VANCOUVER ISLAND UNIVERSITY

Shades of Shame: An Autoethnography Exploring the Role of Shame and the Stigma of Childhood Mental Illness Within the Educational System

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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We accept this Thesis as conforming to the required standard.

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Abstract

This autoethnographic study explores the challenges faced by a parent caring for a child with serious mental illness through a storied reflection of personal experiences, focusing on the internalization of stigma, reactions to perceived stigma, and related consequences. Within the context of parental advocacy within the educational system, it addresses the research question:

As a parent of a child with severe mental illness, what meaning does my experience with parental shame and stigma have for myself as a parent and as an educator? In this reflective study, personal narrative is interpreted through authentic, relevant research from the field, addressing themes of teacher-parent relationship, caregiver stress, isolation, failed parent ideal, delayed help-seeking, blame, care burden, shame, and support and validation. The study’s findings encourage empathy and understanding of these potential impacts, with recommendations for the provision of stigma reduction interventions by teachers and schools, and the promotion of educational advocacy for families caring for children with serious mental illness.

Keywords: autoethnography, childhood mental illness, shame, self-stigma, school advocacy, education, parent
Acknowledgements

I would like to extend my greatest appreciation to all who supported me during this journey. Thank you to my husband, daughter, and son. You are the loves of my life and in a multitude of ways, made this autoethnography possible. Thank you to my dearest friend, K. Our simultaneous pursuits of higher education kept me motivated. Thank you to my dearest friend, N. Your mother-child journey helped pull me through my own. Thank you to my Supervisor, Mary Ann Richards. You provided me with much needed confidence and the belief that my story was worth sharing.
Dedication

To B.H., our tireless CYSN worker.
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Chapter 1: Promise Me

“Promise me you will never be violent again.”

I sit in a small school office facing my 10-year old son, Malcolm. He is bundled up in a heavy winter jacket, hood pulled over his forehead, arms and legs squeezed tight against his chest. Malcolm’s jacket collar, soaked and torn from obsessive chewing, hides his mouth and nose. I feel a sense of panic as I notice his eyes, barely visible through the crack between his collar and hood, flitting back and forth. *Can he see me? Does he realize I’m here?*

“You were violent. You are not allowed to be violent. Promise me you will never again be violent.”

My focus is pulled away from Malcolm and onto Mrs. Mackie. She is focused hard, glaring. Her lips are moving. She is speaking. The sentences are long. But I can’t understand her. Is she angry? Sympathetic? I am stuck and can only hear: *Violent. Promise. Never again.*

Mrs. Mackie shuffles her chair close to Malcolm, searching for his hidden eyes.

“I think he’s got it,” she says, “Let’s have him go back to class now.” With that, Malcolm stands up and walks past me out the door of the office. He does not acknowledge me, and I don’t turn to watch him go. I can’t move from my chair. I am silent, feeling an overwhelming sense of shame. Violence is scary. Violence means beatings, stabbings, murder. Violence means prison time. Violence means no remorse. Was my son really violent?

Earlier that morning, I received a phone call from Mrs. Mackie, asking for a meeting. Malcolm had been disruptive in class by suddenly throwing a series of items within arm’s reach across the room, frightening most of the students, including Mrs. Mackie. I was told over the phone, “This situation has been very upsetting for us. We need to say our part.”
The emotions I experienced that day were raw: embarrassment, inadequacy, shame, abandonment by the educational system I worked hard to support through my own profession as a teacher, frustration, and anger. I said nothing in Malcolm’s defense. I apologized profusely to Mrs. Mackie. The exhaustion of parenting my son, along with Mrs. Mackie’s accusatory delivery, prevented me from advocating for Malcolm’s needs and his right to be respected in school. I felt like a failure.

That particular encounter with Mrs. Mackie occurred at a pivotal point in my family’s life. A few months earlier, Malcolm had received a diagnosis of bi-polar disorder with psychosis. It was both a devastating and hopeful label, as I navigated the plethora of emotions which had emerged within me over the preceding year from living through the waves of Malcolm’s intense mania. I had become torturously sleep deprived, managing my new night-time routine of chasing, pleading, bribing, ignoring, yelling, and crying, while Malcolm’s hysterical laughter, banging fists, and racing feet echoed through the dark hallways of our home at midnight, one a.m., two a.m., three a.m., and four. When Malcolm wasn’t laughing, he was raging; crying, kicking and hitting himself or others, sometimes for three hours without reprieve. He heard and saw things that were not there; people with shotguns and knives, threatening voices and screams. Embarrassment rumbled in my gut as profanity-laced language escaped Malcolm’s mouth without warning. Panic swept over me as he attempted to outrun any moving vehicle he saw. The intense energy and paranoia, cyclical screaming and hysterical laughter crushed us as a family as we desperately tried to see glimpses of our past life through the turmoil. I was propelled into resentment. Mrs. Mackie repeatedly sent him home, sometimes within the hour of the start of his school day. I was desperate for support and on the brink of a family breakdown. Throughout my day, I fantasized of running away to escape the torrent, leaving Malcolm behind. I was drowning.
Through my unbearable misery, I attempted to present a façade of control and resilience, while I squeezed out tiny drops of reserve to fight for Malcolm’s acceptance at school.

After two and a half years of living with Malcolm’s disorder, I am now adept at recognizing signs when he is unwell. Failing to respond to us, darting eyes, dilated pupils, increased hyperactivity, and bizarre statements are characteristic signs for him. Yet, sitting in the office that day, I was unable to express a reason for his behaviour and explain the actions which led to Mrs. Mackie needing to “say her part”. I was paralyzed by shame.

**Purpose of the Study**

Reflecting upon that moment, I now understand two things: Malcolm was experiencing mania and psychosis and was unable to control or comprehend his actions; the effects of shame helped to perpetuate the lack of empathy and understanding of mental illness I had come to expect from the small school district I worked for. I knew the situation needed to change. If I could not advocate for my own child within the school system, how could I be an effective teacher for others?

The Oxford University Press Dictionary (2019) defines shame as “A painful feeling of humiliation or distress caused by the consciousness of wrong or foolish behaviour.” It is not uncommon for me as a parent to feel responsible for my child’s actions. I felt compelled that day to profusely apologize for Malcolm’s behaviour as if it had been a purposeful and malicious act, ignoring the fact that he did not have the capacity to defend himself or fulfill a promise of never again throwing items across a room. Fueled by anger a month later, I drafted a letter to Mrs. Mackie requesting a school transfer for my son. It was a letter I never sent. Again, the pain, exhaustion, shame, and incompetence I felt parenting a child with severe mental illness overshadowed my resilience, my skills as a parent and teacher, and my perseverance.
Background

I recognize I am not alone in my experience. The stigmatization of mental illness is a pervasive issue (Eaton, Ohan, Stritzke, & Corrigan, 2019) and approximately 22% of children in the U.S. will develop a mental health disorder with severe impairment or distress by the age of 18 (Merikangas et al., 2010; Weisman, Kia-Keating, Lippincott, Taylor, & Zheng, 2016). Weisman et al., (2016) state that as early as kindergarten, negative attitudes are developed towards children with mental health disorders, supporting stigmatizing attitudes which then contribute to negative effects for those with mental health disorders, such as a reduction in general well-being and academic performance.

Research has also found parents of children with mental health disorders are stigmatized as “incompetent, blameworthy, and shameful” (Eaton et al., 2019, p. 83) while in addition, a parent’s self-stigma can negatively impact their self-esteem and empowerment. Stigma also affects the caregiver’s help-seeking behaviour (Mukolo, Heflinger, & Wallston, 2010). This was acutely true for my own experience. Specifically, in the early years of his illness, feelings of self-blame and shame prevented me from advocating for Malcolm and in turn, affected his ability to access the school system in a positive way.

Justification

Currently, research on the self-stigma of parents of children with mental illness is limited by a lack of comprehensive measures developed for this specific population, while existing measures are not recommended for the development of measures of stigma as they were not formed in collaboration with parents of children with mental health disorders, or informed by qualitative work on parents’ self-stigma (Eaton et al., 2016).
Research studies by Fernandez and Arcia (2004), Mak and Cheung (2008), and Eaton, Ohan, Stritzke, and Corrigan (2016; 2019) examined the various conceptualizations of stigma in an attempt to understand the complex and multi-levelled effects of stigma on well-being. Self-stigma is an important issue of concern among caregivers as these studies show that parents of children with mental illness experience self-stigma, while their self-stigma is significantly related to negative perceptions, often characterized by self-blame, self-shame and/or bad parent self-view (Eaton et al., 2016; Fernandez & Arcia, 2004; Mak & Cheung, 2008). Due to the restrictions of the study, Fernandez and Arcia (2004) offered only two reasons for mothers’ feelings of stigma, and although Mak and Cheung (2008) extend the knowledge on stigma by proposing that affiliate stigma contributes to parental self-shame, in my opinion, it may also not fully capture the range of self-stigma, which Eaton et al. (2016) describes as being multi-faceted and includes affiliate/courtesy stigma as one part of a larger issue. With a fundamental difference between the studies being the involvement of parents in the development of the study, I am inclined to hypothesise that the consideration of parents’ expertise in this topic is an essential component for collecting more comprehensive data on a parent’s self-stigma. This hypothesis is supported by the further study by Eaton et al. (2019) which utilized a participatory action research group (PARG) so that item generation was participant-centred, rather than research-centered, as the PARG assisted in the creation of the research questions. The development of the parent self-stigma scale provides a more comprehensive tool to access parent self-stigma which may be used to assess outcomes of parent self-stigma interventions in the future, with the understanding that further research is still needed in this field.
Overview of the Study

Autoethnography, a research method that enables researchers to use data from their own life stories in an attempt to represent cultural experiences through reflexivity (Adams & Manning, 2015; Chang, Ngunjiri, & Hernandez, 2013), has the potential to fill the need for one type of qualitative, sensitive, and authentic research measure within this research area. Acknowledging the limitations of current measures, I formulated my own research question to explore through autoethnography: As a parent of a child with severe mental illness, what meaning does my experience with parental shame and stigma have for myself as a parent and as an educator?

My hope is that sharing my story will not only allow me to become a more empathic and empowered teacher, but will also help others to reflect on their own attitudes towards children with mental illness, and how those attitudes can affect a child’s school experience through the family members’ ability to advocate within the educational system.

“Social life is messy, uncertain, and emotional. If our desire is to research social life, then we must embrace a research method that, to the best of its/our ability, acknowledges and accommodates mess and chaos, uncertainty and emotion” (Adams, Jones, & Ellis, 2015, p. 9).

My life with Malcolm is messy. It is uncertain, and it is highly emotional. Autoethnography is a research method that embraces my intention of creating post-positivist, subjective knowledge through deep and careful self-reflections of my personal experiences. As my research question explores the role shame plays within our ability to advocate for a child suffering from severe mental illness, autoethnography is best suited as the research method, for it allows readers to “feel emotions, visualize experience, or have an overall lived sense of a situation” (Adams & Manning, 2015, p. 360). Within this autoethnography, I offer an account of
my past interactions with my son, our family and friends, the hospital, and his school, in an attempt to achieve an understanding of our circumstances through reflexivity.

Focusing on how the emotion of shame and self-stigma influence my ability to advocate for my son within the school system, my research consists of re-visiting all the medical and school documentation I amassed over the years, penning the memories and feelings these documents spark, and relating them to examples of reduced advocacy.

**Mental Illness and Serious Mental Illness**

According to the National Institute of Mental Health (NIMH) (2019), mental illness includes many different conditions that vary in degree of severity, from mild, to moderate, to severe. In addition, the categories of Any Mental Illness (AMI) and Serious Mental Illness (SMI) are used to describe these conditions, with SMI being a smaller and more severe subset of AMI.

SMI is defined by NIMH (2019) as “a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities. The burden of mental illness is particularly concentrated among those who experience disability due to SMI” (Mental Illness Definitions section). SMI is an umbrella term used by researchers to categorize the most serious mental disorders, such as schizophrenia, bipolar disorder, major depressive disorder, and schizoaffective disorder (Whitley & Campbell, 2014). Psychiatric epidemiologists may also include substance use disorder and personality disorder within their definition (Whitley, Palmer, & Gunn, 2015). As I reference the terms “mental illness” and “serious mental illness” within this autoethnography, the definitions of these terms within a general context and also within my own particular research are important. While I focus specifically on my son’s diagnosis of bipolar (which I describe as a serious mental illness) he also carries other diagnoses. Attention Deficit
Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) were diagnosed early in his life and remain impactful components of Malcolm’s personality. Over the years, and in many environments, these other two diagnoses have elicited feelings of shame; however, these past emotions I experienced pale in comparison to the impairments incurred through the self-stigma of Malcolm’s bipolar diagnosis. As such, my reference to “serious mental illness” is defined by experiences which occurred with Malcolm’s onset of mania and psychosis: an arresting and forceful deviation from the “norm” of his ADHD and ASD. It could be argued however, that Malcolm’s diagnoses are inextricably entwined, and the process of attempting to extrapolate one component from another becomes a moot point, for certainly, I understand that each diagnosis impacts and overlaps the other. In addition, Malcolm’s bipolar diagnosis was recently split into two: a diagnosis of Psychotic Disorder and Mood Disorder, in order to begin a rule out process of Schizophrenia. Despite changing or additional labels, for this autoethnography, the term SMI refers specifically to episodes of mania, psychosis, depression, and mixed mood, both witnessed by me, and as defined by Malcolm’s pediatric psychiatrists and under the labels bipolar disorder, mood disorder, and psychotic disorder.

Limitations

By embarking on autoethnographic research, I acknowledge that this research reflects my own personal interpretation of the scenarios I experienced. This approach challenges objectivity since, as both researcher and participant, I have the ability to interject my personal story into the research process, ultimately reflecting my own “level of comfort with emotive self-disclosure and personal orientation in conducting research” (Chang et al., 2013, p. 18).
**Ethical Dilemmas**

As the only participant within this autoethnography and in consideration of the current requirements of my university, research ethics board approval was not sought, however, addressing ethical dilemmas are a critical consideration of this autoethnography. Following the approach by Bochner and Ellis (2016) to create an “evocative” autoethnography, I aim to create research which “seek(s) to make people feel deep in their guts and in their bones, using various forms of literary artfulness and storytelling to place the reader in the action” (p. 63). However, the amount of sensory detail required to create an evocative autoethnography which produces “lifelikeness” poses ethical dilemmas through the writing of personal narratives which involve people who may be identifiable (Bochner & Ellis, 2016). Bochner and Ellis (2016) state that doing ethical research requires we assume a “relational ethics” view, and make wise decisions about fulfilling our responsibilities towards participants and ourselves, especially when we engage in research that reveals intimate or traumatic events:

> When you’re writing about family members or intimate others, you have to go to great lengths to take the role of the other, to interrogate your own role and motives, to imagine how other people will respond and how you and they may feel later. (p. 150)

Mindful self-reflection about my own motives and feelings during the research process supports me in the telling of a true story, while balancing loyalty, friendship, and confidentiality of those within my story. This self-reflection is not materialized without support, however, and I have committed to regular self-care through my own, personal psychotherapy as an essential component to completing this emotional work. In addition, I also employ Bochner and Ellis’ (2016) suggestion of using fictional, composite characters to protect those reflected within this
research, specifically the participants involved within the educational system (as represented by ‘Mrs. Mackie’), medical system (as represented by ‘Dr. Olan’), and my small community.

While my own consent is implicitly implied through the dual roles I play as both researcher and participant (Ryerson University, 2017), and this autoethnography speaks exclusively from my own perspective, my life is inextricably intertwined with my son’s and as such, additional safeguards have been taken to protect my son’s privacy by using a pseudonym for him and myself, while informed consent for my son’s inclusion in this research is obtained through my husband as an acting representative for initial and ongoing consent, providing an additional layer of reflection for me.

A Call for Action

Understanding the role stigma plays within our educational system and our society is important. Negative attitudes developed towards those with mental illness, such as the belief that people with mental disorders are difficult, not intelligent, or are untreatable, are widespread throughout our culture (Weisman et al.; WHO, 2019). This stigma can lead to negative effects for those with mental health disorders, resulting in abuse, rejection, isolation, and exclusion (Weisman et al.; WHO, 2019). While much knowledge exists on the effects of stigma for those suffering from mental illness, this autoethnography speaks to the lack of comprehensive and authentic measures developed to assess parental self-stigma and shame, creating a gap within this field of research. Understanding that both mental health education and stigma reduction are important elements in reducing the shame of mental illness, autoethnography may be one method which could offer further insight, addressing the negative impact self-stigma can have on parents of children with a mental health disorder, through authentic, qualitative research.
This autoethnography researches several impactful moments experienced during my journey with Malcolm and I explore my story with the hope of becoming a more educated and resilient caregiver and teacher.

**Storytelling and Structure**

My father was an artist and a storyteller. As a young child, he would animate my bedtime with wild and creative tales from his own imagination. I listened intently as an audience member peering into his fabricated worlds, while at other times, I was an active performer, the hero of his stories, battling dragons and defeating witches and goblins. As I grew older, his stories carried more meaning, and by the time I was a young adult, the knowledge of experience was rich in his narration as he told me of his many travels, his views on politics, art and culture, and the rights and wrongs of the world. To this day, I absolutely love a captivating story.

Scott (2017) refers to personal storytelling as research, pedagogy, and artistic expression that “opens space to allow human beings to connect with one another, to understand different experiences and interpretations of identity and culture” and identifies critical autoethnography as “a research lens through which we can consciously attend to personal storytelling” (p. 20). To achieve the goals of an autoethnographer, Adams, et al. (2015) state that autoethnographers not only use storytelling to research and represent experience, but also must attend to how these stories are constructed and told, and are required “to place as much importance on developing the craft of writing and representation as they do on developing and honing their analytic abilities” (p. 103). Therefore, I have considered and addressed both the storytelling elements and structure of this thesis.

The power of stories can describe and critique culture, create knowledge, and create understanding. Scott (2017) describes storytelling as a highly personal, visceral experience that is
collaborative in which “individuals simultaneously take on the roles of performer and audience” (p. 10). Within this autoethnography, I am the storyteller, however, I am also an audience member as I must interpret both the events I describe, and the portrayal of myself to others. The reader of this autoethnographic text will also have their own response to my stories, becoming both listener and performer, influencing the stories within this text with their own thoughts and critiques. My expectation is that the reader will allow themselves to experience some intimacy with me in order to fully engage in the moments I share. At the same time, I intend for the reader to have the space to place a critical eye on this autoethnographic text. With these goals in mind, I crafted this autoethnography in a way that depicts a novel or memoir with the structure of a traditional thesis purposefully oblique. It is divided into thirteen chapters and follows a chronological timeline beginning with my son’s adoption, through the onset and development of his illness, to present day. I do not offer a traditional review of the literature, rather, the review of the literature, results and discussion, are woven between the autoethnographic narrative. Each chapter, with the exception of the final one, begins with a vivid depiction of a particular situation I experienced, providing an evocative and relevant entry point for the emerging findings and embedded literature. The layering of theory and narration is intended to help the reader empathise with the story, while providing the opportunity to pause from the autoethnographic text and question the experience. As both researcher and participant, these pauses also created times of personal distance from the shameful and self-stigmatizing moments I experienced as Malcolm’s parent, allowing myself space to reflect upon my research. The resulting thesis is an autoethnographic narrative construction presented in a reflective, first person voice, layered with academic theory and literature. It is also, I hope, a captivating story.
Chapter 2: Piety/Piety

“You are a Saint for what you do.”

No. I am not a Saint. I am a normal person, just like you.

“I’m so sorry, but I don’t know how you do it... I wouldn’t be able to.”

I do it because I don’t have a choice. If this were your life, you would do it too. Because you wouldn’t have a choice either.

“You are exceptional.”

I am actually completely average, living in an exceptional situation.

Over the years, I have heard comments from family, friends, and strangers as they attempt to offer their opinion surrounding the complicated and intertwined relationship I have with my son, a child with severe mental illness. The comments are familiar versions of one another, either revolving around my unwavering devotion, strength, and superpowers, or my sad dedication to pure selflessness and martyrdom. I feel continually placed upon a pedestal of both admiration and pity, neither which I desire to embody or reflect upon my family, friends, and community.

Despite my own simplified interpretation of how I feel people must see me, I am also aware that my experience living with a son with mental illness offers knowledge that may contribute to a larger societal and educational arena. Although feeling anxious that embarking on an autoethnographic journey may feed into my beliefs that I am cornering myself into either a pity or piety camp, I am also eager to reflect upon those concerns. Acknowledging the limitations of current measures, and wishing to contribute first hand experiences to enhance understanding of this cultural phenomenon from the perspective of someone who experiences it, I embarked on this research question with feelings of excitement and trepidation, asking: As a
parent of a child with severe mental illness, what meaning does my experience with parental shame and stigma have for myself as a parent and as an educator?

My hope is to produce a meaningful answer to my question surrounding parental shame and stigma, creating insight to fill a gap in current knowledge, revealing a true lived experience through autoethnographic research. It is also to provide insight to those interested in serving both the child suffering from mental illness, along with their families, specifically those in the educational system. The stories I share within the next chapters have been chosen specifically to illustrate moments which I feel contributed to feelings of shame and self-stigma, and the consequences those feelings had on my ability to advocate for my son within the school system.

**Methodology**

Autoethnography is both a practice and a product, and combines techniques of ethnography and autobiography (Ellis, Adams, Bochner, 2011; Adams & Manning, 2015). Originating from concerns and considerations about social scientific and qualitative research, it is a method that challenged canonical ways of doing research which privileged objectivity and research neutrality, by using a researcher’s subjectivity, reflexivity (deep and careful self-reflections), and personal experience, in order to understand cultural experience (Ellis et al., 2011; Adams, Jones & Ellis, 2015; Adams & Manning, 2015). Autoethnographies can include personal narratives, the use of storytelling techniques, and conversational language, alongside fieldwork, and the review and analysis of research (Adams & Manning, 2015), creating accessible and impactful texts. Ultimately, autoethnographic stories “are stories of/about the self, told through the lens of culture” (Adams et al., 2015, p. 1).

As autoethnography can offer nuanced insights about how family members think, act, and navigate their social worlds (Adams & Manning, 2015), it presents itself as a strong method of
research for me as I seek to achieve an understanding of my life with my son through personal narrative, story, and emotions. By “turning the research lens toward the self, sharing highly personal accounts, and theorizing about one’s lived experiences” (Adams & Manning, 2015, p. 351), I attempt to describe and critique cultural beliefs and practices through the autoethnographic presumption that “writing about the self is simultaneously writing about cultural values, practices, and experiences” (Adams & Manning, 2015, p. 3). Autoethnography has the potential to fill the need for one type of qualitative, sensitive, and authentic research measure in the field of self-stigma of parents of children with mental illness; an area which has historically been under-researched and has lacked literature addressing a comprehensive understanding and description of this specific type of stigma (Eaton et al., 2016; Fernandex & Arcia, 2004; Mak & Cheung, 2008).

**Theoretical Framework**

The theoretical framework that guides this research is Bronfenbrenner’s bioecological model of development. Urie Bronfenbrenner (1917-2005) pursued an interest in family, family support, and social policy during his career, seeking to persuade policymakers of the importance of family support and early childhood education while drawing attention to the understanding that social context influences individual learning and development (Hayes, O’Toole & Halpenny, 2017). This became the precursor to Bronfenbrenner’s ecological model, which later developed into the bioecological model (Hayes, O’Toole & Halpenny, 2017). Here, it is understood that the child exists within the centre of a complex structure of systems of interaction: (1) Microsystem, (2) Mesosystem, (3) Exosystem, (4) Macrosystem, and (5) Chronosystem (Hayes, O’Toole & Halpenny, 2017).
The impact of family shame and stigma on a child’s educational development can nest within Bronfenbrenner’s model. For example, the microsystem (the closest system to the child) involves not only the child’s family, friends, and school, but also the family’s hopes, expectations, plans for the child, family culture, and the influence of family friends (Strnadova, Cumming & Danker, 2016); all which are impacted by shame and stigma. The macrosystem includes overarching values and belief systems (Strnadova, Cumming & Danker, 2016) and is relevant within the context of understanding the impact of society’s views of people with serious mental illness and behavioural problems. The chronosystem can include environmental events (Strnadova, Cumming & Danker, 2016), and supports experiences within this autoethnography including the diagnosis of my son’s mental health disorder, and transitions between school and hospitalization.

As Bronfenbrenner’s ecological model focuses on the quality and context of a child’s environment, it provides a useful framework in offering an understanding and perspective on families under stress who endure shame and stigma. Specifically, this model supports access to my son’s educational experience through my experience as his parent.

**Data Collection and Analysis**

My approach to creating an evocative autoethnography offers “a new and unique vantage point from which to make a contribution to social science” (Stahlke Wall, 2016, p.1) by drawing upon my own experiences with shame and self-stigma as it relates to my son’s mental illness. My research consists of a review of my son’s medical and school documentation, along with personal diary entries involving my son and his illness. This review acts as a stimulus for my personal journal writing, exploring feelings and emotions related to past significant interactions between myself and my son, our family and friends, medical professionals and the school.
system. My personal story is the data that informs this study, and through recursive review, reading, and coding, specific themes emerge that provide understanding and application to both my role as a parent and as an educator, along with other parents, educators, and researchers in the field. I relate findings from my first-person narrative with relevant research in my identified themes of teacher-parent relationship, caregiver stress, isolation, failed parent ideal, delayed help-seeking, blame, care burden, shame, and support and validation.

**Ethical Considerations**

Autoethnographers typically explore difficult and private life events involving those they are in ongoing relationships with, and according to Lapadat (2017), “must wrestle with competing desires to present an authentic interpretative account, protect the well-being of the others, maintain their ongoing relationships, and not stigmatize themselves” (p. 594). Autoethnography is highly subjective and the ethical dilemmas must be considered a part of both the research and writing process (Adams & Manning, 2015). Bochner and Ellis (2016) state that ethical decision-making is not a one-time occurrence and involves continual monitoring. Addressing the ethical concerns of my autoethnography was an ongoing practice, evolving as my research progressed.

**Portrayal of Self.** As both researcher and participant, I must address the ethical concerns my autoethnography creates for myself. While my own consent is implicitly implied through the dual roles I play as both researcher and participant, I am not immune to ethical considerations as it is understood that within autoethnography, “the researcher is a complete member in the social world under study” (Anderson, 2006, p. 379) and therefore at risk of exposure, vulnerability, and pain (Bochner & Ellis, 2017).
To begin debating my role as participant, I asked myself: How will my research place me in a vulnerable position? Will those who read my text look upon me with pity? Will they conclude I am a bad parent? Too selfish? Too selfless? A narcissist? A Saint? Will my writing cause me professional difficulties, considering that some may interpret my interactions with the educational system as being critical of the institution within which I work? Or will I relive the trauma, shame, and self-stigma I have worked hard to overcome as I explore those emotions again through my research? Even more painful to contemplate, how will I feel if I inadvertently harm those I love dearly, my son, husband, daughter, family, and friends, through the stories I share? Lapadat’s (2017) statement exemplifies both the acceptance and challenge I faced determining my own level of comfort with emotive self-disclosure within autoethnographic research: “In having the courage to make the private visible, autoethnographers embrace personal vulnerability but cannot know how it will play out as the written material takes on a life of its own” (p. 594).

**Portrayal and Confidentiality of Others.** Autoethnographic stories can be seen as not wholly owned by the researcher, and managing the portrayal of others is often the primary concern for an autoethnographer as they attempt to understand who could be implicated in or by their stories (Adams & Manning, 2015; Lapadat, 2017). This constitutes a significant ethical challenge, specifically in relation to my son, a minor, who does not have the capacity to consent based on his age and personal relationship with me as both mother and researcher.

Considering all participants within my study, I question: How do I ethically present participants who have not consented to being included as characters within my research? Is my portrayal of those who work within the educational system fair or even correct? Does sharing my emotions around an incident inadvertently portray those involved in a negative light, demonize,
or stigmatize them? Am I unknowingly projecting my own feelings onto others? Am I doing a disservice to my son and family members by only representing a story from one point of view?

In addition to the portrayal of others, confidentiality of participants poses an ethical challenge. Autoethnographers typically use their own name in publishing research, making it difficult to protect the anonymity of others, such as family members, and although researchers may try hard to camouflage groups and communities with the use of pseudonyms, intimate others can sometimes be easily identified or recognized by community members or themselves (Lapadat, 2017; Bochner & Ellis, 2016).

Living within a small community, I am acutely aware that confidentiality poses a challenge. Will the omission of names and generalized description of places be enough to protect those involved? Will focusing on my personal thoughts and feelings, rather than the actions of others strip my research of detailed and crucial information? How can I divert focus from others and onto myself, while still providing a rich, descriptive account of my story?

A Way Forward

**Relational Ethics.** One way to address the ethical concerns of this autoethnography is by adopting a “relational ethics” view. Relational ethics involves “mindful self-reflection about the researcher’s role, motives, and feelings during the research process” and “can offer needed guidance to autoethnographers” (Bochner & Ellis, 2016, p. 139). Using a relational ethics process, I interrogate my own role and motives, imagining how other people will respond and how we both may feel later. Using Bochner and Ellis’ (2016) ethical questions provides a framework for this process:

Will you create a world/relationship you later have trouble living in, or act in a way that you wish you had done differently?
Are there other solutions or ways to say what you want/need to say to take care of yourself without hurting someone else?

Can you write to understand how others in your life put their worlds together?

Can you write yourself out of the trauma or figure out a way to be a survivor of the situation you’ve been handed that doesn’t involve demonizing others? (p. 150)

Applying these questions to my research not only helps to address potential harm to myself and others, but relational ethics also focuses my research to the core of what is important within my study: the feelings and consequences of shame and self-stigma experienced by me, rather than a specific episode or encounter experienced by my son.

Bochner and Ellis (2016) state that working from a “relational ethics of care” also acknowledges that “as in any relationship, a researcher and participant must try to negotiate and resolve misunderstandings and disagreements” (p.154) by repeatedly asking ethical questions and building trust. This became critical, as it is impossible to know ahead of time all the moral dilemmas which would unfold as my research progresses.

**Anonymity.** Along with applying a relational ethics process to the research I gather, I include other methods to preserve the reality of my stories, while also creating anonymity for those within this autoethnography. Bochner and Ellis (2016) suggest using pseudonyms, creating composite characters, collapsing several characters into one, and putting characteristics of one person into different people as a way to camouflage participants.

For my autoethnography, I introduce a fictional, composite character, Mrs. Mackie, who embodies all school staff and school administration. She exists to illustrate the real interactions I experienced with my son’s school, while blurring the boundaries on which school staff I engaged with, protecting individual identities, while also moving focus from these participants, and
directing it upon myself and my feelings by generalizing the source which contributed to my feelings of shame and self-stigma. I have adopted this same method to represent my encounters with medical professionals through the character, Dr. Olan.

In addition to creating composite characters, I use a pseudonym for both my son, myself, and other family members. I feel that becoming “anonymous” through the use of pseudonyms does not lessen the validity of this study, rather, it allows me to more openly address the shameful and negative feelings I have associated with my son. As my feelings towards my son will continue to develop and change, I feel I must take as many precautions to protect his identity as I can for I cannot project what our relationship will become in the future, nor will I be at liberty to retroactively change this autoethnographic text.

Consent. Despite the ethical safeguards in place to minimize risk to myself and participants, it remains possible that the amount of sensory detail required to create an evocative autoethnography will reveal the identity of my son, along with sensitive personal medical information which may have unintended consequences for his future. As such, informed consent for my son’s participation in this study is obtained through my husband as acting representative for initial and ongoing consent. While it can be argued that my husband is not objective in this role (as his dedication to me may influence his decisions), he does provide an additional layer of concern for my son and the implications this study has for him and his future.

Accountability. I realize it is not possible to anticipate the full consequences my research may have for both my life, and others’ lives in the future, as Lapadat’s (2017) statement is a clear reminder that the text I produce is out of my hands once published:
An autoethnographer’s point of view and understanding will change over time, but the text persists, frozen in time, and tends to be read as an authoritative account. The consequences of the story can be hard to anticipate at the outset (p. 594).

Understanding that ethical concerns remain an overarching and ongoing issue for me as an autoethnographic researcher, my goal is therefore, to mitigate these concerns as best I can, to be able to live with the decisions I make, and despite always having questions, to feel ethically comfortable with the product I produce, and ultimately accountable for what I include or omit from my story.

Value

Autoethnographers place value on being able to analyze topics that usually lie beyond the reach of other research methods, such as innermost thoughts and self-analysis (Chang et al., 2013). My personal goal in conducting this research is to explore the meaning my experience with parental shame and stigma has for myself, both as a parent of a child with mental illness and as an educator, in the hopes that the knowledge I create will help to fill a void within this research area, while allowing myself and others to become more educated and resilient parents and educators.

Limitations

Despite the value and benefits of autoethnography, limitations exist. Chang et al. (2013), describes the danger of self-perpetuating perspectives: “Since researchers are dealing with self-data all too familiar to themselves, they could be easily influenced by their own presumptions about personal experiences without the benefit of fresh perspectives from others who could question their presumptions” (p. 21). As I am both researcher and participant, objectivity is challenged as the research reflects only my own personal interpretation of the scenarios I
experienced. Therefore, critical self-reflection is paramount in my ability to address this potential lack of accountability.
Chapter 3: Essential Ingredients

Today is adoption day. Malcolm is bright and precocious; a nearly five-year old pre-schooler still clinging to toddlerhood. The meaning of this special day feels incongruous to our setting. The walls of the Ministry’s child and family social services’ fourth floor offices are stark, the furniture uncomfortable. I sit across from my husband’s parents, my six-year old daughter, and two social workers who have been involved in Malcolm’s case management since he was removed from his birth parents’ home two years ago. I’m happy. I’m nervous. I think only of the good moments, like the time he came running to me across the grass with his arms outstretched and smiling. Today I am wide-eyed and innocent, and I can feel that special feeling. I love Malcolm.

Malcolm is big for his age—his size inherited from his birth father’s side I’ve concluded. The family history report tucked away in Malcolm’s “special box” describes Dad as an “imposing man”, six foot seven inches. Grandfather was “tall and stocky”. With Malcolm’s wide shoulders and big feet, he easily looks a year older than his age, but physical features aside, Malcolm could be mistaken for a much younger child. He’s clumsy, often falling and bumping into things. He mouths objects--licking everything from toys to table legs. He’s only recently started stringing words together to make simple sentences.

We all crowd around a large table. I coax Malcolm to sit on my lap, determined to hold him on this exciting day, but he squirms out of my arms, and avoids my attempts at affection, pushing away my face as I lean in for a kiss. He bounces around the plain office, until one of the social workers takes it upon herself to give him a “break”. As Malcolm runs up and down the hallways, and we sign documents and eat slices of cake. Our adoption worker smiles at me from across the table. “A perfect match,” she says. My heart skips a beat. Her words are proof:
Everyone believes in this adoption just as strongly as I do. Two weeks from now, the legal papers will arrive in the mail, and Malcolm will be officially ours.

Two years of fostering before adoption day had given me a good dose of life with Malcolm. Hyperactive, nearly completely non-verbal, and still in diapers at 3 years old, Malcolm was easily categorized as “high needs” within the fostering system. He needed speech therapy, occupational therapy, attachment therapy, and regular pediatric monitoring. I did it all with him, dedicating countless hours of my life to his. I shuttled him to and from appointments, up to three times a week, and each day set aside hours of one-on-one time to practice our home programs. I felt like super-mom, and slowly, as validation of our efforts together, I saw signs of improvement.

When Malcolm received his diagnosis for Attention Deficit Hyperactivity Disorder (ADHD), and later, Autism Spectrum Disorder (ASD), I welcomed it each time. Prior to this, my evenings had become dedicated to Google searches on the effects of trauma. Now, there were two new avenues to explore. It also meant more therapy and I had become an expert at engaging in therapy with him. Two independent psychoeducational assessments had told us that Malcolm’s IQ was average. I clung to this, feeling compelled to preface his other diagnoses with this statement of fact: “He has Autism, but he’s got a normal IQ,” I would say to friends, family, and his school team. Somehow, knowing there was an intelligent child underneath the ADHD and ASD gave me hope. I fantasized his future: school graduation, employment, marriage--a rewarding and happy life. With early intervention he would become independent in his future. Medications, therapies, and social programs would create the support structure, but my targeted motherly love, boundless energy, and feverish dedication were the essential ingredients to Malcolm surviving and thriving. What I could not have predicted, however, was that despite my
unrelenting determination for success, Malcolm would face a challenge which would put our relationship on a new trajectory, and nearly break us apart forever.

**Parent-Teacher Relationship**

When Malcolm began school, I freely shared information about his diagnoses of ADHD and ASD and felt happy with the support from his school. Mrs. Mackie and I had frequent communication in some form or another, and even when days were a challenge, I saw the humour in Malcolm’s missteps. There was safety in Malcolm’s diagnoses as well. Teachers seemed to immediately understand (at least on a surface level) ADHD and ASD. I never had the impression that people were judgemental, and a cursory internet search would lead me to an entire community of support. I felt no shame or stigma. In fact, I felt part of a *team*. Malcolm’s behaviours were also very manageable at this time in our lives. He had some tantrums, but they felt in context with his other delays. I simply perceived him as a younger child, and so his speech delay and social and emotional delays were fitting and “normal” if I thought of him as a year or so younger than his chronological age.

However, over the development of Malcolm’s illness, a wider variability in my parent-teacher relationship emerged. My belief system changed from being part of the team, to having feelings of otherness and exclusion. At times I was furious at the school, feeling unsupported, marginalized, stigmatized, and shamed, while my difficulty to honestly engage with the school compounded my stress. In reflection, I understand it was not the school’s intention to create this discord, but unfortunately, it was my lived experience.

Understanding the teacher perspective can help bridge the gap from research to practice by providing information about contextual influences, such as teachers’ perceptions of current mental health needs in schools, their training needs, and their roles for supporting children’s
mental health (Reinke, Stormont, Herman, Puri, & Goel, 2011). In the study by Reinke et al. (2011), 292 teachers participated in research examining teachers’ perceptions of needs, roles, and barriers in schools within the context of mental health. While teachers perceived themselves as having primary responsibility for implementing classroom-based behavioural interventions, they reported a global lack of experience and training for supporting children’s mental health, with only 4% strongly agreeing and 30% agreeing they had the knowledge required to meet the mental health needs of the children with whom they work (Reinke et al., 2011). The top three areas which teachers felt they needed additional knowledge or skills training were strategies for working with children with externalizing behaviour problems, recognizing and understanding mental health issues in children, and training in classroom management and behavioural interventions, while in addition, a large number of teachers reported the need for training in engaging and working effectively with families (Reinke et al., 2011).

Parent and teacher interactions are one of the most common social interchanges, and existing literature indicates there is a wide range of parents’ and teachers’ perceptions of the family-professional partnership experience (Lalvani, 2015; Lasky, 2000). Lasky (2000) analyzed fifty-three teachers’ interview responses describing parent-teacher interactions, concluding that teacher-parent interactions are interwoven intellectually and emotionally, with teacher emotions influenced by personal and cultural beliefs, largely shaped by professional values within the culture of teaching. Teachers feel more comfortable with parents who share their value systems, and judge and classify parents according to a range of normality, along with their own moral purpose and caring ideals (Lasky, 2000). In addition, Lasky (2000) states that working conditions which encourage teachers to develop relationships with parents are lacking, making “emotional understanding virtually impossible, as sustained contact, depth of relationship and trust are
critical to such a quest” (p. 857). As a result of interactions between parents and teachers, both sometimes felt confusion, powerlessness, and misunderstanding (Lasky, 2000).

A qualitative study using semi-structured interviews by Lalvani (2015) explored the perceptions of parents and teachers in context of the implications of disability and schooling. Thirty-two parents of children receiving special educational services and thirty teachers provided rich descriptors regarding the meaning of disability, and their beliefs about families of children with disabilities. In general, most teachers held beliefs about parents of children with disabilities that were consistent with dominant cultural narratives characterized by burden, grief, and stress, while many teachers understood this stress and grief to be a direct result of the child’s disabilities (Lalvani, 2015). Views of families of children with disabilities varied, and although eight teachers felt these families were no different from families in general, remarks from this group exposed the belief that having a child with a disability was undesirable (Lalvani, 2015). Surprisingly, teachers did not acknowledge societal attitudes toward disability as potential stressors for families, the contexts in which the experiences of families are situated, or the difficulties parents may experience communicating with education professionals and negotiating the special education system (Lalvani, 2015). In contrast, most parents attributed stressors to both their child’s impairment, and to environmental factors such as cultural stereotypes, efforts to protect their child from rejection, negative experiences as a result of feeling stigmatized, and from their high levels of involvement in the special education process (Lalvani, 2015). Lalvani’s (2015) findings suggest that parents are more apt to locate disability within cultural and educational practices, as well as within their children, whereas teachers located disability solely within individual students.
Chapter 4: Happy Birthday

It’s that moment between sleep and wake when a disorienting wave of fear envelopes my body, and the fleeting calm becomes abruptly replaced with panic.

What is that horrible sound?

As if a gong has been rung beside my ear, I feel immediately shattered. My eyes spring open and my ears tune in. High pitched, irritating, and loud, the repeating squelches bounce off the walls through the darkness. I think of animals fighting over prey. The noise is suddenly interjected with hand claps and joyous screams of “Happy Birthday!”

What time is it?

I fumble with my phone, pressing the home button and squinting at the fuzzy dim clock display when my bedroom door bursts open with such force and the wall becomes an unexpected victim of the door handle, a deep indent now scar ing the drywall. Before I can form the word “Stop!” eighty pounds of frenetic energy slam into me with the motion of a pro wrestler flying from the top ropes. It is 4:00 am, and I am pinned under my nine-year old.

I tense my stomach and try to maneuver Malcolm’s poking elbows and knees that have landed in my midsection. The start of the day is upon me and I quickly retrace our steps, filing through the previous night’s episodes in order to orient myself and regain my authority:

7:30 pm: Bedtime. Malcolm won’t sleep. He is running, laughing, crying, screaming, hitting. He bites his hand, hits his head with his fist. Screaming on and off lasts 2 hours. I finally coax him to bed with stuffed toys and reading.

11:30 pm: Malcolm finally falls asleep and I go to bed.

12:00 am: Malcolm is awake, laughing, running through house, jumps off back of couch.

He says he is Superman.
12:30 am: I am able to coax Malcolm back to bed with more stuffed toys and reading. He falls asleep and I return to bed.

2:30 am: Malcolm is awake again. I find him running around in his room, fully dressed in daytime clothes. All his books and remaining clothes are piled high in the middle of the room. The shelves and drawers are empty. Malcolm is excited and tells me he’s packing for vacation. He runs to the front door and tries to leave the house insisting he’s going to school.

3:15 am: I have finally convinced Malcolm it’s the middle of the night and he will go to school tomorrow. He falls asleep again.

4:00 am: Malcolm is awake and body slams me in bed. He is awake for the day and insists it’s his birthday.

Months earlier, Malcolm became more animated, like a finger-in-the-socket buzz which pulsed through his muscles. Chalking it up to his ADHD somehow getting worse, I joked about it at first: “Our entire home could run on a Malcolm battery if we could only harness his energy…” But when this potent power started taking pieces of his night, I became concerned. Was it normal to fall asleep hours later and wake up hours earlier?

“He must be growing, so he needs less sleep,” I would say in defence, meanwhile feeding him Melatonin before bed in a fruitless pursuit to make him drowsy. Malcolm’s hyperactivity increased until finally, his uncontrollable energy ruled most of his night and without a choice, I was pulled into the exhausting new dimension of living a second day in the dark. In an attempt to evidence my own sanity, competence, and control, I became obsessed with memorizing Malcolm’s movements through these nights, scribing them into the logbook of my brain until I had the opportunity to enter the data into my computer. Malcolm’s unpredictable, out of control behaviours were carefully calculated into neat charts and spreadsheets, void of emotion, and
contained. I clutched to this data entry for guidance, as if at some point I would crack the code and have an explanation for his changes. The charting also provided a distraction from the persistent, anxious “butterflies” which had recently developed in my stomach. Other times, a hot wave would rise through my body, from my feet to the top of my head, and the feeling of witnessing the last fleeting moments before the end of the Earth would make me shut my eyes and gasp for breath.

**Caregiver Stress**

With the onset of Malcolm’s bipolar symptoms, the following years saw nighttime as a battlefield of chronic sleep deprivation, with me seesawing between high alert, hypervigilance, and extreme focus, to blurry vision, delayed response, and confusion. My pre-adolescent boy’s waking attacked without warning to an unknown ending. It was unnerving, unpredictable, and extreme. In addition to the new unsettling feeling in my stomach and the hot rushes, the emergence of eye-watering, nausea-inducing headaches began, at times forcing me to stay in bed full days and nights, while the chaos of Malcolm ran free. To avoid the disapproval and judgement that I feared my peer group all believed—that I failed at the fundamental parenting skill of putting a child to bed--I resorted to keeping much of my night life a secret, instead summarizing these experiences as simply “rough nights” to those who asked.

The sleep deprivation and chronic exhaustion I experienced in the years of parenting Malcolm had a profound effect on my ability to advocate for him at school and Mrs. Mackie did not have a full understanding of my reduced capacity during this time. It became a struggle to concentrate in the day, and my thought processing became slower than anyone would have known. I often nodded to the school’s suggestions and comments, in desperation to speed up a meeting. It was often not until later when I had time to reflect on an encounter with Mrs. Mackie,
would I become upset about the outcome, wishing I had responded differently or spoken up. At that time, I did not appreciate or acknowledge my level of caregiver stress.

It is only recently, through therapy sessions with my psychologist for this autoethnography, have I started to acknowledge and understand the physical and emotional toll parenting a child with serious mental illness has taken upon me. My “butterflies” and hot rushes with feelings of impending doom were physiological signs of anxiety and panic attacks, and while they have subsided to some degree since the height of Malcom’s illness, they do continue to this day. I knew self-care would be an essential component of this autoethnography, yet I naively thought my psychologist would be a sideline support. I admit I was not fully prepared to hear that she was diagnosing me with a generalized anxiety disorder which often manifests itself in anxious over-control. In reflection, my ignorance or avoidance of these symptoms influenced how those around me treated me. My exterior often presented a high-achieving, controlling, workaholic with a dry sense of humour; a contrast to how I felt on the inside: anxious, unhappy, out-of-control, and in desperate need of help. What began as short-term support for writing an autoethnography, has now turned into a longer-term treatment plan. This revelation has made me recognize the effects of parental stress are not isolated to a singular place and time, but have long term health implications, all which contribute to my ability to not just advocate for MalcolM, but to function in daily life beyond the scope of my child.

A systematic review by Ohayon, Goldzweig, Lavi-Rotenberg, Roe, and Pijnenorg (2019) aimed to summarize existing literature on illness perceptions held by parents of children with SMI, exploring characteristics and outcomes. With the assumption that similar challenges would be faced by parents of adults and children across different serious mental illnesses, the review included studies comprised of people with different types of SMI including psychoses, affective
disorders, and OCD, while developmental disorders including ASD were excluded (Ohayan et al., 2019). In addition, studies which focused on parents’ perceptions of mental health services, their views disclosing the illness, or their general health literacy were also excluded (Ohayan et al., 2019). The authors identified and screened 31 studies, separating 8 qualitative methods from 20 quantitative methods and 3 mixed methods. Overall, the literature review by Ohayan et al. (2019) indicates that parents tend to endorse stigmatizing beliefs, blame themselves, and “struggle to make meaning of child’s illness and to construct cognitive perception of this illness” (p. 35), while in addition, the way they think about their child’s illness affects their own, and their child’s psychological outcome. A greater awareness of the illness label was related to greater family burden and to the parent’s attitude toward their child, while the authors’ found internalizing stigma was positively related to self-blame and negatively related to self-esteem and empowerment. Increased parental distress was related to parents’ perceptions that the illness was caused by them, that it was chronic, that it affected identity, and that the patients could control their illnesses (Ohayan et al., 2019). The literature review concluded parents’ self-blame was also found to be related to higher criticism toward the child, higher emotional over-involvement, higher distress, and poor psychological well-being. Limitations within this review acknowledged the studies mostly used patient scales that had been adapted for parents, along with mixed samples of carers, resulting in little information on its application among parents only (Ohayan et al., 2019). It was noted within the study that the Eaton et al (2019) study provided an exception to the other studies through its development of a self-stigma scale based on parent measures.

Often, life-long care and support is provided by parents for their children with mental health issues or developmental disorders, contributing to chronic stress, psychological distress, a
diminished quality of life, and negative health outcomes (Song, Mailick, & Greenberg, 2018; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016; Caicedo, 2014). In the study by Song et al. (2018), researchers examined the longitude effect of parenting status and the experience of embarrassment/shame, and perceived daily discrimination on parents’ self-rated health and number of chronic conditions, using a sample group of 128 parents of children with developmental disorders or long-term serious mental health problems and a comparison group of 2256 parents of unaffected children. Results of this study indicate that the parents of individuals with disabilities experience a significantly higher level of embarrassment and shame than parents of children without disabilities, and parenting children with disabilities has a significant impact on self-rated health and number of chronic conditions via the indirect effect of embarrassment/shame and daily discrimination (Song et al., 2018). Parents with higher levels of embarrassment/shame and daily discrimination are significantly associated with poorer self-rated health nearly ten years later, and poorer health profiles were seen in parents of individuals with disabilities than their counterparts twenty years later (Song et al., 2018).

Research by van der Sanden et al. (2016) examined 503 family members of people with mental illness, the prevalence and role of 14 coping strategies as mediators of the relationships between stigma by association, and family burden, along with outcomes, such as psychological distress and quality of life (van der Sanden et al., 2016). This study reports family members of people with mental illness use a variety of both adaptive and maladaptive coping strategies in an attempt to mitigate the negative outcomes of stigma by association and family burden (van der Sanden et al., 2016). Adaptive coping strategies including acceptance, positive reframing, and planning, are used most often, while maladaptive strategies including self-distraction, self-blame, and behavioural disengagement, are shown to be used less frequently, and within the context of
family burden and stigma by association, this is a positive finding, as maladaptive strategies increase psychological distress, while most adaptive strategies help to mitigate the negative outcomes of family burden and stigma by association (van der Sanden et al., 2016). Further findings within this study suggest that family members who share the stigma and practical issues that arise from having a family member with mental illness experience psychological distress and lower quality-of-life (van der Sanden et al., 2016).
Chapter 5: A Short School Day

“But it’s 9:30,” I say into the phone, “He’s only been in school for an hour. It’s just the start of the day…”

Mrs. Mackie is unmoved. After jumping up on tables and unleashing a barrage of swear words, Malcolm must come home, and I must yet again, account for his behaviour. *He’s my responsibility, therefore, I am responsible.* Last night was “rough.” I had planned to sleep, just for an hour, before picking up groceries and then cleaning the house. This changes everything. Now I’ll have Malcolm all day, without a break.

When I arrive at school, it’s clear walking Malcolm home will be difficult. Despite the warm weather, he has bundled himself up in a toque, thick winter gloves, and ski goggles. An argument I couldn’t win, I had let him take these items this morning in exchange for the large dust mask he had initially refused to take off, believing winter attire was somehow more appropriate for a warm school day.

Malcolm fidgets, touching and tapping the walls, the door, and Mrs. Mackie’s arm. With a calm voice, I negotiate stripping off the hot layers, and stuffing them into my bag for “safe keeping” I say. I take his hand, and we leave school.

Chatting away, I attempt to keep Malcolm distracted. We are almost home, but as we step off the sidewalk for the final crossing before the last block, Malcolm abruptly pulls away from me and makes a dash in the opposite direction. Malcolm is fast, but erratic. He zig-zags back and forth, darting and jumping, allowing me moments to catch up. Each time I get close, Malcolm darts again, as if we are playing a game of tag. Landing on a main road, he continues to weave in and out of traffic as I hang back on the sidewalk.
A crowd begins to gather. I avoid their eye contact, pretending not to see them. Malcolm is seemingly unaware of these concerned community members; his arms flailing, hysterical laughter now filling the air.

“Stop! You’re going to get yourself killed! Get off the road, kid!” A man shouts. A hot rush travels to my head and I close my eyes and swallow. *They must know I’m his mother. Are they judging me?*

The cars continue to move in stop-and-go fashion as Malcolm darts between them. Finally, the vehicles make their way through and the street is clear. I take the opportunity to coax Malcolm back to the sidewalk.

“Over here, Malcolm! Come see me!” I try to make my voice sound light and happy, but there is obvious tension within it. The road will not be clear for long—I notice a truck is now driving towards us. Malcolm sees too and immediately runs for it.

“We’re racing!” he yells. He tucks up close to the moving vehicle, running alongside as fast as he can. Then, without warning, Malcolm sprints, turns a hard right, throwing his body in front of the bumper. The crowd screams. Tires squeal from a sudden stop. Malcolm rolls. My stomach drops and I’m frozen. *Was he hit!?* I see him on the ground, but before I can move, Malcolm jumps up, uninjured, laughing his high-pitched, frantic laugh. I fight back tears. *If I don’t catch him, he really will kill himself.*

I quickly crouch low to the ground. Cupping my hands together, I stare intently at them, my mouth open in surprise.

“Oh my! I can’t believe I found this!” I exclaim loudly, “It’s amazing! Look what I have!” Malcolm’s curiosity is piqued. He darts close to me, jittery and arms waving. *Closer, closer...he’s so close...* I carefully extend my cupped hands towards Malcolm, opening them
only slightly to increase his obvious anticipation. Eager for the big reveal, he leans in. With a quick and unexpected jolt, I grab his arm. Malcolm screams and immediately goes limp, dropping to the ground. He’s furious.

“She’s hurting me! Help! Help! Call 911!” he yells, begging and pleading to the crowd now standing speechless, uncomfortable, and staring at the two of us. I maneuver behind him, hook both my arms under his armpits and hoist him up as much as I can. He is a dead weight, refusing to stand; a defiant protester only half resigning themselves to arrest. I am determined now--focused. I clench my teeth, tighten my grip, and begin walking backwards. With Malcolm’s feet trailing along the pavement, I literally drag him home.

**Isolation**

The thought of having to manage Malcolm’s behaviours outside of our home became a paralyzing fear for me. During the height of his illness, simple activities such as grocery shopping, buying shoes, or going to the post office were carefully constructed to *not* include him. This made school’s repeated decision to send him home for “unacceptable behaviour” extremely impactful for me. Not only was my small moment of recharge time cut short, but once Malcolm was back in my care, I became instantly trapped inside. My isolation increased with Malcolm’s repeated public episodes, until I finally believed I could not possibly step outside with him. To do so I felt, would ultimately place me in a position of living through another stigmatizing experience. I was also ashamed and embarrassed by Malcolm’s behaviours and didn’t know how to explain them. Believing my experience couldn’t possibly relate to anyone else’s, I became obsessively private, keeping my life with Malcolm to the confines of my home. I stopped calling my sisters, brother, and eventually, my mother.
A study by Fernandez and Arcia (2004) attempts to identify if mothers of children with mental health disorders feel stigmatized, describe the sources of stigma, identify associated factors such as blame and self-blame, and describe maternal responses to it. Both quantitative and qualitative analyses were performed on data taken from a set of open-ended interview questions conducted with 62 Latina mothers actively help-seeking for their child’s disruptive behaviour. Findings by Fernandez and Arcia (2004) suggest mothers feel stigma because they ultimately feel responsible for their children, and because stigmatizing experiences are often repeated. Along with reactions of self-blame and anger, the most common response to stigma from the participants was a feeling of isolation, with 71% of mothers reporting restrictions on their personal and family social activities (Fernandez & Arcia, 2004). The authors conclude that “feeling stigmatized may have a negative effect on maternal sense of parenting competence and on maternal activities” (p. 369). This study used data taken from a larger study designed to understand help-seeking behaviours and is limited by the lack of in-depth data collection on stigma and self-blame, while the cross-section design does not address the issue that feelings of stigma fluctuate over time: an observation which became apparent from the qualitative findings (Fernandez & Arcia, 2004).
Chapter 6: The Koi Pond

Malcolm is talking to himself, a low quiet discussion which I can’t quite hear or understand. I think he’s calmer today. I make a mental note: *On a scale of one to ten, he’s a five.* I’ll log this into my computer later. I’ll compare it to my other charts. *Perhaps things are turning around.* I seize the opportunity to start dinner early. I fry some onions. I feel good.

“I want to go outside!” Malcolm informs me. I draw a large breath. Yes, perhaps we can go out. *Today he won’t run away.* I turn down the heat and we walk outdoors.

Malcolm bounces his ball. *He is being well-behaved! Perhaps I can nip inside, just for a moment to stir the onions.* I tell Malcolm not to move. He looks preoccupied with something but nods his head in agreement. With Mrs. Mackie’s warning of Malcolm being a “flight risk”, I walk to the edge of our driveway, tracing the perimeter with my footsteps, telling Malcolm he is not to cross this area. He nods again. *I’ll just run in for a moment.*

Inside, I stir the onions and turn up the heat. I chop peppers and tomatoes and add them to the pot. *He’s still there. He’s fine.* I stir some more before turning the heat down again and running back outside. I’m immediately angry at myself. *What was I thinking?!* Of course, Malcolm is gone.

I walk to the park, only two houses away. He isn’t there. I walk a little further to his school. Still no sign of him. Twenty minutes have passed and I’m feeling nervous. I run home. *Perhaps I missed him. Perhaps he is there.* I run through each room, calling his name. Silence. A sick feeling comes over me. *I have lost my son.*

Within moments, the front door swings open. Malcolm steps through the threshold, a grin on his face. The smell of gasoline burns my nose.

Piecing together Malcolm’s movements between being lost and being found was not an easy task. Malcolm has an ongoing struggle with communication as he almost always describes
life from his own singular perspective, often unable to see the “big picture”. His tunnel vision hinders his social interactions and ability to turn take during conversations. In addition to this, Malcolm’s speech had changed during the onset of his illness. It was erratic, pressured, and he spoke non-stop. It felt nearly impossible to understand, with many of his stories sounding unbelievable, a mixture of fact and fiction, and despite his assertion they were true, I often lectured him on what I perceived was blatant fibbing.

Following the breadcrumb trail of his words this day sent me out on a fact-finding mission to several of my neighbours’ homes. In the end, I solved the mystery as close to the truth as I could determine. Within those missing twenty minutes, Malcolm had walked into a neighbour’s garage, found a jerrycan of gasoline, trailed the liquid from one driveway to another, entered another neighbour’s backyard, and proceeded to dump the remaining gasoline into their outdoor pond, effectively killing all living things within it. Ten bright, mature Koi once swimming happily, now dead at the hands of my child. In addition, while I was frantically searching the park, I had missed Malcolm going door to door, asking anyone who would answer, for matches and a hatchet. One neighbour speaking on behalf of the others, politely informed me they felt Malcolm needed “more supervision” as what I currently provided was simply “not enough”.

The Failed Parent Ideal

This is a painful story for me. For a long time, I tried to convince myself that Malcolm must have thought he was playing, or perhaps it was somehow an accident. I tried my best to disassociate from the feeling I had deep down—the belief that it was all my fault. I should not have left him for those few minutes. I cannot trust myself to make good choices. I lost him. I failed as a parent. I could not have conceived at this time that Malcolm had been suffering from
the onset of a serious mental illness and was experiencing mania and psychosis. Many more months would pass before I finally sought help from the medical system, for this was a time in my life where a shift of mindset had begun; one where feeling responsible for my son’s behaviours was beginning to solidify and I was becoming a “bad” and “failed” parent. This failed parent ideal spilled over into my interactions with Malcolm’s school. Often, I sat in meetings, brainstorming with Mrs. Mackie a list of what I must have done wrong that morning or the night before to cause Malcolm’s behaviour, or what I should be doing to improve it.

The study by Eaton et al. (2016) investigates a parent’s lived experiences of self-stigma using a descriptive qualitative approach in an attempt to understand the causes and consequences of self-stigma among caregivers of children with mental illness. In order to answer the authors’ research question of how parents of children with mental health disorders experience self-stigma, a participatory action research group (PARG) was created to assist in the development of sensitive and respectful interview questions for the parent participants of the study. 12 Australian biological parents of children diagnosed with an emotional and/or behavioural disorder participated in 12 semi-structured individual interviews, directed by the set of interview questions the PARG assisted in creating. Probing questions were used to explore responses and participants were encouraged to provide examples to highlight their experiences. Giorgi’s (2009) descriptive qualitative method of exploring lived experiences was used for data analysis, resulting in a rich, descriptive account of parent self-stigma, rather than a theoretical account (Eaton et al., 2016). Key findings show mothers experience stigma from three domains: bad-parent / parent blaming stigma, courtesy stigma, and vicarious stigma (Eaton et al., 2016). While mothers’ self-stigma is characterized by a view of self as a failed parent, Eaton et al. (2016) also found self-stigma can be minimized by mothers who are able to refute the stigma through
evidence seeking. Limitations include a small sample size and no fathers. Also, participants required their children to have a diagnosis which potentially excludes parent experiences where self-stigma may be impeding the ability to seek treatment.
Chapter 7: Reaching Out

I sit in the doctor’s office alone. With a pale face and dark circles under my eyes, it’s evident that I’ve had little sleep, but I couldn’t avoid this appointment any longer. The many months of Malcolm’s erratic behaviour, sleepless nights, and school complaints have worn me down. After trying increased doses of ADHD meds, I’m finally resigned to the fact that something else is wrong, and I need help.

“He must be immune to them now. His meds don’t seem to work anymore,” I tell Dr. Olan, “And I know he has Autism, but he’s never been like this. It’s getting worse.” The doctor listens as I describe life in my home. It spills out in a continuous tangle of words and I barely pause for a breath. “He has rages lasting three hours—sometimes he suddenly switches to hysterical laughter—and he won’t walk down the hallways of our home—I don’t know why—I found him wedged between the toilet and the wall hiding—he looked genuinely scared—he ran out of the school mid-day without a coat or shoes and just spun around in circles and laughed in the snow—he’s jumping off furniture—running in front of traffic—laughing, screaming, crying—I don’t recognize him at all—did I mention how he talks nonstop—he went three days without sleep and he’s still hyper—Malcolm doesn’t even look the same anymore—I can’t explain it—his eyes dart around and he just looks different…”

Dr. Olan listens intently. He doesn’t interrupt until I finally take a moment to swallow. I feel a hard lump in my throat and realize I’ve been choking back tears.

“First of all,” he says, “I believe you.”

I feel some relief. He believes me. Although, I’m not completely sure. Perhaps I sound irrational, unhinged, or worse—like an incompetent mother. Maybe the problem is me. We continue talking about home and school and then Dr. Olan begins a line of questioning, “Does he
start fires? Does he hurt animals?” And then, “Does he see or hear things that are not real?”

Instantly, I feel guilty about revealing so much. Dr. Olan has struck a nerve.

I hesitate. “No…” I say, “I don’t think so…” It’s an automatic response—my protective response—and a lie. I stop short of telling Dr. Olan everything. He may believe me now but once he hears the entire story, he might change his mind. I mean, I don’t even fully believe it myself. I shift the attention away from Malcolm and admit to Dr. Olan that none of the parenting strategies I’ve practiced in the past seem to work anymore. I pride myself on strategies—as a Learning Support Teacher, it’s my job—yet at home, all the patience and support I provide just doesn’t seem to be enough. Maybe I’m too permissive, or too strict, or simply, maybe I’m just not a good enough parent. Dr. Olan looks concerned. He wants to see Malcolm as soon as possible.

I’m scared of two things: admitting I’m a bad parent and living with Malcolm’s behaviours. The latter outweighs the former and so the morning after seeing Dr. Olan, I sit down and write a long email to him, revealing details I carefully omitted during our appointment:

*I think maybe Malcolm does see or hear things, or maybe he just has a really vivid imagination. I’m not sure, but he talks about men with shotguns pointing at him, and that they are trying to catch him. He insists they are real. He says they talk to him and say bad things. He says he sees them… He says he wants to stab people. I’m concerned I must have put these thoughts in his head somehow or I must have led him in some way to say that because of something I said. We don’t watch scary or violent shows at home, but he is very easily led. Or do you think he is making this up…?*

As soon as I send the email, I panic. What will Dr. Olan think? It seems outrageous to even suggest Malcolm is seeing and hearing things that aren’t real. *Maybe he’s just been playing all along. Maybe I have it all wrong. Maybe it’s just a phase.*
**Delayed Help-Seeking**

Before finally seeing Dr. Olan, I spent many months struggling to understand Malcolm’s behaviours, searching for an answer which would make sense to me. I continually attributed his over hyperactivity and decreased need for sleep to a growth spurt, while Mrs. Mackie described his school behaviours as negative reactions to math class. I did not want to face my own uncertainty and fear around his psychotic symptoms, and the onset of Malcolm’s extreme behaviours created a new burden for me as a caregiver. Between managing Malcolm at home and responding to school, making a doctor’s appointment became both a difficult and secondary task.

As I reflect upon the time between the onset of Malcolm’s first psychotic symptoms and my attempts at seeking help, I’m drawn to the research by Czuchta and McCay (2001). This study aims to understand twenty parents’ experience of help-seeking in response to their child’s first episode of schizophrenia or schizoaffective disorder, using both qualitative and quantitative methods to validate findings related to stigma, parental care burden, and uncertainty in illness and help-seeking (Czuchta & McCay, 2001). Participants included a well-educated group of Canadian parents with a mean of 14.5 years of education; the majority female; and a mean age of 49.7 years. Results of this study found that a mean of 4.89 months elapsed before parents sought help from non-health professionals, and a mean of 7.33 months elapsed before parents sought psychiatric help, including family doctors, psychologists, or psychiatrists (Czuchta & McCay, 2001). Parents held some stigmatized attitudes towards those with mental illness and as these attitudes increased, so did parental burden, while in addition, there was a significant correlation between the number of reported symptoms that caused distress and parental burden, with parental burden increasing as symptoms increased (Czuchta & McCay, 2001). Similar to my own experience, parents within this study frequently mistook their child’s behavioural changes for
developmental characteristics, and along with their feelings of uncertainty related to these changes, contributed to a delay in help seeking (Czuchta & McCay, 2001). A mother participant in the study by Czuchtra and McCay (2001) describes her feelings when her son was admitted to hospital and diagnosed; feelings which are relatable to my own:

I think I broke down and cried, but I tried to keep the tears in because they all wanted to know, so what happened? My daughter and (my husband were) home; and I find I just couldn’t talk. I said, “They kept him in”. I felt…I wanted to get help from him—for him, have…him kept there at the same time I wanted them to say, ‘you’re okay, go home’, you know, ‘you’re just depressed.’ So when the reality hit that hey, he’s really…sick, he needs to stay here, it really…it bothered me. It really bothered me. And it got worse when I found out he was psychotic. The doctors were saying he was hearing voices and getting messages from the TV and the radio. I thought, no! (p. 167).

I can also trace my own delay in seeking help to the emotional response I had when suspecting Malcolm may indeed be hearing voices. I spent a prolonged period of time attempting to find evidence which would contradict my suspicions, and the thought of admitting Malcolm heard voices or saw people who weren’t there, was a devastating situation to face. Even after giving Dr. Olan this information, I continued to suggest to him that there must be another reason for Malcolm to be acting this way, as I believed a psychotic episode could not possibly be true.

A New Diagnosis

“My head isn’t going crazy anymore,” Malcolm says to me as I tuck the bed covers under his chin. I smile, feeling a sense of relief. He’s been calmer lately, more like his old self. It’s been four weeks since Dr. Olan saw Malcolm and prescribed Olanzapine, an anti-psychotic. Despite the glimpse of calm, I feel uncomfortable. What kind of parent puts their child on an
anti-psychotic? Yet, I can’t deny I see a positive change. Malcolm’s speech has slowed to a regular pace, his eyes are focused again, and he seems more “present”. He is also sleeping, walking down the hallways of our home again, and hasn’t mentioned the “screaming and swearing” in his head, or the men with shotguns. Perhaps this is it. Perhaps he will be okay.

Malcolm’s improvement becomes short-lived. He spirals time and time again into a hyperactive, unpredictable, sleepless child, to one with intense, chronic irritability. He becomes unable to function at school, spending most days in a learning support room. He hits, swears, and spits if more than two people come near him. We visit Dr. Olan monthly. He suspects bi-polar and describes mania and psychosis—describes my child. He prescribes additional antipsychotics at higher doses. Eventually, we begin to see a predictable pattern of Malcolm’s symptoms; an intense irritability, then spiraling hyperactivity, with Malcolm seemingly becoming immune to latest new dosage.

A year later, when Malcolm is ten and finally receives an official diagnosis of bi-polar I with psychosis, I am numb, void of much feeling. There is no time for grief; no time to reflect upon anything. I continue to run through an excruciating parenting marathon both day and night, through medication changes and dose increases which do little to contain his mania and psychosis for longer than a few weeks at a time.

Prevalence of Childhood Mental Health Disorders

The growing number of children and adolescents requiring pharmacological and psychotherapeutic treatments, educational interventions, and other special services has prompted an interest in childhood mental health over recent decades (Merikangas, 2018; Merikangas et al., 2010; Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). Merikangas et al. (2010) provided the first prevalence data on a broad range of mental disorders in a nationally representative sample.
of U.S. adolescents in 2010, concluding that “approximately one in every four to five youth in the U.S. meets criteria for a mental disorder with severe impairment across their lifetime” (p. 980). Since then, the literature on the prevalence of mental disorders affecting children has increased around the world (Polanczyk et al., 2015).

A systematic review of the literature on the prevalence of childhood mental health disorders by Polanczyk et al. (2015) identified 23,191 abstracts, of which 198, along with an additional 82 subsequently identified, were selected for full-text review. From 1985 to 2012, 41 studies from 27 countries from every world-wide region were included in the authors’ literature review. Meta-analysis indicated a prevalence of any mental disorder of 13.4%, indicating that mental disorders in children and adolescents are frequent across 27 countries in all continents, with approximately 241 million youths around the world affected by a mental disorder (Polanczyk et al., 2015). While these studies represented anxiety disorders, depressive disorders, ADHD, oppositional defiant disorder, conduct disorder, and any disruptive disorders, most did not represent what was considered less frequent disorders, including eating disorders, obsessive-compulsive disorder, psychotic disorders, and autism spectrum disorders (Polanczyk et al., 2015).

In contrast to the approximate 241 million youth identified from its own literature review, Polanczyk et al. (2015) stated findings from the 2014 US Census Bureau, which estimated a population of approximately 1.8 billion between the ages of 5 to 19 around the world were affected by mental disorder. The authors’ exclusion of what was considered less frequent disorders in the literature review may have contributed to the contrast in estimations. Today, the World Health Organization (WHO) estimates 10-20% of the world’s children and adolescents experience mental disorders (WHO, 2019). Despite inconsistencies between these reviews,
research contends that neuropsychiatric disorders are among the leading causes of worldwide
disability in young people, creating severe impairment across their lifetime (Eaton et al., 2019;
Merikangas et al., 2010; Polanczyk et al., 2015; WHO, 2019).
Chapter 8: An Awkward Question

I sit at the table, tense and rigid. It’s a familiar place for me: the 3:30 school meeting. Mrs. Mackie stares at me.

“We need to discuss Malcolm’s behaviour,” she says. “He slammed the door on my foot and trashed my classroom. Honestly, the other students are frightened of him.”

“He has bi-polar disorder,” I say in defense. Initially numb to it, I’m now trying to adopt Malcolm’s diagnosis as my new armour. I have not told my mother, my siblings, or my co-workers, but have provided the school with a letter from Dr. Olan. Finally, a reason for the atrocious behaviour that has plagued my home and the school: A medical excuse, diagnosed by a psychiatrist. I’m beginning to believe it’s not my fault and it’s not my parenting. Malcolm can’t control his behaviour. I continue, “He hasn’t been sleeping. He’s up through the night. He’s manic.” There is a pause.

Mrs. Mackie rolls her eyes and coyly, from the pursed side of her mouth, she speaks,

“I think he’s just trying to get out of math.” I stare, quickly taken aback. My shield is broken. I open my mouth to speak, but nothing comes out. My moment is lost, although I’m confused if I even had a moment in the first place.

Mrs. Mackie fills the quiet space, her voice swift and loud, “But the issue we need to discuss today is Malcolm’s bathroom behaviour. He’s urinating and defecating on the floors. He can’t be trusted anywhere in the school now, and I really must ask you something…” There is an uncomfortable pause and she shifts in her seat, glancing to one side as if asking for validation, “and this may be uncomfortable, but I’ve been discussing it with others and…well, it’s awkward to ask but…has Malcolm been sexually abused?”
I sputter out a few words before my emotion hits, “No…well, no…not that I know of… I mean, I suppose it’s a possibility before he came to us, but there’s been no signs in his past, and he’s always with me, virtually all the time…and this behaviour is completely new…I mean…is that the reason..?” My voice trails off and I feel a rush of embarrassment and panic.

Did I let something happen to him? Did someone abuse him? When did I let him out of my sight? Was it that time I lost him? Does the school think something happened? Do they suspect my husband? Is this the real reason he’s been acting like this? Maybe the psychiatrist has it wrong. Am I responsible for all of this??

The rest of the meeting is blurry. It seems to quickly end, the awkwardness of the question lingering as Mrs. Mackie and I walk down the hallway of the school. Maybe I am responsible, and the diagnosis is wrong. A failed parent who can’t keep her child safe. Is that what they believe? I place my hand on the door, ready to push it open, and pause.

“Have you ever had a student like Malcolm before?” I ask. Mrs. Mackie takes a deep breath and hesitates.

“No…” she says.

I nod and feel some sympathy for this teacher and administrator who struggles to maintain order during her workday. Perhaps she also feels incompetent, a failed teacher, a failed principal, incapable of controlling a child wreaking havoc within her building. Perhaps the thought of teaching a student with bipolar disorder is a monumental task, and one she wishes she could avoid. This is all speculation. I don’t know how Mrs. Mackie feels, but imagining we may share a sense of being overwhelmed and a desire to deny the diagnosis, gives me some solace.

She continues, “Parents are unhappy. I have to answer to them. I have to keep their children safe. They have concerns when they see Malcolm with their children.”
I’m curious. “What do you tell them?”

“I tell them we are aware of the situation and are doing our best to try and work with the family of this student.”

Mrs. Mackie’s words confirm a low-lying belief of mine: we must be that family. That family which requires intervention from the school. That family who is at fault. Uncooperative, incompetent, and blameworthy. I’m desperate to shift the attention to someone other than myself.

“Please,” I say, “just tell them this is a student who has special needs.”

Depleted of all my energy that evening, the unrelenting cycle finally breaks me. I have failed. Love, determination, those essential ingredients, are simply not enough. A perfect match? How could we have been so wrong? Any flicker of optimism has been snuffed out. I can’t even defend Malcolm so what hope do I have as a parent? The reality is stark: I have a child with a serious mental illness and I’m failing. Angry and sobbing, I write an email to our adoption worker:

“We can’t continue. We need to talk about giving him back. Please contact me immediately...”

Blame

In my years with Malcolm, no one has outwardly blamed me for his behaviour; rather, I perceived blame through comments and questions, side glances, eye rolls, and stares. I’ve replayed this school meeting many times in an attempt to imagine another outcome; one in which I defend Malcolm and take Mrs. Mackie to task for asking what I considered to be an inappropriate question, but the reality of this moment was, I said nothing. Like many times before, I was silent. It was not for lack of desire, but for lack of ability. In reflection, this question may have been the school’s genuine attempt at finding an answer for Malcolm’s severe
behaviour; the thought of an abused child perhaps more familiar or comfortable an explanation
than a child with psychosis and mania. I internalized it however, as disregard for the medical
information presented, and a questioning of my ability to keep my child safe from harm, both
which compounded a sense of self-blame, self-shame, and bad parent beliefs.

In 2018, Eaton, Ohan, Stritzke, and Corrigan aimed to develop a new measure of self-
stigma for use with parents of children with a mental health disorder (Eaton et al., 2019). In order
to overcome the lack of existing comprehensive measures, the authors developed the parent self-
stigma scale (PSSS) using items derived from the Eaton et al., (2016) study which represented
the various forms of self-stigma as evidenced in qualitative work. The PSSS accounts for the
multi-dimensional facets underlying parental self-stigma and closely reflects parents’ lived
experiences of self-stigma. As in the authors’ previous study, a PARG comprised of mothers of a
child with a mental health disorder was used to shape items to best represent the ways parents
experience the key forms of self-stigma, and utilized the exact language and terminology used by
parents, resulting in a meaningful and respectful scale (Eaton et al., 2019). 424 Australian
parents of a child aged 4-12 years diagnosed with a mental disorder participated in the online
survey of the PSSS. Factor analyses indicated the dominant self-stigmas held by parents include
self-blame, self-shame, and bad-parent self-beliefs (Eaton et al., 2019). The authors found these
were negatively correlated with self-esteem and empowerment. This correlation rings true for my
own experience, as shades of shame still exist within me today, and although angry about Mrs.
Mackie’s query of sexual abuse, I still have yet to feel empowered enough to express these
feelings to her.
Chapter 9: Sharing Malcolm

The lowest point of my journey also represents the beginning of hope. Deciding we can’t parent Malcolm any longer has sparked a series of phone calls and meetings between our adoption worker and Malcolm’s Child and Youth Special Needs Worker (CYSN) at the Ministry of Child and Family Development (MCFD). We are officially a family in crisis. I am hopeless, frantic, and irrational, pouring myself into extra work and volunteer jobs in an attempt to distract and avoid the grief and resentment I continually feel. Malcom’s new diagnosis has seemingly done little to change our life. We continue to struggle with finding medication that works, and it feels as though Mrs. Mackie’s proclamation of violence is coming true. Unable to appropriately express his obvious turmoil, Malcolm resorts to biting and hitting me. In addition, his overall functioning has slid backwards. Brushing his teeth, dressing, and washing his hands after using the bathroom—once simple skills for Malcolm—are now difficult for him under the burden of his illness. I am filled with regret and fear, locking myself and daughter into my bedroom at night, convinced Malcolm’s new verbal threats of stabbing me will one day come true. Bright Koi. Dead Mother.

The Holiday

“I feel good about this one,” Dr. Olan says, “It will work.” He scribbles a new prescription on his paper and hands it to me. Lithium.

I can’t imagine how Dr. Olan is so sure of himself. I have given up believing anything will help, but as usual, I fill the prescription and once home, carefully place it beside the other mood stabilizers, anti-psychotics, and ADHD medications which line the medicine cabinet. I close the door and turn the tiny key, locking the pills safely inside. Malcolm races past the bathroom, slapping his hands furiously against the walls.
“Walking feet in the house,” I mumble in a lifeless voice. I drag myself to a chair and slump down, exhausted and defeated. A headache is developing, throbbing over my temple and making me nauseated. Malcolm races around me, climbs to the top of the couch and launches himself off like Superman, again, slamming his hands against the wall. I close my eyes.

_I can’t do it. I can’t stay here with him. I won’t survive the night._

I call the babysitter; my last remaining one.

“Will you consider staying until tomorrow morning?” I ask. Silence. “Please,” I say, “I just need to get some sleep.” She won’t come for less than $350. I agree.

I pack myself and daughter into the car and we drive an hour outside of town. “Just a mini holiday,” I tell her. She is bouncy and cheerful, excited for this unfamiliar mother and daughter time.

“Where are we going? Will the hotel have a pool?” my daughter wiggles her fingers and fiddles with the radio. I nod in agreement and press a smile onto my face. My headache is making my eyes water. It hurts to speak, and I don’t actually have a plan. Eventually, I see a cheap motel and pull in. There is a pool, but it’s outdoors—and cold. My daughter walks to the water’s edge, dips her finger in, and frowns.

“Can’t we go somewhere nicer?” she asks disapprovingly. I shake my head no. If we get back into the car, I don’t trust myself to stop again. I check us in, collapse onto the bed, and fall into a deep sleep.

“Not that much fun,” my daughter says, scowling at me on the drive home. She’s right. I was poor company, and with the cost of gas, hotel, food, and sitter together, I wonder if the money could have been better spent. The night away, however, gives me the first taste of overnight respite and the temporary relief from the persistent stress which envelopes me. So,
when it is finally proposed by MCFD that we access a respite home, staffed with professionals who are trained to handle Malcolm’s behaviours, I cry with relief. Yes. Finally. Maybe if I can get more rest, I can keep him. I won’t have to give him up.

**The House**

“It will be like a sleepover,” I say gingerly to Malcolm, “You will stay for two nights and then come back home. It will be fun for you.” I nervously bite my nail.

_Does he think I’m giving him away? Does he think this is a punishment?_

To my dismay, Malcolm claps his hands and a wide grin stretches across his face. He runs to the stereo, pushes play and turns up the volume to a deafening level.

“Dance party!” he screams. I take it as a yes.

A new sense of guilt sweeps over me. Malcolm swings between excitement and anger on Sundays before leaving for the house. His manic behaviour is difficult for the staff, as is his irritability. Hearing him sob over the phone and asking to come home leaves me insecure and uneasy. I’m obsessed with reading the staff notes. If he’s difficult, I’m ashamed of his behaviour. If he’s happy and more regulated, I feel it’s a mistake sending him. I struggle with these emotions, continually trying to convince myself this is the best thing for all of us, but the guilt seeps in, especially on the days I feel the most relief and happiness. _Am I happy because Malcolm isn’t home with me? Do I still love him?_

There is no way to hide Malcolm’s “second home” from Mrs. Mackie. The respite house staff become a large presence in Malcolm’s life, taking him to and from school, packing lunches, and signing his agenda. It compounds my feeling of being _that family_; one who can’t look after their own son. I’m particularly sensitive at this time, and so when Mrs. Mackie stops me in the hallway to inform me that “Malcolm had a terrible day at school because he missed home so
much,” my heart sinks even further. I can’t win. Helping myself means sacrificing Malcolm. Despite the diagnosis, his behaviours still remain my fault, because for three days and two nights per week, I abandon my child.

**Care Burden**

Serious Mental Illness (SMI) was considered “chronic and deteriorating” for much of the 20th century, requiring institutional tertiary care or high-intensity secondary care (Whitley et al., 2015, p. 951); however, a shift occurred in the 1960s with deinstitutionalization and the advent of antipsychotic drugs, giving new hope for patients with SMI (Whitley et al., 2015). With these historical changes, responsibility for patients was largely given back to families, exerting a significant impact on them (Ohayon, Goldzweig, Lavi-Rotenberg, Roe, & Pijnenborg, 2019).

Caring for children with special health care needs can require parents to perform tasks that are the usual purview of health care professionals (Caicedo, 2014). Aside from Malcolm’s later hospitalization, all medication trials occurred within our home. I tracked efficacy of the drugs and their doses, monitoring side effects. It took a very long time to find a combination of medications which worked together to keep Malcolm’s symptoms at bay, and even now, Malcolm continues on a regular routine of bloodwork. His water intake is strictly monitored at home and school to ensure he is adequately hydrated so he doesn’t become Lithium toxic.

The addition of Lithium to Malcolm’s drug regime became a turning point for him, our family, and the school. We had finally found a medication which Malcolm responded well to. It wasn’t perfect at this stage. Malcolm still had “break-through” episodes, but these were dramatically shorter and less severe. The change was impressive enough for me to feel like Dr. Olan had just performed a life-saving miracle on Malcolm and I even described it to him as such while thanking him profusely. Between Malcolm’s more controlled symptoms and the respite
house, a new sense of freedom was beginning to emerge. Our house became calmer and happier, and I had fewer phone calls from Mrs. Mackie.
Chapter 10: Keeping Secrets

Standing in the staff lunchroom, I’m visibly awkward.

“It’s my son. We need to go to Children’s Hospital. We’ll be gone about a month,” I barely get the words out, “He’s going to the psychiatric unit. It’s called P1.”

There is an uncomfortable pause, some sympathetic looks, and an air of confusion from my co-workers. Until now, I have kept my home life completely secret from my work life. I may have continued to plug along in this manner if it hadn’t been for the district email sent out to all teachers, advertising for a temporary four-week teaching position at my school—my position. I’m embarrassed my co-workers learn of my son’s upcoming hospitalization this way instead of me personally sharing the information, but my ability to mask and pretend is deeply ingrained in me. In fact, I can keep a smile on my face for hours if I stay busy enough. I realized very early on that by using this avoidance strategy, my day would slip by, and the pain and stress of parenting Malcolm would be controlled, contained, just like the tracking sheets and mood charts of a year earlier.

Today, my therapist describes this as my “high functioning anxiety.” It manifests in my ability to stay extremely busy, with hyper-focus and over-control used in an attempt to avoid the discomfort of “sitting with my thoughts.” This was my coping mechanism, my drug of choice. In reflection, this strategy worked well but had other side effects. Aside from the added stress of overcommitting myself, it gave others an unrealistic sense of my own strength. No one suspected I was suffering. Outwardly, they saw a very capable, and very busy person. Despite extreme exhaustion, I was not someone who couldn’t get up off the couch—rather the opposite—I was addicted to distracting myself with anything and everything, desperate to mask my vulnerability. Even today, my desire to quench uncomfortable thoughts has easily propelled me into repainting
all the interior doors in my home after the children were asleep. I’m often labelled by friends, family members, and co-workers as being high-achieving, well-organized, outgoing, and a workaholic. Yet, underneath this exterior, I feel out-of-control, anxious, secretive, and avoidant.

P1

We walk into P1. It is bright and welcoming, but there are signs this is psychiatric care. The doors lock automatically, the nurses’ station is contained behind solid sheets of glass and wall, the furniture is smooth and rounded, and the television sits behind a giant plexiglass shield.

Malcolm’s collar is stuffed in his mouth and a wide wet bib of saliva soaks the front of his shirt. His favourite toy animal, a pink hippo, pokes out from under his arm, its body squeezed tight against Malcolm’s side. The eight-hour drive to the hospital went smoothly. In fact, it was almost pleasant. Lithium is working. He continues to look more like his old self, and his mood has vastly improved. But the break-through episodes continue and so we find ourselves here, at the recommendation of Dr. Olan, to see what more we can try.

Two weeks into our stay, I find myself sitting around a large table with other parents from P1, practicing a guided session of “mindfulness”. We have been tasked with illustrating our “calm space:” a place where we find relaxation. I fiddle with my sketch of a teacup on a table. A café is the best I can come up with. In reality, I have no calm space—the act of sitting quietly and taking deep breaths makes my heart pound faster. Mindfulness is excruciating for me.

A knock at the door interrupts the scratching sound of pencils against papers. My stomach lurches. Instinctively, I know it must be for me. Two weeks ago, the doctors began changing Malcolm’s medications. A few days ago, it was clear to me—Malcolm was sliding into mania.
The door opens a crack and a nurse peeks into the room, making eye contact directly with me. Flushed, I slink out of my chair and squeeze myself through the door into the hallway. What has he done?

There is a pause from the nurse and then an audible inhale. “Well, he ate the butter.”

I blink. What? He ate the butter?

She continues, “He’s extremely elevated. He got into the fridge. We tried to stop him, we did have staff on him, but I’m afraid he devoured the block.”

I’m not sure how to respond. He ate the butter? It must be a joke. The nurse looks concerned at my widening grin. No bread? Just a block of butter? My son, fish killer and now butter eater. I laugh and choke back tears at the same time as a blanket of shame suffocates me.

**Regression.** Malcolm attended school on the unit for the first week and a half, until his mood began to change. Sitting with the P1 teacher, she pulls out a stack of papers.

“I want to discuss my assessments,” she says. “This report is from Malcolm’s school. Mrs. Mackie has him placed at a grade three level for Math. It says he can do multiplication.”

I’m curious and quiet and unsure of what’s coming. With all Malcolm’s behaviours, academics were the least of my concerns. I know Malcolm has not been in class for much of the year. Even his time in the learning support room has been exhausted, and now Malcolm has his own personal space at school—a small converted office, for just him. Academics were pushed to the side while we all focused on how he could simply be in the school building.

“But actually, he’s unable to do addition,” she continues, “and only subtraction if he has manipulatives.” I don’t doubt this. Malcolm seems to not be able to do any academics anymore. In fact, I’ve noticed him struggling with some of the skills I was sure he once had. Reading has completely stopped for instance. I chalked all of this up to Malcolm’s mania—he couldn’t
possibly concentrate on anything more than trying to regulate his emotions. The break from academic work didn’t bother me—he would eventually catch up again—after all, he had an average IQ. We had the assessments to prove it.

A new psychoeducational assessment from the hospital confirms Malcolm’s true ability. A devastating blow, I listen to the psychologist’s words: Intellectual disability. Between the age of a 5 and 6-year old.

“How is this possible?” I ask. The psychologist shakes her head and shares other evidence—old OT assessments compared to the latest ones from the hospital. Two years ago, Malcolm could copy shapes—circles, squares, diamonds, and cross midline—but no longer able to navigate points and transfer them to paper, his diamond shape now looks like a star. In all areas, from intellectual to adaptive functioning, Malcolm has regressed.

I am full of grief. Through the turmoil of our lives, I have clung to a small piece of hope: That underneath it all, there was an intelligent child, an independent child, who would fulfill my dream of a rewarding and happy life: school graduation, employment, and marriage. What will his future hold now?

Cleaning Up. By week four, Malcolm is in full blown mania and psychosis. He spends each night at the hospital under their care while I retire to Ronald MacDonald house, allowing me a full night’s rest before seeing Malcolm. I’m on edge. The fluttering in my stomach has returned and without my home distractions I find it difficult to keep my unsettled feelings in check. Malcolm has stopped sleeping, his hyperactivity is extreme, and he seems unaware I’m even on the unit with him during the day.

Malcolm bounces from table-top to table-top as I putter around, tucking in chairs and straightening the tables after him. If I stay busy, I won’t cry.
“Start your day off with a break,” the nurse says sympathetically. “Come back in a little while.”

“No,” I say, “I’m fine, really.” A tear slips down my cheek and I quickly wipe it away. I clench my teeth and my eyes sting.

“I have to go pee!” Malcolm squeals. He runs to the bathroom and shuts the door. I quickly follow him and stand outside waiting for him to finish. I hear him chattering through the door. I wait some more. He doesn’t come out. I listen and knock. No answer. Nervously I look around. The nurses are in their station, talking amongst themselves and shuffling paperwork. I open the door to the bathroom, and slowly peek in. Panic. A hot rush runs through my body, from my feet to the top of my head. *The last moments on Earth.*

I quickly step into the bathroom and shut the door behind me, the toe of my boot landing at the edge of the large puddle of urine covering most of the floor. Malcolm’s socks are soaked, as are the bottom cuffs of his pants. He’s standing in the wet, unaware, making faces at himself in the mirror. I frantically tear paper towel from the dispenser and throw it down around his feet. I bunch more into my hands and press it against the floor. Urinating. Defecating. The awkward question: Has he been sexually abused? Embarrassment. Shame. The urine soaks through the cheap paper quickly and my hands become wet. I work faster. More paper, more soaking. Sopping bunches of towel soon fill the garbage can. I push them down with my feet to disguise the amount. Yes, the crumpled bunch looks smaller now, like someone used the bathroom only once or twice. On my hands and knees, I begin drying the floor. Malcolm hasn’t noticed me. He’s still making faces, oblivious to the frantic cleaning happening around him. *I’ll keep it a secret. It’s too embarrassing to tell, even to the nurses.* I peel Malcolm’s wet socks from his feet and stuff them into my purse. I flush the toilet in an attempt to convince anyone who may be
listening that we are simply using the bathroom as normal. I scrub my hands and his, and open the door. Malcolm’s room is close by. I shuffle him quickly through, hoping no one notices the wet cuffs of his pants. “Let’s change,” I say as we walk by, “This outfit looks a bit dirty.” I strip the pants off him, roll them up and place them in his duffle bag. *I’ll wash them tonight. No one will know.*

**Shame**

I often attempted to conceal Malcolm’s diagnosis and behaviours in an effort to shield him from shame and humiliation, and by association, myself from shame and humiliation. I often wonder how that day would have gone differently if I had simply asked for help when Malcolm urinated on the bathroom floor. Repeatedly feeling inadequate about my parenting skills, along with my feelings of embarrassment, led me to cover up what (more than likely) would have led to an outpouring of support from the nursing staff.

Research conducted by Mak and Cheung (2008) explores the internalization of stigma among the caregivers of individuals with intellectual disabilities (CPID) and the caregivers of people with mental illness (CPMI). The authors sought to validate their 22 item Affiliate Stigma Scale by examining its factor structure, comparing between CPID and CPMI, thus developing a quantitative measure of “affiliate stigma”, described as self-stigma and the corresponding psychological response. Mak and Cheung (2008) hypothesize that across CPID and CPMI, affiliate stigma is positively related to caregiving stress and subjective burden, and negatively related to positive perception of caregiving. 210 CPID and 108 CPMI participants were recruited to validate the Affiliate Stigma Scale which comprises of Likert rating scales and structured questionnaires, while caregiving stress was measured by the Chronic Stressors Scales, and subjective burden measured by the Caregiver Burden Inventory (Mak & Cheung, 2008). Results
of the study conclude the newly developed Affiliate Stigma Scale provides a quantitative measure with which affiliate stigma can be compared across different conditions, and unlike previously existing scales, this scale taps into the affective, cognitive and behavioural aspects of stigma (Mak & Cheung, 2008). Results also show affiliate stigma is positively associated with caregiving stress and subjective burden, and negatively related to positive perceptions (Mak & Cheung, 2008). The authors state “caregivers with high levels of affiliate stigma are likely to have a sense of shame and inferiority as a result of their association with the affected individuals”, and “to avoid prejudice and discrimination, they may withdraw from social circles and conceal their status from others” (p. 542). These findings are relatable to my own experience as I attempted to conceal what I perceived as shameful moments (including Malcolm’s diagnosis), in an attempt to avoid potential judgment from friends, co-workers, and even hospital staff. At my greatest times of stress, I felt the highest level of shame and self-criticism, often choosing to withdraw and forego potential help and support.

Malcolm continued in mania and psychosis for another week at the hospital. His discharge date was pushed in order for the doctors to stabilize him. In the end, after five and a half weeks in Children’s Hospital, it was concluded that Lithium was the cornerstone medication for Malcolm, and he left on nearly the exact same drug regime as he began.
Chapter 11: Returning Home

Before we leave the hospital, a meeting is set between the psychiatry team and Malcolm’s school and community members. “Roughly an hour long, perhaps more,” I’m told, “to go over our findings and recommendations for when Malcolm is back home in his school and community.” The table is large and looking around the room I fully realize how many professionals have been a part of Malcolm’s care while we’ve been here. Calling in over speaker is Mrs. Mackie, MCFD, our respite care team, and Dr. Olan. This moment is the culmination of five and a half weeks of our lives. We take turns introducing ourselves.

“Mrs. Mackie, representing Malcolm’s school team…I must just inform you that I will need to excuse myself early,” she says. “I only have twenty minutes.”

Early? I’m confused and insulted. We have been away from family and friends for weeks, Malcolm has undergone tests and assessments and medication trials, all to get to this point, to hear first-hand from the doctors, and Mrs. Mackie has twenty minutes to spare.

Malcolm’s diagnosis has changed. Autism is again confirmed, as is ADHD. His bi-polar diagnosis now reads as mood disorder and psychotic disorder. He has an additional diagnosis of intellectual disability. The change from bi-polar to mood and psychotic disorder is no less serious, they stress—it very well may be bi-polar. But the regression is concerning and can be indicative of childhood onset schizophrenia. We should eventually have this ruled out. The treatment regime is the same for all: a mixture of mood stabilizers and anti-psychotics. Regular and continued respite is recommended and considered essential to ensure a family breakdown does not occur. Transitioning from hospital to community and school will be difficult they warn. There is a long list of school recommendations. The meeting lasts over an hour. Mrs. Mackie has heard twenty minutes, ten of which were taken up by introductions.
Support and Validation

Returning home after Malcolm’s hospitalization meant facing my challenge of once again, parenting Malcolm and learning to advocate for him. It was not an easy task, and I am still challenged by it today, but support has come from many areas.

Medication is an essential component of Malcolm’s treatment plan. Both Lithium and Olanzapine are still part of the five medications he takes daily to keep him stabilized. These are currently working, and while the onset of puberty may disrupt this, we are currently enjoying a long stretch of Malcolm as a healthy child.

Children’s hospital provided a thick and full document outlining not only Malcolm’s diagnoses, but the supports that are needed for him both at home, in the community, and at school. This information has become invaluable for the school, giving them knowledge on how to best support Malcolm in an educational setting, with practical strategies for school staff to utilize. Malcolm is no longer sent home from school, and his education combines both academics and life skills programming within the classroom, resource room, and community settings. Our family also continues to engage in respite services, allowing me time to recharge and be the best parent possible to Malcolm when we are together.

In addition to these concrete supports are the emotional and social supports that have been developed. Between Malcolm’s CYSN worker from MCFD, hospital staff, and Dr. Olan, the school has been educated on mental health and the needs of our family. Malcolm’s disruptive behaviours are now acknowledged by the school as part of his medical condition rather than seen as being purposeful, and there is an overall consideration for family impact before school plans are made. This has taken the form of even simple changes, such as the allotment of extra time for IEP meetings, reducing my feelings of school pressure and supporting my perception that I am
an integral part of Malcolm’s education team. I am also no longer called into the office after a behavioural episode, rather, regular communication through texting, emails, and pre-scheduled meetings has allowed for discussions that are not initiated and blanketed by crisis, reducing my feelings of shame. Within my personal arena, I engage in therapy services and am working on ways to cope with my anxiety and stress. The overall feeling of validation and support has increased my own self-esteem, and in turn, my ability to advocate for Malcolm’s education.

The study by Cantwell, Muldoon and Gallagher (2015) describes the relationship between self-esteem and social support, and stigma, as predictors of depressive symptomology in parents of children with Autism, Down Syndrome, and mixed disabilities. One hundred and fifteen parents of children with disabilities and fifty-eight control parents from the Republic of Ireland participated in the study which found that caring for a child with disabilities is more strongly associated with depressive symptomology than caring for a typically developing child, while parents’ perceived caregiver stigma, reduced self-esteem and social support were the psychosocial pathways driving their depressive symptomology (Cantwell et al., 2015). In addition, this study examined the mediating effect of self-esteem, with results that indicate perceived stigma and depressive symptomology is greater for parents who had low self-esteem and low emotional support (Cantwell et al., 2015). Cantwell, Muldoon and Gallagher (2015) state that for parents experiencing stigma with low to medium self-esteem, the benefits of emotional support are evident, whereas high self-esteem independent of emotional support appears to be sufficient to protect against depressive symptoms. This study, as with my own experience advocating for Malcolm within the educational system, highlights the value of self-esteem and emotional support.
Chapter 12: Seeing is Believing

“I’m a fuck-ner,” Mrs. Mackie says with a slight grin.

I let out a little giggle. “A what?” I ask.

Mrs. Mackie’s smile spreads across her face. “Malcolm was pretty angry with me today, and with absolute certainty, told me I was a fuck-ner.”

“He was so angry he inserted an extra letter into the name I think he meant to call you…” I chime in slyly.

Mrs. Mackie shrugs her shoulders. “Well who knows—maybe I really am a fuck-ner? I mean, Malcolm was so confident about it, he also yelled it down the hallway!”

We laugh. We joke about the possible definitions of the word “fuck-ner,” and debate whether it is a more potent or less offensive version of its root word. It has taken a long time for us to get to this point: to be able to discuss Malcom’s behaviour with a tone of humour, rather than blame. Mrs. Mackie does not describe Malcom’s verbal outburst as an assault against her or the school. Nor does she demand an apology or seem offended: rather, the opposite. It feels as though Malcolm has endeared himself to her.

I’m struck by this significant shift within the school. There is an obvious adjusted mindset, and this change in attitude is not one-sided. I too, now play an active role in allowing Mrs. Mackie to both feel, interpret, and describe Malcom’s behaviours in a new way. I have given us both permission to have a laugh. It is the result of less internalized shame and a more positive outlook. This simple and powerful gesture of allowing others and myself to see the humour in a situation has, effectively, lightened the mood. Mrs. Mackie and I have embarked on a new relationship together and seeing the changes in both myself and the school, I believe the future will be positive.
Chapter 13: Venturing Forward

Findings

While the field of mental health has long recognized the stigmatizing effect of mental health disorders, the stigma of parents of children with mental illness has historically been under-researched, resulting in a lack of literature that addresses a comprehensive understanding and description of how these parents experience self-stigma (Eaton et al., 2016; Fernandez & Arcia, 2004; Mak & Cheung, 2008). This autoethnography provided a first-hand experience on the internalization of stigma, reactions to perceived stigma, and its consequences, building upon past research within this area. Within the context of parental advocacy within the educational system, I explored the often-hidden effects of parental stress endured by families who care for children with serious mental illness in order to address my research question: As a parent of a child with severe mental illness, what meaning does my experience with parental shame and stigma have for myself as a parent and as an educator?

The findings from this research brought my personal and professional life together. Through recursive review and reflexivity, a number of themes emerged which aimed to provide an understanding and application to my role as a parent and as an educator: the teacher-parent relationship, caregiver stress, isolation, failed parent ideal, delayed help-seeking, blame, care burden, shame, and support and validation.

The Evolution of Relationships. The teacher-parent relationship defined many of the interactions I had with the school. Often, a perceived imbalance of power led me to believe Mrs. Mackie controlled the gavel of judgement, while I sat in the courtroom of the school office as a parent in deep trouble. Mrs. Mackie is a composite character within this autoethnography but in actual fact, she represents the five school personnel (teachers, administrators, and support staff) I
regularly met with at one time. Despite repeatedly experiencing the stress of walking into a room full of school staff poised to address Malcom’s transgressions, I was naïve of this dynamic from an educator’s position. I can recall holding IEP meetings with parents where I invited the school counsellor, speech-language pathologist, principal, and others, with the intent that their added contributions would enhance the meeting. I did not fully understand from my position of power, that a room of five school staff and one single parent is an intimidating structure and stress inducing for the parent. I am now more aware of this and take the time to focus on developing a positive relationship with the parents I meet by setting them up for success during our interactions. For instance, I no longer add in other school personnel to meetings unless absolutely necessary, and no longer hold meetings in our formal meeting room, instead, choosing places that feel more comfortable, such as the school library. I have even held an IEP meeting outside under a tree for a mother who found it emotionally difficult to enter the school building. I also suggest to all parents they bring an advocate with them to meetings, such as their child’s special needs worker or counsellor. Reducing the amount of potential school stress for families I work with has become a priority for me in my efforts to build and maintain positive relationships and equalize the power balance.

Understanding delayed help-seeking as a phase parents experience has also allowed me to develop a more empathetic relationship between teacher and parent. As this autoethnography revealed, my own delay in seeking help was not for lack of love of my child; rather, I was deeply confused over Malcolm’s behaviours as I tried to rationalize the changes I saw in him. From the outside, this may have been interpreted as denial or incompetence by those who acknowledged Malcolm’s behaviours before I did. As an educator, I have caught myself being annoyed by a parent’s “no show” when attempting to meet with them to go over the referral process or sign
documents in order to implement supports. Acknowledging delayed help-seeking, however, has allowed me to be more understanding when these moments occur, knowing that some parents need extra time to get to a place where they can seek help and accept supports.

**The Impact of Care.** Acknowledging and developing an understanding of stress levels and care burden emerged as other critical themes of this autoethnography. Within my learning support position, I have sat through numerous moments with families hearing their child’s diagnosis for the first time from the school psychologist. I am acutely aware of how this feels as a parent, and how experiencing grief of this type can impact parental functioning when layered upon a higher than average daily care burden. This autoethnographic research revealed my difficulty concentrating, participating, and collaborating fully with the school because of my lack of sleep and increased parental demands. Within my own teaching practice, I understand that parents experiencing extreme stress are disadvantaged when they enter a school meeting and may need additional supports in order for them to effectively be part of the team. As a teacher, I strive to level the playing field for parents with my understanding that they may be severely fatigued, grief stricken, or have reduced capacity because of their stress and care burden. I often allow extra time for these families in meetings and follow up the next day, allowing them the space to digest and respond to information without the barrier of a timed meeting. I now also remind myself that a parent who may present themselves at school as being short-tempered, emotional, disorganized, or chronically late, are often performing at super-hero standards in their home, parenting well above and beyond the norm in order to care for their child with special needs.

**The Negative Effects of Perception and Language.** A negative perception and use of language can have a detrimental effect on a parent’s concept of self. As a mother who
experienced feelings of parental failure, the action of sending Malcolm home from school was highly impactful. I felt blamed for Malcolm’s actions, and as a consequence, was directed to leave work early to take him home. I became susceptible to feelings of failure in the workplace from missed time, was stripped of much needed respite hours, and was exposed to more difficult and stressful parenting experiences within that day, all which increased my failed parent ideal and feelings of shame. This increased my isolation, while also making me resentful of the school.

Having reflected upon my own experience, I am now more responsive to parents who I feel are susceptible to these attitudes and have become careful with my own language and decision making so as to not promote them. In my opinion, sending a child home from school to “try again tomorrow” does not support a family who faces the daily care burden of their child. My hope is that uncovering these domino effects will prompt educators to find other ways to work with families and students which do not perpetuate negative outcomes.

Within my own school, I am a vocal proponent of keeping students within the school, no matter what they are communicating with their behaviours. I also remind other educators and administrators that school has a team of several adults, while home may only have a team of one. Employing the use of “cool down” spaces, sensory paths, break rooms, and having a low demand “Plan B” curriculum for students in distress has allowed for students on my caseload to remain at school, promoting healthier relationships with the families.

**The Positive Effects of Perception and Language.** This autoethnography also revealed how a more positive perception and use of language can support a family and be the catalyst to help parents move from feelings of shame to feelings of support and validation. This research demonstrated examples of how Malcolm’s behaviours were initially seen as being willful by school staff. Malcolm was referred to as violent and was made to apologize or keep promises
that were not within his capacity. It was also suggested his behaviours were from other causes which placed my own parenting skills into question. However, when Malcolm’s behaviours were interpreted as being part of his medical diagnosis and out of his control, the perception and language of the school changed. Blame was removed, and as a parent I began to feel worthy, supported, and part of a team. Meeting and conversing during times of success rather than only during times of crisis also helped to build a relationship between Mrs. Mackie and myself.

As an educator, I am careful to use language that is not divisive with parents. I choose words such as “dysregulated” instead of “violent” and discuss a student’s behaviours as a means of communication. I am often reminded of a phrase that Malcolm’s special needs support worker once said to me: “Kids aren’t shitty.” While perhaps a bit crass, she said this to me during a time when I had come to feel that Malcolm was indeed a terrible kid: the product of a terrible parent. Believing however, that kids are not terrible, or purposefully mean, or “shitty”, supports a mindset that creating self-esteem through emotional support has value, and choosing appropriate language and actions builds relationships between school and family.

**Recommendations for Schools**

This autoethnography supports existing research by Song et al. (2018), van der Sanden et al. (2016), Cantwell et al. (2015), and Fernandez and Arcia (2004) on the impact of stigma, including its consequences on the psychological and physical health of caregivers through isolation and the reduction of coping effectiveness, which result in harmful outcomes for parents of children with disabilities. This provides evidence for the importance of stigma reduction interventions for families caring for children with serious mental illness. By understanding the family impact of caring for a child with significant disabilities, schools can have the opportunity
to adjust how they interact with these families, reducing their stigma, and ultimately contributing to their overall health and well-being.

**Identification of Caregivers Susceptible to Stigma.** The identification of caregivers who may be susceptible to stigma, including those who care for children with significant behaviour problems, is a most critical recommendation for schools. Stigma impedes access to supports (Cantwell et al., 2015). Understanding and embracing this key piece of knowledge can contribute to a shift in a school’s role of supporting students. Promoting access to education cannot be approached through the student alone, as a school’s relationship with the family has a direct effect on that access. For example, providing emotional support to families, rather than placing or inferring blame can mitigate negative consequences of stigma for caregivers, allowing these families greater ability to access school supports for their children. The identification of families who may be affected by care burden can allow schools to adjust their environment specifically to the needs of that family. For instance, choosing to keep a student at school and holding meetings in areas which make a family more comfortable can help to reduce their level of school related stress.

**Understanding Behaviour as a Means of Communication.** For families with children who exhibit extreme behaviours, it can be crucial for educators to frame and communicate witnessed behaviours within a medical context, rather than assuming behaviours are related to poor parenting skills or the willful actions of the child. This can change the communication between parent and educator by reducing shame and allowing for more collaborative and positive interactions within the parent-teacher relationship.

Despite a confirmed diagnosis, it was only after Malcolm’s hospitalization that our school made meaningful change in their perception of Malcolm and response to his behaviours.
The switch to referencing Malcolm’s behaviours as “communication” created a positive and curious outlook, for both myself as a parent and as an educator. The words “promise me you will never be violent again” shifted to “what are you trying to tell us?” Instead of blame and forced apologies for assumed willful actions, I recommend schools engage in the practice of seeing behaviours as a means of communication.

**Keeping Students at School.** A shift in perception and language promoted one of the most impactful implemented changes in Malcolm’s access to education: the elimination of the practice of sending Malcolm home from school. With Malcolm’s behaviours now described as being part of his medical diagnosis, there was a new understanding that he should not, and would not, be sent home from school for actions out of his control and related to his health. This supported our entire family’s wellbeing and began to shift my own failed parent ideal into one of competence. I no longer saw our family as being punished, instead, I felt welcomed by the school community. Rather than contribute to the care burden of a family, I feel it is essential for educators to help relieve that care burden, and support families by providing an educational space for all children, regardless of their behaviours.

**Building Relationships by Using Humour.** Using the strategy of humour is also a recommendation for schools. The practice of having discussions that involved positive moments from Malcolm’s day allowed for my sense of humour to emerge. When a more serious incident needed discussion, a small insertion of humour quickly dispelled the tension between the school and myself, released my own feelings of anger and blame, and opened the dialogue around Malcolm’s behaviour without the weight of shameful undertones. I am reminded of a recent encounter with Mrs. Mackie as she described a difficult situation with Malcom. While previous
descriptions would normally have ended with questions that inferred parental incompetence, in this incidence, Mrs. Mackie used a tone of humour and turned the encounter back onto herself:

“Of course, Malcolm had a screaming outburst—I had just given him a school award for quiet respectful behaviour in the hallways. I must have jinxed him!”

This simple humorous acknowledgement that Mrs. Mackie may have played a part in Malcolm’s outburst by “jinxing him” immediately released me from feeling blame and gave the impression that the school and I were on this journey together.

Humour continues to play a role in my own outlook with Malcolm, and I also employ this strategy with the students and families that I work with at school, often pointing out a positive and often humorous moment in a difficult day. For example: “The student broke a chair in the school kitchen but managed to not burn the toast she was making. She did a great job of regulating herself! Now let’s talk about strategies we can teach her, so both the toast and the chair are saved next time…” In my interactions with parents, these types of comments at the beginning of a conversation can insert a positive tone into an otherwise challenging or heavy discussion. In addition, I am aware of the benefits of sharing positive moments with parents of children with difficult behaviours and actively make a point of building a parent-teacher relationship through this way.

**Recommendations for Future Research**

In addition to pharmaceutical therapies, McGorry (2004) states that psychological and psychosocial interventions are considered a necessary part of treatment for patients suffering from psychosis, while “family interventions are the most strongly evidence-based of all the psychosocial interventions in psychotic disorders” (p. 11). Future research into the development and effectiveness of programs intended to improve teacher-parent relationships which are
specific to parents caring for children with serious mental illness would benefit both schools and families. Potential relationship building programs to examine may include strategies such as emotional support and stigma management.

Future research into the development, implementation, and effectiveness of school programming specific to students affected by serious mental illness is also of potential value. Our educational system is set to progressively move forward in both content and difficulty, with the expectation that both academic and social skills increase as students move up through grade levels. This school model, however, does not address the cognitive and adaptive functioning changes Malcom experienced during and after psychosis. Future research could potentially include the examination of teacher expectations for students experiencing psychosis, the use of self-esteem interventions, administration and staff training programs, crisis intervention programs, and educational programming adapted for students with fluctuating or decreasing adaptive and cognitive functioning due to mania and psychosis.

Value and Limitations

This autoethnography depended upon my ability to accurately assess my experiences to the best of my ability, taking care to not make presumptive statements. This posed a challenge as it was easy to assume a character’s intent based on their actions, however, the reality was such that I did not know the innermost thoughts and feelings of Mrs. Mackie, unless they were explicitly expressed to me in words. While I did my best employing critical self-reflection to address self-perpetuating perspectives, this autoethnography is limited by the fact that it was written from my own perspective, and could be argued that I saw only what I wanted to see, and I believed only what I wanted to believe: the end result being a creation of my own subjective outlook.
While personal interpretation is the limitation of this autoethnography, it is also the value. The analysis of my innermost thoughts was made possible through this autoethnographic experience, exploring topics typically out of reach of other research methods. I believe this unique vantage point contributes in a meaningful way to the research within the field of self-stigma of parents of children with mental illness, an area lacking a comprehensive understanding and qualitative description of this specific type of stigma.

**Autoethnographic Experience**

Writing this autoethnography was not an easy task. My life with Malcolm contains an abundance of experiences which fall into the identified themes of teacher-parent relationship, caregiver stress, isolation, failed parent ideal, delayed help-seeking, blame, care burden, shame, and support and validation. In deciding which episodes of my life to reveal, I deliberated heavily, balancing my need to accurately illustrate the profound challenges of caring for my son, with the portrayal and confidentiality of others. With each narrative, I questioned my own desire for inclusion. Did it have a significant purpose? Could I potentially use a less stigmatizing story to equally illustrate the identified theme? Did I feel that a future, grown-up Malcolm would understand my reasoning for inclusion? The final compilation was intended to provide insight into the issues facing parents of children with serious mental illness in order for educators to see these families and students through a lens of support and understanding, while identifying and acknowledging barriers that parents may have when advocating for their children at school.

Writing this autoethnography has prompted me to believe that further evocative research is needed to effectively represent parents’ experiences of caring for a child with serious mental illness or other special needs in order to promote change within our education system.
What Have I Learned?

In writing this autoethnography, I was most struck by how my own shame and self-stigma overshadowed my skills as a parent and educator. Feeling confusion and blame, I initially delayed seeking help for my son, and as the care burden increased, my ability to take action became more impacted. I am also acutely aware that I come from a position of privilege, influence, and authority. I am educated, have financial security, and enjoy an abundance of family and social supports. Yet, despite these protective factors, I found myself unable to cope, speak up, or advocate for Malcolm. Despite my profession as a teacher, I found myself unable to navigate the education system I knew so well.

This autoethnography brought me to an understanding that shame and stigma is a powerful deterrent for families accessing the education system. I cannot imagine the difficulty I may have had advocating for Malcolm if faced with additional life stressors such as food or housing insecurity. Overcoming my shame and stigma and learning advocacy skills was a long and challenging process which still continues. My hope is that other families will not be faced with a similarly lengthy path.

The intent of this autoethnography was to encourage myself and other educators to adopt skills and attitudes which promote the creation of positive supports for families of students with severe mental illness. In conclusion, this research challenged me to become a more empathetic and empowered teacher. As an educator, I uncovered a new level of understanding of parental shame and stigma and am now more careful to question any assumptions I develop about a student, their behaviour, or their parent’s interactions with the school. As a parent, I continued to learn patience and have embraced a new outlook of optimism towards the education system. This
positive relationship change between family and school is not only felt by me, but also shared by my son.

“I love school. It makes me want to scream in joy!” (Malcolm, age 12).
References


