrum disorder who engage in self-injurious behavior. (LeCavalier, Leone & Wiltz, 2006; Rose, Horne, Rose & Hastings, 2004). Rivard, Terroux, Parent-Boursier and Mercier (2014) stated parents of children with autism spectrum disorder are known to experience more stress than parents of children with any other condition. More specifically, the presence of challenging behavior such as self-injury may predict higher levels of parenting stress (Argumedes, Lanovaz & Larivee, 2018).

Lovell and Heslop (2013) reported, “the impact of having a child who self-injures is considerable, and it is likely to result in a narrowing of horizons, restrictions of activities, day-to-day adaptations and stresses over and above those required by other families (p. 82). Some of these stresses include strain on marriages and relationships, compromised health and well-being.

In addition, research has addressed the burnout of teachers and staff who support children with complex behavior. Hasting and Brown (2002) claimed special educators and teaching staff that work with students with ASD reported higher levels of emotional burnout from exposure to challenging behavior that they could not deal with effectively. Moreover, Ingersoll (2001) reported one of the primary reasons for leaving the teaching profession is when staff members are not equipped with the knowledge and skills for dealing effectively with challenging behaviors. As a learning support teacher I have experienced emotional distress from witnessing SIB and the resulting injuries. The perplexing nature of SIB has at times left me feeling powerless and overwhelmed.
Current Research

Recent research in the field of self-injurious behaviour in autism has focused on the efficacy of sensory integration treatments (SIT) (Devlin, Healy, Leader, & Hughes, 2011; Davis et al., 2013; Demanche and Chok, 2013). The fundamental belief of SIT is that people with autism may experience neurological processing problems making it difficult to integrate and interpret sensory information (Matson & LoVullo, 2018). SIT is designed to restore neurological processing by enhancing the vestibular, proprioceptive and tactile systems (Devlin, Healy, Leader, & Hughes, 2011). Examples of this type of treatment include:

- use of a weighted vest (Davis et al., 2013)
- wrist weights (Demanche and Chok, 2013)
- body-pressure (Doughty and Doughty, 2008).

Sensory integration treatment (SIT) has been a common treatment option for children and adults with autism who engage in self-injurious behavior (Devlin, Healy, Leader, & Hughes, 2011).

Despite its popularity, Pfeiffer, Kinnealey, Sheppard, and Henderson (2011), reported that current research has received mixed interpretation of the value of sensory integration treatment and is dividing professionals. This seems evident in the conflicting results of the studies (Devlin, Healy, Leader, and Hughes, 2011; Davis et al., 2013; Demanche and Chok, 2013) summarized below.

The purpose of the intervention study conducted by Devlin, Healy, Leader, and Hughes (2011) was to compare the effects of sensory integration therapy with a behavioral intervention in reducing SIB in four boys with autism. Each of the participants
attended a school that used applied behaviour analysis (ABA). An alternating treatment and best treatment phase were devised.

The results of the study for each participant showed a reduction of SIB on the behavioral intervention days in comparison to the SIT days. Limitations noted by the authors included the small sample size of their study. These authors also recognized that the randomized alternating design of the study could have prevented limitations to the therapeutic value of SIT.

Davis et al. (2013) conducted a study of the effects of wearing a weighted vest (a common SIT technique) to reduce aggressive and self-injurious behaviour in a nine-year-old child with autism. The participant was selected as the weighted vest protocol was part of his Individualized Education Programme (IEP) and had been wearing a five-pound vest for seven months prior to the start of the study.

The main results of the study suggested that no dramatic difference in the levels of SIB or aggressive behaviour occurred across nearly all of the conditions when wearing the weighted vest. The authors asserted that weighted vests are a commonly implemented form of sensory integration for children with autism despite compounding evidence they do not appear to reduce SIB. They suggested further research needed to occur to determine if the increased response effort while wearing the physically restricting vest was creating misleading results of its effectiveness.

Recognized limitations of the study included the sample size, short duration of the study and the lack of a formal sensory needs assessment of the participant. Another notable limitation was that the participant had already been wearing the vest, and so may have had some ‘successful’ sensory integration and reduction in behaviour prior to the
study. Perhaps choosing a child who had never worn a weighted vest before may have been a better determinant if the treatment was successful.

In another study, Smith, Press, Koening, and Kinnealey (2005) compared the effects of the sensory integration approach and a control intervention of tabletop activities on the frequency of self-stimulating behaviours in seven children with ASD. These authors hypothesized that the sensory integration intervention would reduce the frequency of these behaviours.

The participants were recruited from a large residential facility for children with a variety of developmental disabilities. Each participant was assessed (by their teacher) using a sensory integration inventory to provide information on the subject’s sensory processing abilities and specific behaviours.

Interventions consisted of a variety of tactile, proprioceptive and vestibular input designed to meet the subject’s individual sensory needs. The control intervention consisted of tabletop activities related to each participant’s specific educational goals. The study took place over a four-week period. In weeks two and four a sensory integration approach was employed for 30-minute sessions, five times per week on an individual basis. During weeks one and three the control session was implemented using the same schedule.

The results showed a decline in self-stimulating and self-injurious behaviour by 11 percent one hour after the sensory integration intervention was administered in comparison to the tabletop activity intervention. There was no change immediately following each intervention.
Limitations of the study noted by the authors included the small sample size and the use of a single clinical site. Other researchers may argue that an 11 percent reduction in the targeted behaviours does not constitute a successful intervention. Also the recruitment of participants from a large private residential facility may have impacted the results, as the educational practices employed may not reflect practices utilized in more inclusive and heterogeneous classrooms.

The purpose of another study conducted by Demanche and Chok (2013) was to examine if wearing wrist weights in tandem with receiving vibratory stimulation was effective in eliminating or reducing SIB in a twelve-year-old boy with ASD with a prolonged history of SIB. The authors asserted that more studies existed on the efficacy of wrist weights and not on their proposed combination treatment.

The researchers used a multiple treatments reversal design for their study. Effectiveness of each intervention was evaluated in isolation and in combination. Baseline data was collected using a frequency chart. Two hundred and eight six sessions occurred.

The results showed that during the wrist weights only stage there was a reduction in SIB. The baseline was at 83.5 per hour compared to 1.7 per hour when the 4lb wrist weights were worn. With no weights SIB spiked to an average of 86.5 per hour. When the weights were put back on average rate of SIB dropped to again to 7.1 per hour. During the combination, unmatched vibratory stimulation stage the rate of SIB was 9.1 per hour. While an initial decrease of SIB was observed the rate of SIB increased to 39.0 per hour.
Limitations revealed by the researchers included that if was the only study of its kind and further research was required to validate their findings. Other limitations appeared to be the confusing nature of the data collection and the frequent changes in the weights heaviness. The data seemed confusing and inconsistent making it difficult to determine the overall results. Their citation list was also small and dated. Only eight works were cited from 1970 to 2003.

The effectiveness of SIT to reduce self-injurious behaviour in children with autism remains unconfirmed. The conflicting results of the studies serve to confirm this point and highlight the need for further research. As most of the studies of SIT have been in clinical settings, using small sample sizes over short periods of time it is necessary to expand the scope of research. Utilizing long-term studies, with larger sample sizing, in regular classrooms may be able to determine the efficacy of this intervention and resolve the debate.

Gaps in the Literature

Through extensive exploration into the literature a noticeable paucity of research that looked at the transition of students who self-injure into inclusive educational settings was evident. Machalicek, O’ Reilly, Beretvas, Sigafoos, and Lancioni (2007) proclaimed there is “a gap in what is known about the classroom treatment of students with ASD who engage in challenging behaviour (p. 230). Moreover, this lack of school-based research is affirmed by Montgomery et al. (2013) who reported that the majority of published reviews document one-on-one interventions for challenging behavior in a therapeutic or care facility and not in inclusive school environments. These authors stated there are few reviews that explicitly summarize the research regarding interventions administered in
formal preschool and K–12 school environment. Horner et al., (2002) asserted that “given that interventions will most likely occur in typical home, school and community settings, there is a real need for more research on the feasibility of using behavioural interventions in typical contexts by typical support agents” (p. 435).

This disparity is alarming considering “much of the treatment of challenging behaviour for students with ASD has been placed on schools” (Machalicek et al. 2007, p. 229). These authors offered several factors that make research in classroom settings challenging. First, Machalick et al. (2007) reported that teachers often take on the role of interventionist but lack the knowledge, resources and time to develop effective behaviour intervention plans. Second, interventions to reduce challenging behaviour must be designed to fit within classroom routines and expectations. A final challenge for researchers is they must overcome the distractions common to classrooms that are absent from experimental settings such as other students and activity transitions.

With an increased emphasis on providing children and adolescents with ASD with more opportunities for inclusion and socialization through access to regular classroom environments, classroom-based research needs to be prioritized. This narrative inquiry may contribute knowledge from the perspective of the parents of children who self-injure.

In addition, there are very few narrative studies that explore the topic of SIB from the perspective of parents or caregivers. One qualitative study somewhat related was conducted by Drysdale, Johoda and Campbell (2009) and utilized semi-structured interviews to explore mothers’ attributions of self-injurious behavior of their children with intellectual disabilities. This inquiry highlighted the need to listen to mother’s views
about their offspring’s self-injurious behavior and concluded by stating, “It is about ensuring that services appreciate the inter-personal context of a person’s self-injury, and the impact that it might have on the family” (Drysdale, Johoda & Campbell, 2009, p. 205). This correlates back to Bronfenbrenner’s Ecological Systems Theory and why it is vital to examine multiple perspectives and contexts.
Chapter Three

Research Methods

Research Question

The research questions guiding this study are: 1) What are the experiences of families and students with autism who exhibit self-injurious behaviour? 2) What practices and supports do families hope schools could provide to support the needs of their children with SIB?

Methodology

This research employs the tradition of narrative inquiry that adopts an interpretivist paradigm that emphasizes social interaction as the basis of knowledge (O’Donoghue, 2006). Lieblich, Tuval-Mashiach and Zibler (1998) claimed, “one of the clearest channels for learning about the inner world is through verbal accounts and stories presented by individual narrators about their lives and their experienced reality” (p. 7). Furthermore, Moen (2006) believed a way of structuring the complexity of our experiences and dialogic interactions both with the world and with ourselves is to organize them into meaningful units such as in a story or narrative. For most people, “storytelling is a natural way of recounting experience, a practical solution to a fundamental problem in life, creating reasonable order out of experience” (Moen, 2006, p. 56).

The initial rationale for this choice was based on my research goals and objectives. As an experienced Learning Support Teacher, I felt uncomfortable and stressed from the unexpected responsibility of supporting complex learners who self-injure. I knew I needed to inform and educate myself; the topic of SIB was therefore a
natural choice. In addition, while conducting preliminary research, I found there was very little research focusing on the parent’s experiences and perspectives on raising children who self-injure. I felt strongly that this knowledge was important and could meaningfully contribute to understanding SIB and to creating responsive supports for children and their families.

A final, yet important rationale, for using this method was to allow the researcher to explore this unique phenomenon using an authentic and personalized framework to capture humans’ experience. As I was interested in obtaining specific and detailed descriptions from parents it became apparent that a qualitative approach was appropriate. This meant fewer participants with more one to one interaction where a deeper understanding of the perspectives and experiences could emerge. As Maxwell (2013) states, “qualitative researchers typically study a relatively small number of individuals or situations and preserve the individuality of each of these in their analyses” (p. 30).

**Participants**

One of the most important undertakings in the design phase of a study, according to Sargeant (2012), is to identify appropriate participants who can best inform the research and enhance understanding of the phenomenon under examination. The participants accessed for this study were five families/caregivers of school-aged children and or young adults with a diagnosis of autism who currently self-injure or who had a history of SIB. The participants had children that attended public schools (elementary and high school) across a range of dates and times; spanning the early 1990s to present day. These families lived in various parts of British Columbia, Canada,
The nature of the SIB included the variety of topographies as reported in the literature such as head banging, self-biting and self-scratching. The SIB for each child also varied in onset, duration and intensity. The children or adults attend a public elementary school or high school in the lower mainland and Vancouver Island.

One on one interviews were conducted which allowed the participants to feel at ease sharing their experiences and perspectives on sensitive and personal topics. Each interviewee was asked the same open-ended questions; though probing questions varied. The intention here was to identify possible themes, similarities and discrepancies across interviews. Moreover, the open-endedness of the questions encouraged flexibility and autonomy in acquiring responses from the participants that were unique and personal.

**Access and Participant Recruitment**

In order to find potential participants, recruitment was first accessed through formal means. I contacted four agencies well known for supporting students with autism. These were: Autism Support Network, Autism Community Training, Family Support Institute and the Provincial Outreach Program for Autism and Related Disorders. I sent these agencies a recruitment letter outlining the nature of the study (see Appendix C). Additionally, after recruiting only one participant I accessed four more participants through informal means by way of parent networking. I avoided selecting individuals or families that had any affiliation or connection with the school or district I was employed in. Due to the difficulty of finding participants, I only recruited five individuals.

Interested families were asked to call or email me to address any questions or concerns they may have before committing to the study. At this time, I discussed confidentiality and anonymity to ensure the participant’s right to privacy was upheld.
Upon agreement to participate each participant was provided with a consent form to be signed and returned (see Appendix A).

**Ethical Considerations**

Narrative inquiry is a “profoundly relational form of inquiry” and attending to ethical matter plays a central role throughout the research process (Clandinin, 2006, p. xv). Several ethical considerations related to this study were identified. First, in order to comply with Vancouver Island University Research Ethics Board’s (REB) ethical policies and regulations, I consulted with my Faculty Supervisor and reviewed the REB website to ensure that I adhered to the application process and submission guidelines.

Secondly, as Caine, Estefan and Clandinin (2013) asserted, at the forefront of any narrative study is the responsibility to the participants. As my research involved human participants I needed to be thorough when determining the potential risks and benefits of this study. Since the topic of SIB could potentially elicit sensitive responses, it was essential that my participants realized that they could withdraw from the study at any time without penalty, and that their emotional state and privacy were (and are) my main priorities of the study. A list of counseling services (see appendix D) was available if requested.

As a new researcher I needed to be aware that I may “confront the potential risks involved in inadvertently touching on highly charged emotional issues in the course of an interview, especially when dealing with individuals from highly vulnerable populations…” (Smythe and Murray, 2000, p. 321). Being prepared and comfortable with the emotional responses of the participants was therefore important. I was willing to postpone or conclude any interviews if any of the participants displayed signs of distress.
or discomfort. Fortunately, each participant seemed comfortable and I did not have to do end any interviews before I had completed asking all the questions.

To ensure privacy, I made sure that the participants were aware that their responses would remain confidential and that their names would not be published; instead non-gendering pseudonym would be used. After transcription, the audio recordings were destroyed and the only people to have access to participant responses are my supervisor and I.

A final common ethical consideration I identified was researcher bias. As Birchall (2014) recognized a researcher’s history, beliefs, values and interests will affect what he/she chooses to study, how he/she approaches the study, and how she/she ultimately interprets the findings. To help mitigate this I followed recommendations offered by Malterud (2001) whereby I identify my biases at the outset of the research and maintained a reflexive approach throughout the research process. I was also careful with the wording of my questions, and tried to make sure I did not guide my participants to answer in certain ways. The questions were primarily open ended and left room for exploration and freedom of expression.

**Data Collection**

**Data Collection Methods**

The data collection in qualitative descriptive studies is typically directed at “discovering the who, what, and where of events or experiences, or their basic nature and shape” (Sandelowski, 2000, p. 338). The main type of data in this inquiry was the dialogue and responses collected from the semi-structured conversational interviews. Longhurst (2003) believed the semi-structured interview method allows participants the
chance to discuss issues they feel are important. This author goes on to say that the informal tone of this interview process allows for open responses in the participants’ own words.

All the interviews were recorded using a recording device. A journal of the interviewing process noting location, time and length of each interview and any other relevant information were also kept in a private and secure location. A selection of questions (see Appendix B) were prepared and shared ahead of time to each participant to guide the interview.

Interviews took place over one meeting and varied in time from 35 - 60 minutes long, depending on the participant and the detail in their responses. A follow-up session was also scheduled, where each participant had the opportunity to read over their transcribed interview and check to make sure their perspectives and experiences were accurately represented. This negotiation process between research and participant, Caine, Estefan, and Clandinin (2013) stressed, helps the researchers to understand and honor that a person’s lived and told stories are who they are and who they are becoming. In addition, Clandinin and Huber (2010) believed that, “Ongoing negotiation with participants allows narrative inquirers to create research texts that both critically and deeply represent narrative inquirers’ and participants’ experiences while also maintaining each person’s integrity and their relationship into the future (p. 11).

Further, each participant was also debriefed about the direction of the study and their confidentiality rights.

**Data Analysis and Interpretation Procedures**

The data analysis method I employed for this study was constant comparison
inquiry. This method “is a thematic form of qualitative work that uses categorizing, or the comparing and contrasting of units and categories of field texts, to produce conceptual understandings of experiences and/or phenomena that are ultimately constructed into large themes” (Butler-Kisbler, 2010, p. 47).

To ensure accuracy I began my data analysis by transcribing each interview word for word. Once this process was complete, I sent the individual documents to the participants so that they could read over their interview. Participants were advised to make changes or revisions if they felt their experiences and perspectives were not accurately represented or required further clarification and elaboration.

Once the participants had given their approval, I read each interview several times to gather a broad sense of each interviewee’s answers and to strategically familiarize myself with the data. I then began a closer reading of each and started highlighting and underlining themes and patterns in responses. The overall goal of constructing these themes was to obtain and develop common themes and or anomalies. Once these common themes were identified I constructed the rules of inclusion for each. Once these rules were established I looked for sections of text from the interviews to support each theme. The overall goal of constructing these themes was to obtain a broad yet detailed understanding of families’ experiences and perspectives raising children with autism who self-injure.

**Applications of Understandings**

The knowledge procured from this research could be used to identify best practice for supporting complex learners. It could lead to an improved awareness of SIB from the perspective of the parents and guide and or support an ecological framework of service
delivery that addresses the needs of the student from multiple perspectives. Additionally, it may foster a deeper understanding of the needs of families to develop or improve home-school relationships.

**Limitations**

The present study was not without limitations. A small sample size and limited variance amongst participants were noticeable drawbacks. All the participants were living in British Columbia and their children attended public schools at different dates and times between the early 1990s and present day.

**Significance**

SIB is a complex phenomenon that has serious and detrimental consequences. Given the prevalence rate and impact on quality of life for the child and their families the far-reaching consequences of SIB (Boesch, Taber-Doughty, Wendt, & Smalts, 2015) it is important that research is pursued to support students, families and schools to better understand the phenomenon and create appropriate supports, practices or interventions that may reduce or alleviate SIB.

It is hoped the knowledge that is created in this narrative inquiry will be confirmable by those who have had similar experiences and potentially transferable to families and schools who are providing support to students with SIB. By exploring the stories of challenges and successes for families of students with SIB, schools may be able to create collaborative models of service delivery where effective interventions and supports are employed that “have the potential to prevent or reduce the frequency and severity of SIB and its negative consequences” (Chezan, 2017, p. 294). Additionally,
through listening to the voices of the participants new insights and perspectives may be gained on this challenging phenomenon.
Chapter 4

Findings and Results

In this chapter I present the results of this study. I begin by restating the purpose of the study and the research questions. Next, I break down and discuss the findings into four dominant themes and related categories. Tables are provided to show the overview of themes.

The purpose of this study was to explore the perspectives of families with children who have autism that exhibit SIB. The study employed the qualitative method of narrative inquiry to acquire a deeper understanding of the families’ lived experience. It was designed to explore and answer the following questions:

1) What are the experiences of families and students with autism who exhibit self-injurious behaviour?

2) What practices and supports do families hope schools could provide to support the needs of their children with SIB?

The results were synthesized into themes established from an analysis of the data collected during the participant interviews. Under each thematic analysis, individual categories are explained and addressed. Data from interviews were used to provide direct evidence to support each category development. The categories connected under effects of SIB on families are linked by the parent’s personal experiences and challenges. The categories connected under schools are ill prepared for complex learners are linked by the perceived shortfalls of schools at addressing the needs of these learners. The categories connected under parents’ perspectives on treatment, discusses different treatment options to address SIB. Finally, the categories under what parents want from
Schools are associated with the specific recommendations parents would like to see that will improve service delivery and outcomes for their children who self-injure.

The table below provides an overview of each category, the rules of inclusion and the conceptual theme.

<table>
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<th>Table 1</th>
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<tbody>
<tr>
<td><strong>Overview of Themes</strong></td>
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<tr>
<td><strong>Categories</strong></td>
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<tr>
<td>Stress on Marriage</td>
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<tr>
<td>Stress on Work and Finances</td>
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<tr>
<td>Impact on Health and Well-Being</td>
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<tr>
<td>Judgment and Social Isolation</td>
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<tr>
<td>Isolation/Seclusion of Student</td>
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<tr>
<td>Not Attending School for Full Days</td>
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<tr>
<td>Parental Advocacy</td>
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<tr>
<td>Support of Behavioral Approach</td>
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<td>Support of Medical</td>
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<tr>
<td><strong>Approach</strong></td>
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<tr>
<td>Flexibility in Service Provision</td>
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<tr>
<td>Acknowledging Parent Voice</td>
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<tr>
<td>More Specialized Training and Consistency of Staff</td>
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It is the hope of the researcher that the knowledge gained from this study might be used to inform schools about practices that can support the meaningful inclusion of complex learners, reduce or alleviate SIB and promote collaborative partnerships between school and home.

**Theme One: Effects of SIB on Families**

All the parents interviewed expressed they had experienced negative effects, which was directly associated with raising their children who had complex needs and engaged in SIB. According to the interviewees, the stress they faced on a daily occurrence had substantial impact on their personal, and even professional, lives, and compromised many other areas of their livelihood, including their marriage, finances and overall health and well-being.

Furthermore, several of the participants indicated that they faced judgment and social isolation, because of their children’s diagnosis and SIB. It is important to acknowledge in no way did the participants blame their child for the situation and loved their children unconditionally.
In this section, I present the theme of \textit{effects of SIB on Families}, as outlined in the table below, by providing a detailed analysis of each category.

<table>
<thead>
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<th>Table 2</th>
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<tbody>
<tr>
<td><strong>Effects of SIB on Families</strong></td>
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<tr>
<td>Categories</td>
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<tr>
<td>Stress on Marriage</td>
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<tr>
<td>Stress on Work and Finances</td>
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<tr>
<td>Impact on Health and Well Being</td>
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<tr>
<td>Judgement and Social Isolation</td>
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\textbf{Stress on Marriage} “… for the sake of my marriage.” \textit{Participant C}

Marital and relationship stress was a category identified in the data collected. The majority of the participants reported a strain on their marriages and personal relationships. The limited amount of quality time they spent with their significant other was discussed. Participants noted if they did have time with their partner it was typically spent talking about the needs of the child. Common dialogue between partners often involved organizing appointments, therapies and childcare as well as the discussion of the day-to-day needs. The following experts from the data highlight the marital and relationship stress discussed.
“It’s hard on our marriage and I’m actually going to resign from my job... just because it’s too much. It’s too much coming home, being a single parent to a child like this and those sleep issues, she needs constant care. It’s going to hurt us financially, but for the sake of my marriage... .” Participant C

“The stress was very hard on our relationship as a couple at times.” Participant B

“... it has impacted our marriage - my husband works a lot away from home because it is hard for him to watch his son deteriorate and there isn’t anything anyone can or will do. It’s been hard on me as I’m left to manage everything including making all the decisions. We’ve been in and out of counselling; we take holidays separately.” Participant E

**Stress on Work and Finances** “... it’s going to hurt us financially... .” Participant C

Alterations to work life and the financial situation were identified as another category in theme 1. Four out five participants talked about the impact on their work and finances as a result of managing their child’s complex needs. Two out of five reported they could not work due to the daily commitments of medical and school appointments, attending therapies and the extra care needs required for when their child was not in school. This put a strain on the family finances.

One participant talked about how the time missed from work to meet the needs and demands of caring for their child affected their opportunity for a promotion.
“The experience completely changed the course and pathway of my life and I was told by my employer I was not considered for promotion advancement because I had become unreliable.” Participant A

Another financial stress mentioned by participants was the cost of respite care and other expensive services not covered by funding. These additional costs often created financial stress and hardships.

“We were very close to serious financial detriment because of the care gap... .”

Participant A

**Impact on Caregiver Health and Well Being**

“I think there were times I was extremely burnt out.” Participant B

The health implications for several participants were of significance. Four out of five participants reported experiencing physical and psychological health issues as a result of the stress associated with caring for their child. A key acknowledgment among these participants was the limited time for self-care as a result of the care demands.

Physical symptoms reported by the participants included weight gain, sleeping issues and adrenal fatigue.

“But well, and then there’s also the not being able to take care of yourself part of things so I have gained I have gained 70 pounds in the last couple of years... which is terrible too ... .” Participant C

“I’ve got to be up at 5am...to get ready for work and I’ve got between four and five hours sleep.” Participant C

“I now have adrenal fatigue due to stress.” Participant E
The psychological and mental health implications were also discussed by several of the participants. The ongoing stress and worry for their children’s welfare created personal challenges.

“There was always a lack of sleep and a great deal of worry about why Terry was hurting herself, questioning myself about whether we were doing the right thing and making the right choices about medication. And worrying about her future.”

Participant B

One participant shared her experience regarding the impact on her mental health as a result of her son’s negative school experience and her decision to remove him from the public-school system.

“I finally had time to go to the doctor and was diagnosed with major depressive disorder and missed many months of work. I directly attribute this to the crushing experience my son and us as a family went through as a result of our experience in the public-school system.” Participant A

Judgment and Isolation “The isolation is also huge.” Participant E

Three out of the five participants reported experiencing cost to their social lives as a result of having a child with complex behaviour. These participants shared their experiences about feelings of judgement by the community and the social isolation they faced. Here are the excerpts from the transcripts of Participant C that reflect this sentiment.

“There are those other things we have to live with, being parents ... of a child who is self-injurious, is you know, judgement. There is not much support, even from the community ... .” Participant C
“Parents often lose the ability to just parent, they become case managers, researchers, advocates and it leaves little time for socialization.” Participant E

“... having a child like this is very exacerbating. First of all, there is no time to socialize with anybody... . And we can’t bring anybody into our house, because Riley, you know, freaks out ... .” Participant C

Four participants shared their experiences with restrictions to daily functioning. Some participants shared how their day-to-day activities such as grocery shopping and socializing with friends and family were restricted. Another participant talked about avoiding social situations or being uncomfortable in social situation because of their child’s behaviour or as a result of social stigma. Here are some excerpts from the data that depict this.

“Parents cannot get out of the house as often - they often refrain from taking their children into the community to get groceries because if their child has SIB, they are often stared at, people make snide comments and it’s rare to find people who understand.” Participant E

“And that’s the hard thing too, when your child is self-injurious and they have black eyes, you know, you may be misjudged... . The community immediately thinks, what the hell are you doing to your child and she’s covered in bruises because she pinches and bites herself all the time.” Participant C

“We have no friends except through work as they had a very difficult time having our son over – so they slowly over time, just stopped inviting us as a family over.” Participant E
Another challenge for some participants was finding suitable respite care so they could spend some time socializing. Participants stressed the difficulty in finding trained staff that was capable of managing/supporting such extreme behaviour.

“It is hard to find respite workers so that you can go out and if you child has SIB it makes it harder to find someone that is willing to come for 2 hours a week to let you have 120 minutes without your child.” Participant E

“Oh they gave us more money for respite, but it’s brilliant giving us money for respite but she can’t really have anybody working with her.” Participant D

To conclude this first theme, one participant’s words encompassed the categories presented in theme 1 and poignantly summarized the toll of raising a child with SIB had on their lives.

“The toll of daily advocacy, complex Healthcare provision, therapeutic intervention, and putting food on the table by working full-time to make ends meet for the care required because my child couldn’t attend school full days frequently made it impossible for self-care, impacted my relationship, impacted my productivity at work, deteriorated my mental health. It reached into every conceivable area of our lives. Unlike teachers or Administration Professionals in the school system, we don’t get to go home at the end of the day or the school year and put it down.” Participant A

**Theme Two: Public Schools are Ill Prepared for Complex Learners**

Frustration was expressed by a number of the respondents about the ability of schools their children attended to appropriately and effectively support their children in
an academic environment, despite their complex needs and SIB. These families felt that the school lacked the resources, space, and staff who are trained with the specific requirements of assisting students with complex and challenging behaviours. Many parents noted that the school was unable to take their children for full-days, and depending on staff availability and difficult behaviours, their children would often be sent home. This not only affected the child’s academic progress, but it also impacted the parents’ work schedule, and was costly to the family, who often had to find child-care, which can be difficult for children with complex needs. For those children who did not get sent home, they were often placed in isolating spaces, especially when they would engage in SIB and other challenging behaviours. Moreover, four out of five respondents felt the school did not advocate for their complex students, and instead parents had to take on this responsibility, which took time and energy from their already busy and demanding schedules. Rather than building a supportive and nurturing space, and being proactive, parents felt that the schools instead took a reactive stance, which left parents feeling frustrated and alone in their child’s school life, and picking up the pieces when things fell apart at school.

In this section, I present the theme of *public schools are ill-prepared for complex learners*, as outlined in the table below, by providing a detailed analysis of each category.

<table>
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<th>Table 3</th>
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<p>| Public Schools are Ill-Prepared for Complex Learners |  |
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<table>
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<tr>
<th>Categories</th>
<th>Rules of Inclusion</th>
<th>Themes</th>
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<tbody>
<tr>
<td>Isolation/Secluded Environment</td>
<td>...highlight the isolation students faced because of their complex needs and SIB</td>
<td>Public Schools are Ill-Prepared for Complex Learners</td>
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<tr>
<td>Not Attending School Full</td>
<td>...highlight the practice of</td>
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Isolation and Seclusion of the Child - “She didn’t spend a lot of time ... within a classroom setting; most of her education happened in a room away.” Participant C

A category that emerged from the data was the practice of isolating a child due to their challenging behaviour and SIB. Three out of five participants reported that their child had been secluded from their peers and provided support in a separate setting for periods of the day because the school did not know how to deal with their behaviour. These participants expressed frustration and disappointment with this practice and felt it was unfairly penalizing the child and detrimental to their child’s overall self-esteem and educational growth.

“So even though she was in a typical classroom, she spent most of her time alone with the EA doing play dough. And so, it did not feel successful to me.”

Participant B

“... at the end of elementary school he was basically alone in a room with two adults. It was a room in which the safe space was, it was only him in the room, ... and nobody else went in the room. So he would spend isolation time in the isolation... kind of inside the room he was isolated in.” Participant A

“She didn’t spend a lot of time...within a classroom setting; most of her education, happened in a room away. I don’t know what you call that, but she had
her own room, which she occasionally shared with other kids with autism; like one person. But mostly she was alone.” Participant C

**Not Attending School Full Days** “The school wouldn’t take him the full school day, so that was challenging, and expensive…” Participant A

The restriction to the child’s school hours was another category identified in the data. Two out of five participants shared their experience of their child not being able to attend school full days because of the school’s lack of resources and inability to manage or understand their behaviour. This practice was very stressful to parents, particularly for working parents who had to arrange additional childcare; which was often difficult (and costly) to find due to a lack of trained personnel available. Participant A discussed how the school’s inability to support her child resulted in escalating behaviour, followed by the reduction of support and learning opportunities her child could access.

“The issue was that they were wholly and completely unprepared and ill-equipped to deal with this level of behaviour… .”

“... they were running up against their walls in terms of being able to know how to react and handle specific behaviours.”

“... it went from full time very quickly down to just a couple of hours a day and it was a repeated battle every school year trying to get them to take him. It was extremely difficult.”

“He’s doing this all as a nonverbal child using self-injury and sometimes aggression to establish the rules of the jungle there. Because of their institutional, built-in fear and liability issues...they were... reactant and lacked training... .”
In contrast, one participant shared that the school her son attended was very supportive and did not restrict his attendance because of his SIB and challenging behaviour.

“I never, ever got he can’t be here, we can’t help you, so I feel very fortunate.”

Participant D

**Parental Advocacy** “Stepping back wasn’t an option when it’s your own child.”

Participant E

All five participants shared their experiences with the role of being principal advocate for their child. These participants detailed the time and effort required to ensure the educational and social needs of their child were being met at school and the additional stress it often created.

“Being an advocate is a full-time job and it takes its toll. The challenges are having to tell the same story over and over each time when there is a new person involved with my son.” Participant E

Several participants expressed that a source of conflict between themselves and the school were the discrepancies that each party held in relation to their child’s needs and abilities. Participants expressed frustration with “not being on the same page” and felt their advocacy efforts were viewed as adversarial and confrontational. This created additional stress and eroded the home-school relationship.

“... and I never advocated to be the mother from hell, like I wanted to be a team, I wanted us to work together, but you know, it’s so difficult when you have people that have their own ideas . . . .” Participant B
“You become very overprotective when you’re ground into the ground like that and you’re trying to protect him from the system, so you’re in mother-bear mode and you can’t stop doing for them and trying to make sure they’re okay.”

Participant A

One participant shared a story about the cost of advocacy and it was this dialogue that inspired the title of this study; “It is a price we all pay”.

“…there was a father I knew who was very involved with non-profits as a board member, ..., and was a vigilant advocate for his daughter. We were once at a strategic planning meeting as board members ... and during a break he said to me, “I’ll always wonder if the years I spent advocating for my daughter wouldn’t have been better spent with my daughter”. That really haunted me. I think it is a price we all pay – we aren’t as present for our families when we spend so much time advocating.” Participant B

Theme Three: Parent Recommendations/Suggested Interventions

The treatment options for SIB are diverse and highly debated in the research (Bleiwiss, 2016; Chezan, McWhorter, & White, 2017). This sentiment was reflected in the responses of the participants regarding what they perceived as the best treatment for their child. Each participant shared their diverse beliefs and experiences regarding the etiology and corresponding effective interventions to reduce or alleviate SIB. There was no overall consensus of what causes SIB and the treatment option that was best; though three participants felt environmental factors (such as noise and sensory overload) could impact SIB.
Overall, the participant’s responses highlighted the complex and highly individualized nature of SIB as reported in the research.

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<th>Table 4</th>
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<tr>
<td><strong>Parent Recommendations/Suggested Interventions</strong></td>
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<td>Categories</td>
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<tr>
<td>Support of Behavioural Approach</td>
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<td>Support of Medical Approach</td>
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**Support of Behavioural Approach** “What works for the SIB is the behavioral model.” Participant A

The use of the behavioural approach has been well documented in the literature (Azrin, Gottlieb, Hughart, Wesolowski, & Rahn, 1975; Banda, McFee, & Hart, 2012; Boesch, Taber-Doughty, Wendt, & Smalts, 2015). Three participants were advocates on the behavioural approach and the importance of recognizing the environmental factors or conditions that can contribute to SIB. These participants felt strongly that schools needed to collect data and conduct a functional behaviour assessment to identify the possible factors or setting events. Then results of the data could then be used to create an intervention plan and alter setting events. Here are participants B and C’s perspectives on this approach.

“What works for the SIB is the behavioral model. Not necessarily ABA, I think that can actually exacerbate SIB sometimes. An evidence-based functional
behavioral assessment is the only way to determine what the purpose of the self-injury is, in order to determine what replacement behavior can be substituted through methodical repetition as prescribed in a positive behavioral support plan. Without this A would not have recovered. The spiraling deterioration of behavior worsens when a behavior is reinforced unintentionally by caregivers or education assistant because they don’t understand the function of the behavior and either react, or fail to recognize the function and support the child in transitioning to the replacement behavior.” Participant A

“The best thing you can do is ... through the environment, through positive reinforcement through reading the person ... .” Participant C

“So a lot of the, reducing the self-injury is environmental, it’s trying to make sure that you do respect that when they are being self-injurious that they are stressed out ... .” Participant C

Participant B offered a compelling description of her child’s SIB and the environmental triggers.

“I would describe it as a storm in her brain. Things were just erratic, I think it was sensory overload, I think it was frustration, not communicating, I think it was too many people supporting her in too many different ways, because the crying and the self-injurious behaviour was really hard on support staff.” Participant B

Surprisingly, the topic of sensory treatments, such as those presented in the literature review in chapter 2, was not heavily discussed. Several participants acknowledged the sensory component being a possible contributor to SIB but felt SIB was more complex than just meeting a sensory need.
“We got an OT who thought that maybe the behaviours were caused by some kind of sensory issue... chewelry that kind of thing, to stop her chewing, from biting herself and some putty stuff that she could pinch instead of pinching herself, thinking it sensory. It didn’t help because I think you have to go and find out what the root cause is for the SIB before you start.” Participant C

Support of Medical Approach “... I’m a firm believer in, when these children are self-abusive or outwardly aggressive – and I am not saying every child, but for some children there’s a medical reason... .” Participant E

As reported in the literature many divergent perspectives on the etiology of SIB exist (Bleiwiss, 2016; Carr, Smith, Giacin, Whelan, & Pancari, 2003; Jyonouchi, 2016). One participant in this study felt strongly that SIB was in many cases related to a specific medical condition such as inflammation, migraines or seizures. This participant cautioned against making assumptions about why the SIB was occurring and to have comprehensive testing to rule out any medical reasons or factors. The following series of quotes extracted from the interview with Participant E reflects their beliefs regarding the medical approach.

“Don’t make an assumption it’s just a behavioural issue. Look, you know, find ways to ask for blood work and stool and urine and EEGs; look at this from a medical perspective. A child who bangs their head on the table, don’t make assumptions that it’s a behavioural issue. It could be migraines. You cannot ABA a migraine or seizure out of a child. You can’t!”
“So often, when people self-abuse it is often due to inflammation in the body somewhere, so they’re in pain and so they hit themselves I order to try and stop the pain. They are trying to create a different kind of pain.”

“SIB is often a sign of something medical and needs appropriate medical treatment by someone that really understands the issue.”

“... I think one of the concerns and the issues is that ... we don’t actually look to see whether or not there’s a medical condition for hurting themselves.”

This dialogue provides a strong argument for looking at SIB from a medical perspective and does mirror the recommendations from some researchers (Mahatmya, Zobel, & Valdovinos, 2008).

Another participant felt that a contributing factor to SIB was anxiety and that medication directed at reducing anxiety helped minimize SIB for her child.

“The anxiety meds helped quite a bit and a lot of the strategies that he was using; the self-mediation ... had really helped him to be able to manage.” Participant D

In contrast, one participant shared their frustration with the medical profession and the over-prescribing of medication to try and control or alleviate the SIB.

“They admitted [medical professionals] that they didn’t know, they had her on seven different medications at the same time... . Antipsychotics, we’re talking Benzodiazepine, the Adderall’s and then Lithium; they threw the pharmacopeia at her, nothing was working.” Participant C

**Theme Four: What Parents Want from Schools**

All five participants openly provided their recommendations to improve the service delivery at the school level and support the meaningful inclusion of their child
with complex needs. Each participant offered several areas in which improvements could be made. These included: flexibility with services, improved communication and teamwork with parents and school staff as well as more specialized training for teachers and support staff.

In this section, I present the theme of *what parent want from schools*, as outlined in the table below, by providing a detailed analysis of each category.

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<td><strong>Categories</strong></td>
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**Flexibility in Service Delivery**

The rigidity and inflexibility of service delivery was a dominant topic identified in the data. Four out of the five participants expressed frustration with specific school policies and their inability to be flexible and adaptable in how services were delivered to their children.

Participant A spoke specifically about the practice of preventing private support such as a behaviour interventionist to work directly with their child in the school setting.
“They are very protective and defensive and territorial about reading or accepting or listening, to any of the private consultants, approaches, thoughts, assessment reports, any of that.” Participant A

This participant felt the schools’ unwillingness or reluctance to allow private support to come into the school was a significant barrier to addressing their child’s SIB and highlighted the rigidity of the school system.

“I think the whole thing could have been avoided if the school was open to private input, like external input. They were very resistant.” Participant A

“they don’t have the resources or facility or flexibility because that is the way the system is structured, it isn’t designed to meet those kinds of needs. It’s not tailored education.” Participant A

Two participants expressed their frustration with the policy of prohibiting parents from talking directly to the education assistant at the end of each day. They felt this caused a breakdown in communication, as the teacher was not often able to share accurate information, as they had not been with their child as much as the Educational Assistant. This practice participants felt hindered the accurate exchange of information about the child’s day.

“Not being able to talk with the EAs and then the teacher ... telling them not to basically include much about what happened in the day, just highlights in the day. We had a communication book, but it was, “Yes, he ate his lunch. He did pretty good today. That sort of thing. There were no deliverables.” Participant A

“... at one time they said [the school] well you can’t talk to the classroom assistant at the end of the day, you’ll have to talk to the resource teacher, well but
the classroom assistant is the person ...that’s spending every day with Terry.”

Participant B

In contrast, one participant was satisfied with the flexibility of support for her son at his school; particularly the school-wide initiatives implemented by the administrator. This participant shared she felt the school was accommodating, communicated well and employed a responsive non-stigmatizing approach to behaviour that looked at preparing all learners, not just those with specific challenges, to be ready to learn.

“... she [Administrator] brought in each classroom a wiggle cushion. Each classroom had noise-cancelling headphone. Each classroom had fidgets. It was encouraged if the teachers so chose to create quiet corners, so they supported that. So, I really feel that there was working towards getting him as a learner ready to learn.” Participant B

“Reading, writing, and arithmetic, just get it done. But now I think there is definitely a focus on, you know, creating an environment where children feel safe.” Participant B

Acknowledging Parent Voice “Hearing the words that parents are the experts, but feeling like you are not taken seriously.” Participant A

A lack of respect and acknowledgement for the parent voice was an emergent category in the data to support theme 4. Several participants felt the school did not value their opinions or recommendations and were not taken seriously by school personnel. This created tension and hindered the development of solid home-school relationships.
“I think if I could, having the school open to having the parent as a significant part of the team… And helping and being supportive of the parents who are having to deal with this, as opposed to, you know, trying to fix it.” Participant E

“They don’t take parents seriously when they’re talking about what’s needed and even when they do, … .” Participant A

“They were very resistant. They were also poo-pooing mom’s knowledge because I don’t have letters, well I have letters behind my name, but not those letters.

There is utter disrespect for parental input, rights and perspective. Generally speaking special needs parents are swimming in oceans of experts. Lip service is given to the fact that we are the experts on our child, but when it comes down to it our directives as to what will work or not are completely disregarded in institutional contexts yes, particularly education. In this respect, this same system that permitted residential schools and disregard for family priorities has not changed significantly.” Participant A

One participant shared this analogy about her perspective on the lack of cohesion and teamwork with her child’s school team.

“I remember at one point we had a team meeting at the school, and I just said, you know, sometimes I think we’re all in this big canoe with Terry in it, and we’re all paddling as hard as we can, but we’re not all going in the same direction, and we’re all getting wet and we’re not getting anywhere.” Participant B

This example highlights the need for a collaborative decision-making process where goals and objectives, as well as roles and responsibilities, are clearly defined.
More Specialized Training and Consistency of Staff

The topic of specialized training for teachers and support staff was a consistent topic of discussion among participants. Four participants felt more training was required for teachers and staff to understand and manage SIB.

“Over time, I developed an understanding that essentially, sometimes, and I don’t even fault them, but teachers think that they know how to teach, and they do, but complex-health needs children don’t learn the same way as, I call them ‘neurotypical’ learners. I’ve come to understand there is no training, not a lot of training in regular teacher lines, about how to support these kids and certainly, the teachers aren’t doing a lot of actual hands-on stuff, it’s all the EAs that are…” Participant A

Several participants felt schools needed to specifically hire specialist teachers and prohibit teachers with limited training from bumping into special education positions just because of their seniority.

Participants also noted their frustration with frequent changes and turnover with teaching and support staff. They discussed the disruption this created to their child’s education; particularly if the new personnel were not as trained and knowledgeable at supporting children with complex needs.

“I met with the resource teacher, it was shaping up to be beautiful, and then we started in September and the resource worker had taken on another job. And the resource teacher that was there was a history and P.E teacher who took a summer course and bumped into the job of resource worker, and it was a very
difficult year. But I know the next year we had a different resource worker... I was really glad to see him gone.” Participant B

Conclusion

The purpose of this study was to explore the experiences of a small sample of BC families with children diagnosed with autism that engage in self-injurious behaviour.

It was designed to explore and answer the following questions.

1) What are the experiences of families and students with autism who exhibit self-injurious behaviour?

2) What practices and supports do families hope schools could provide to support the needs of their children with SIB?

The results show that there are far-reaching challenges and stresses in raising children with ASD that self-injure. Additionally, the results show that schools are ill prepared to support complex behaviour and engage in practices that are restrictive and isolate the child. Another finding was that participants do not feel heard or validated as an integral member of the school team.

Theme 1—Effect of SIB on Families

An overarching theme unearthed in the data was the challenges and negative effects participants encountered from raising children who engaged in SIB. The effects were far-reaching and compromised different facet of the participants' lives. For example, martial and personal relationships were impacted. Participants shared their experiences regarding the stress placed on their relationships due to the challenges of raising a child that engaged in SIB. Additionally, participants reported influences on their finances resulting from additional costs of services and respite care. Other effects reported were an
altered lifestyle, restrictions to day-to-day living and fewer opportunities to socialize.

**Theme 2—Schools are Ill Prepared for Complex Learners**

Another dominant theme extracted from the data was schools’ inability to understand and properly accommodate children (in the public-school system) with complex needs such as self-injury. Participants reported several shortfalls such as the practices of secluding or isolating their children because of their behavior and shortening their school day because they were at a loss as to how to support them. The lack of targeted training and high turnover of teachers was also discussed. In addition, participants reported a high level of parental advocacy because of their dissatisfaction with the social and educational outcomes for their children.

**Theme 3—Perspectives on Treatment for SIB**

The third theme to emerge was perspectives on the appropriate treatment to alleviate or reduce SIB. Each participant told a different story about their treatment journey that was unique to his or her family and defined by their child’s individual needs. The most discussed treatment method however, was Applied Behavior Analysis that focuses on data collection, forming hypotheses as to why (and under what conditions) the SIB is occurring and then creating an intervention plan. In contrast, one participant felt SIB was a result of a medical condition and endorsed treatment from a medical perspective.

**Theme 4—What Parents Want from Schools**

The final theme was derived from the commonalities of what participants wanted from schools to better support their children who engaged in SIB. Participants reported they wanted to see more flexible and responsive service delivery that was tailored to the
individual needs of the child. This included permitting private specialists into the schools to work directly with their children and other members of the multidisciplinary team and allowing education assistants to speak directly with parents. Another suggestion put forth by the participants was that they be perceived and treated by school personnel as a valued member of the team. A final proposal was more specialized training for teachers and support staff in dealing with complex needs and behaviors.
Chapter 5

Conclusion

Overview

The study concludes in this chapter and discusses the contributions of the findings to the field. Recommendations for schools and districts that link to the findings are then offered within the four dominant themes presented in chapter four. These themes include: theme 1, effects of SIB on families, theme 2, schools are ill prepared for complex learners, theme 3, parents’ perspectives on treatment, and lastly, theme 4, what parents want from schools. Using the data and information collected from and explored within the themes links to research and suggestions for future inquiry are offered. Then, the chapter discusses the limitations and value of the study. Finally, it ends with the conclusion.

Theme 1—Effect of SIB on Families

The far-reaching effects on families was a dominant finding of this study and supports a large body of research detailing the numerous challenges of raising children with autism (Fletcher, 2012; LeCavalier, Leone, & Wiltz, 2006). The narrow focus of this study, looking specifically at children with autism who engaged in self-injurious behavior, is an extension to the body of existing research. While some challenges remain similar such as strain on martial relationships, finances and social lives, this study revealed the additional stressors of raising children who self-injure. The unique stressors included the worry of serious injury and the challenges of finding trained personnel to provide respite.

The professional implications of this theme identified in this study convey the need for teachers and school staff to be cognizant, and sensitive to, the challenges and
stressors families face when raising children with complex needs. Future research could center around teachers and staff perceptions of supporting students who engage in SIB, in the classroom and school community. Understanding how these professionals feel about, and deal with, the challenges of these students could help to develop staff training initiatives.

**Theme 2—Schools are Ill Prepared for Complex Learners**

Schools’ inability to understand and properly accommodate children with autism who engage in SIB was another finding of this study. Specific practices of shortened days as well as secluding and isolating children with challenging behaviors were documented spanning a period of several decades. These findings highlighted the slow pace of change in educational practices aimed to include students with complex needs in the public-school system.

The inclusion of students who exhibit self-injurious behaviour undoubtedly raises some unique and complex challenges for schools. Muscott (1995) believed that appropriately including students with severe behaviour challenges “requires a system-wide response; a significant infusion of resources and support for students, faculty, and a process that focus on best practices and validated programs” (p. 373).

Future inquiry could address the lack of school-based research, as reported by Machalicek, O’ Reilly, Beretvas, Sigafoos, and Lancioni (2007), and investigate the efficacy of classroom interventions used to target challenging behaviour such as SIB.

**Theme 3—Perspectives on Treatment for SIB**

The findings of this study regarding perspectives on treatments or interventions for SIB echoed the existing research in that there is no definitive or “one size fits all”
treatment to alleviate this condition (Taylor, Oliver, & Murphy, 2011). This study also emphasized that SIB is highly individualized and unique for every child.

The professional implications of these findings highlight the importance of approaching SIB from a multidisciplinary perspective. SIB in children with autism is a complex phenomenon that has shown to be challenging to treat (Chezan, Gable, McWhorter, & White, 2017). It is essential that schools adopt policies and practices that allow specialized supports, (such as private behaviour consultants) to work collaboratively with schools and families. As discussed in Chapter 2, a barrier to creating effective treatment approaches, reported in the literature is the disciplined nature of the field. Minshawi (2015) argued that a more integrated and multidisciplinary approach to supporting children who self-injure may advance the field and reduce or alleviate the suffering of these children and their families. Additionally, Levine (2002) believed a multidisciplinary team might protect the student from “disciplinary biases related to their clinical training or a form of therapy they feel most comfortable administering” (p. 272). With this in mind, school boards may need to revisit policies that prohibit or restrict private professionals from offering their expertise. Future research could explore the benefits and challenges of allowing these private professionals into the school community.

**Theme 4—What Parents Want from Schools**

The findings of this study indicated that schools need to develop more flexible and personalized service delivery models to support children with complex needs. This links to Muscott’s (1995) term, “responsible inclusion”; a process he believed “necessitates that we follow two distinct paths at the same time. These paths include
building each school’s capacity to efficiently educate students with more complex and challenging behaviours while simultaneously making case by case decisions for individual students” (p. 373).

Another important finding of this study is that schools do not often view parents as integral members of the multidisciplinary team. This finding echoes recent research by Moriwaka (2012) showing that school personnel have not seen parents as equal partners in the educational setting. Despite this disparity, parent participation is considered to be a vital component in the education of students with disabilities (Yssel, Englebrecht, Oswal, Eloff, & Swart, 2007). Soodak and Erin (1995) asserted,

“Meaningful collaboration between parents and professionals requires a new way of thinking about the roles they assume as well as the change in the way educational decisions are made. Professionals need to recognize that parents’ knowledge of their children and personal philosophies on childrearing are as important as their own professional knowledge. Therefore, parents’ observations and opinions should factor decisions pertaining to the education of their children” (pg. 275).

Additionally, Soodak (2004) suggested schools need to actively facilitate the home-school partnership by providing workshops to school officials, and parents on advocacy, communication and supports, including training on standards based special education services. With a structured support system and building a trusting relationship, through these means recommended by Soodak (2004), families struggling with the needs of their children who engage in SIB may experience less stress and feel more supported at the school level. This is especially important as burnout and stress impact the level and
quality of care these children receive from their primary caregivers (i.e. their parents or guardians).

A final recommendation put forward by the participants in this study was more specialized training for teachers and support staff. There is no doubt that creating a safe and inclusive school environment for children with complex needs requires trained personnel with specific education and experience. This study addressed the need for educators to receive more intense training. School districts should offer ongoing training and support in the area of challenging behaviour and SIB in children with autism. The additional training and support to teachers may help to reduce staff turnover and burnout as reported in the literature (Hastings, & Brown, 2002) and create fewer disruptions to the children and their families.

**Limitations**

A limitation acknowledged in this narrative inquiry was the small sample size. Only five participants were interviewed and their perspectives may not represent the views of all parents with children with ASD that engage in SIB. Additionally, “The knowledge developed from narrative inquiries is textured by particularity and incompleteness; knowledge that leads less to generalizations and certainties and more toward wondering about and imagining alternative possibilities (Clandinn & Huber, 2010, p.12).

**Value of Study**

By exploring the work of scholars in the field of autism and self-injury and interviewing families about their experiences of raising children with this condition I have gained a deeper understanding of the challenges parents face. The stories shared by
each participant illuminated their lived experience and moved beyond the clinical nature of the literature to show their resiliency, courage and unconditional love for their children. The narrative methodology contributes the voices of families to the literature, fostering a deeper understanding of how student needs impact the student himself/herself, and those around them.

The knowledge created from this inquiry may serve to build schools’ understanding of SIB and provide opportunities to gain insight into practices to promote inclusion and to improve outcomes for students who self-injure. The findings may also support the gap in research and stimulate more qualitative research on supporting students with SIB in inclusive classroom environments. Moreover, the study demonstrates the importance of eliciting parental expertise when supporting children with SIB and developing positive home-school partnerships.

By working together with families and other professionals, school boards’ have the opportunity to genuinely fulfill the policies and practices mandated in the Special Education Policy Manual released by the British Columbia Ministry of Education in 2016 and provide students with complex needs a more meaningful and enriched school experience.

**Conclusion**

This study served to highlight the complex nature of SIB in children with autism and the impact this behavior had on their families. The findings showed the impacts were far-reaching and touched important facets of families’ lives such as relationships, finances and ability to socialize. Moreover, the study addressed the schools’ challenges in including these children in the mainstream classrooms and the use of outdated practices.
such as seclusion and segregation. Due to these practices and lack of respect for the value of parental input participants of this study reported a high level of advocacy; creating additional stress in their already challenging lives.

Given the outcomes of this study, it is important to conclude with one final reflection. Although SIB is a complex and troubling condition:

“The welfare and safety of those in our care are dependent upon our willingness to tirelessly seek to understand SIB, and creatively endeavor to provide the resources and support necessary to help staff and the individuals in our care to battle this complex phenomenon (Fucilla Rustic, 2005, p. 7).
References


Birchall, J. (2014). Qualitative inquiry as a method to extract personal narratives: Approach to research into organizational climate change mitigation.


doi:10.1023/A:1005939901


**ADDRESSING THE NEEDS OF STUDENTS WITH SIB**


do:10.4300/JGME-D11-00307.1


ADDRESSING THE NEEDS OF STUDENTS WITH SIB

(Eds.), *Crucial reading in special education* (pp. 260–273).

Upper Saddle River, NJ: Pearson Education.


doi:10.1177/0741932507028006050
Appendix A – Consent Form

I am a student in the Master of Education in Special Education program at Vancouver Island University (VIU). My research, titled “Supporting Children with Autism who Self-Injure: A Narrative Inquiry” aims to explore the experiences and perceptions of families who have school aged children or young adults with autism (or other developmental disabilities) with a history of self-injury. The aim of my study is to gain insight into the experiences and perceptions of families to inform school decision-making regarding supporting students with self-injurious behavior in school settings.

Research participants are asked to participate in a face-to-face interview at a location and time of choice. If you agree, you will be asked questions concerning your experiences in parenting and supporting children with autism who exhibit self-injurious behaviour such as head banging, biting and punching. You will be asked specific questions about the supports you provide to your child, and their experiences in school. Your participation will require an interview lasting approximately 60 minutes and an additional 15-30 minutes to review the written transcript. With your permission, the interview will be audio-recorded. The recording will be transcribed for later review. The research report will not directly identify you.

The information collected may pose risks to participants as it explores topics of sensitivity. Some participants might find the discussion stressful. Should the discussion appear distressful or uncomfortable to participants, I will immediately end the interview and provide you with a list of counselling or support services available in the area in which you reside.

No directly identifiable information will be reported in the thesis or products of research. Your identity will be protected by referring to you by an assigned pseudonym. You will be asked to provide permission to be quoted, but without direct identification, or you may choose not to provide permission to be quoted directly, but only have the information you provide described generally. In any of these situations, there is a risk that you could be identified based on situations and information you describe, even if your name is not used. The thesis will use assigned pseudonyms to introduce participant’s direct quotations. You will have an opportunity to review the transcripts and make changes or delete sections as desired.
If you choose to participate, all records will be confidential. Information provided in the interviews will only be accessible to myself as the researcher, and my VIU Supervisor. The only two people with access to information will be the researcher and the individual participant. With permission, an audio recording of the interview will be transcribed into writing. You will be provided with a copy of the transcript. Any alterations to the transcript will be made at your request. Both the audio files and transcripts will be stored on a password protected PC in my home. Signed consent forms will be stored in a locked filing cabinet in my home. In the research paper, all personal identifiers will be stripped. All data related to this research will be shredded and deleted from the computer by approximately June 30th, 2021.

The results of this study will be published in my Master’s thesis available on VIUSpace in the Vancouver Island University Library, and may also be published in a peer-reviewed journal.

All participants participate voluntarily and you may withdraw participation at any time during the study for any reason. Participants do not need to provide any reason or explanation for this withdrawal. Interview transcripts will be provided to you. You will have two weeks to review and revise the statements you made. After being provided with a copy of the transcript, you may request withdrawal from the study at any time. If you decline a copy of the transcript, you may withdraw from the study at any time before it concludes. Upon withdrawal, written transcripts and audio files will be destroyed.

I have read and understand the information provided above, and hereby consent to participate in this research under the following conditions:

- I consent to the interview being audio recorded.
- I consent to being quoted in the product of the research.

Participant Name ________________________ Participant Signature ________________________

I, Joanne Drew, promise to adhere to the procedures described in this consent form.

Principal Investigator Signature __________________________ Date _______________

Thank you for providing your consent to participate in this study. If you have any concerns about your treatment as a research participant in this study, please contact the VIU Research Ethics Board by telephone at 250-740-6631 or by email at reb@viu.ca.
Appendix B – Interview Questions

Prompts

1. Please tell me about your child.

2. Tell me about your child’s experience in school.

Probes - Public or private? How long at each school? What grade? Full or partial day? Positives? Negatives?

3. How is your child supported at school?

Probes - Special needs designation, EA support, resource room

5. Please tell me about your child’s challenges with self injury.

Probes - Frequency, duration, protective equipment, impact

6. Tell me about the level of involvement the school administrators have with you and your child?

7. Tell me about any challenges you have faced having a child who self-injures.

Probes – types of supports or resources accessed

8. Tell me about the skills you have developed as a parent of a child who self-injures?
9. What advice do you have for other parents who have children with autism who self-injure?

10. If you could design the ideal school/home environments and connections for your child, what would these be like?
Attention Interested Parents - Do you support a child who injures himself/herself?

My name is Joanne Drew. As well as being a Learning Support Teacher I am a student in the Master of Education in Special Education program at Vancouver Island University. I am conducting a research study exploring the experiences and perceptions of parents who have children or young adults with autism or other developmental disabilities with a history of self-injury. The aim of my study is gain insight into the experiences and perceptions of parents that might inform school decision-making regarding supporting students with self-injurious behavior.

I invite you to be a participant in the study. If you choose to participate, you would be interviewed in person and audio recorded. You would be asked to share stories about your child, specific home and school supports and challenges that occurred with having a child who self-injures. I will provide you with interview questions at least one week before your interview. The interview would take approximately 60 minutes and could be done at a time and location of your choice.

My hope is that this study will increase understanding and provide strategies and information that will be useful in supporting children more effectively in school contexts. If you are interested to volunteer as a participant, or if you have further questions, please contact me at jdrew@sd44.ca or by phone at 778 837 8490.

Sincerely,

Joanne Drew
Appendix D – List of Available Counselling Supports for Participants

**Jericho Counselling**
Suite 1004-750 West Broadway, Vancouver, BC
604 537 4246

Suite 906 - 510 Burrard, Vancouver BC
604 537 4246

1150 – 4720 Kingsway, Metrotower 2, Burnaby BC

**Bach Counselling Group**
203 – 145 West 15th, North Vancouver
604 904 0898