MOTHERS OF CHILDREN WITH AUTISM FROM THE SOUTH ASIAN DIASPORA: THE LIVED EXPERIENCES OF THE HOME-SCHOOL RELATIONSHIP

by

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B.A., Simon Fraser University, 2012

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

in

The Faculty of Graduate and Postdoctoral Studies

(School Psychology)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

October 2018

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Mothers of Children with Autism from the South Asian Diaspora: The Lived Experiences of the Home-School Relationship

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Abstract

There are a myriad of cultural factors that influence the home-school partnership for families with children with disability (Boyd & Correa, 2005; Harry, 2002; Kalyanpur, Harry, & Skrtic, 2010). South Asian families contend with community stigmas, which may prevent them from openly discussing their child’s disability and actively engaging in their child’s school (Heer, Larkin, & Rose, 2015; Ravindran & Myers, 2012; Rizvi, 2017; Zechella & Raval, 2016). Teachers and schools need to understand the best way to communicate with the families, and encourage their involvement (Welterlin & LaRue, 2007; Zhang & Bennett, 2003). Trust is an essential component to the development of a positive partnership between schools and families (Adams & Christenson, 1998; 2000).

The primary objective of this research was to gain a better understanding of the school experiences of South Asian parents of children with autism spectrum disorder (autism) as well as the role of trust in their school relationships. Using qualitative methods and an Interpretive Phenomenological Analysis (IPA) approach the researcher conducted semi-structured interviews with four South Asian parents of children who have been formally designated with autism. Participants were asked to share their experiences regarding their interactions with their child’s school and what role trust played in their experiences.

Findings indicate that South Asian parents tend to have an innate trust with schools and teachers. As they interact with their child’s teacher and the school system, the frequency and severity of their positive and negative experiences impact their level of trust. Differences in experience relate to the differences in each participant’s contextually bound lifeworld.
Lay Summary

A positive relationship between home and school is a key factor in student success (Welterlin & LaRue, 2007; Zhang & Bennett, 2003). Trust is a key part of that relationship (Adams & Christenson, 2000; Adams & Christenson, 1998). There are cultural factors that impact home and school relationships (Harry, 2002; Kalyanpur, Harry, & Skrtic, 2010). South Asian families may approach disability in different ways from mainstream, Caucasian families (Heer et al., 2015; Ravindran & Myers, 2012; Rizvi, 2017; Zechella & Raval, 2016).

This research study looks at the experiences of South Asian parents of children with autism spectrum disorder in schools, and the role of trust in their relationships with teachers. Four South Asian mothers were interviewed. The results showed that families had an innate trust with schools and teachers. Their trust changed after they had either positive or negative experiences with teachers and the school system.
Preface

This thesis is original, unpublished, independent work by author, Shalini Arya. Conducted under the supervision of Dr. Laurie Ford. It was conducted under approval from the UBC Behavioural Research Ethic Board (H16-00587). The original title on this ethics approval was “South Asian Mothers with Children with Autism: The Role of Trust in Their Relationship with Schools”. The title was changed after analysis and interpretation was completed and the supervisory committee and the researcher believe this to be a better fit for the title of this thesis.
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Acknowledgements

I would like to acknowledge and express my eternal gratitude for my supervisor, Laurie Ford, for her patience as I went through this journey and her support of my academic career. Thank you for taking a chance on an eager undergrad, looking for a mentor.

I would also like to acknowledge Matthew Waugh for taking the time to shine light on my thesis journey when I was just “shooting rubber bands in the dark,” and for building my academic confidence through encouragement.

To the families I have interviewed - it was your willingness to bring an outsider into your homes and ask you questions about your life, that has allowed this research to happen. Thank you for your strength and resilience; your stories have helped me see the world in different ways.

I would like to express love and appreciation for my cohort, our bond has grown as strong as a pack of wolves. To my friends that have always supported me and have ‘bean’ there for me at all hours of panic and stress. Finally, I cannot describe the gratitude I have for my family. Their powerful love and care for me have led me to the water. Here I am, drinking it.
Chapter One: Introduction

Overview

A key to student success for children with a disability is a strong family-school partnership (Kim & Bryan, 2017; Epstein, 2001; Tschannen-Moran, 2014). Positive outcomes in student achievement have been shown when parents of children with autism have direct involvement in their child’s education (Johnson, et al., 2007; Kim & Bryan, 2017; Ozonoff & Cathcart, 1998). Trust is an essential component in the development of a positive partnership between schools and families (Adams & Christenson, 1998; 2000; Tschannen-Moran & Gareis, 2015). Much of the literature on trust and schools describes the importance of trust in the parent-school relationship, however this research is typically situated in Caucasian-dominant samples (Blue-Banning et al., 2004; Stoner & Angell, 2006).

The differing values of minority families with children with disabilities may impact their level engagement with schools (Boyd & Correa, 2005; Harry, 2002; Kalyanpur et al., 2010). Cultural factors influence a parent’s conceptualization of their child’s disability, impacting their approach to intervention (Berry, Portinga, Segall, & Dasen, 2002; Cummings & Hardin, 2016; Harry, 2002; Hodges, 2013; Rosetti, Sauer, Bui, & Ou, 2017). South Asian families may experience unique stressors regarding their child’s diagnosis compared to Caucasian-dominant research populations (Grewal, 2010; Heer, Larkin, Burchess, & Rose, 2012; Rizvi, 2017). While research has documented the differing experiences and perceptions of South Asian families with disabilities in the school system, there are is no research to-date that this researcher could locate examining the role of trust within this community and special education specifically.
The South Asian population is Canada’s largest visible minority, making up 25% of the total visible minority population (Statistics Canada, 2016). South Asian families may benefit from a more relational approach to intervention (Grewal, 2010; Hatton et al., 2004). Service providers should be culturally sensitive when approaching parents regarding supports (Shah, 1995). However, little is known about how this research applies to the unique situation of having a child with autism (Grewal, 2010). To empower South Asian parents and promote their active participation within schools, we must understand the reciprocity of trust between teachers and parents. In this study, unique insight into the strengths and needs of a large group visible minority group in Canada, South Asians, is offered. It is hoped that this will allow professionals to better understand what is needed to provide effective support for South Asian families of children with autism within schools.

Key Terms

Trust. Trust has been defined across multiple fields and disciplines and there are common elements across the literature. Tschannen-Moran and Hoy (2000) developed a definition of trust as it relates to relationships within schools: “One party’s willingness to be vulnerable to another party based on the confidence that the latter party is benevolent, reliable, competent, honest, and open” (p. 556). As this definition of trust has been created based on the school context, it will be used in the present study.

South Asian. South Asian will be used in the present study to describe individuals who are members of the South Asian diaspora, defined as a person of South Asian descent that does not live in their homeland. The countries that make up South Asia are Afghanistan, Bangladesh, Bhutan, India, Maldives, Pakistan, Nepal, and Sri Lanka.
**Parent/Caregiver.** Within the context of this study, parents and caregivers will be used interchangeably. The parent or caregiver is the primary individual who cares for the child with disability. This may include a mother, father, aunt, grandparent or other person who has the primary caregiving responsibility for the student.

**Autism spectrum disorder (autism).** Autism is a pervasive developmental disorder characterized by challenges in social communication and repetitive or stereotyped interests and behaviours (American Psychiatric Association, 2013). This description is consistent with the diagnostic criteria for autism used in British Columbia (BC), where this study was completed. Students in the present study met eligibility as a student with special education needs and was receiving special education services as defined by the British Columbia Ministry of Education Policies and Procedures Manual for Special Education Services as a student with autism.

**Summary**

Research has shown the unique ways South Asian families of children with disabilities approach special education (Grewal, 2010; Heer et al., 2012; Rizvi, 2017). Trust is a key factor in the development of a positive home-school relationship (Adams & Christenson, 1998; 2000; Tschannen-Moran & Gareis, 2015). In this research study the experiences of South Asian parents of children with autism and their experiences in the school system, particularly surrounding the role of trust was examined.
Chapter Two: Literature Review

The family-school relationship between parents and educators is impacted by different factors. Additional layers, such as having a child with special needs, as well as the unique needs of being from a different culture than that of the dominant population, increases the complexity of that relationship (Boyd & Correa, 2005; Harry, 2002; Kalyanpur et al., 2010). An underlying mechanism of the effectiveness of this relationship is the phenomenon of trust (Angell et al., 2009; Stoner & Angell, 2006). This chapter provides an examination of the layers of the complex relationship parents of children with special needs have with their schools, and discusses how each of those layers relate to trust. Consideration is given for the additional challenges that may be faced by South Asian families.

Family – School Relationship

Special education in British Columbia. In Canada, there is no federal department for education or federal legislation for special education; education laws are specific to each province. In B.C., the provincial legislation that addresses public education is called the School Act. To help the reader contextually understand the school system, a summary of the relevant legislature for parents of children with autism are described below. Per the School Act, parents have the right to be informed about a student’s behaviour and progress in school, to be consulted about their child’s Individual Education Plan (IEP) before it is finalized, and to appeal a decision made by an employee of the school if that decision significantly affects the education or safety of the child (Autism Community Training Society [ACT], 2016).

The School Act also delineates the responsibilities for parents and school employees. Parents are required to consult with school personnel about the student’s educational program, when it is requested by the school (School Act Regulation 7(1)(a)). Teachers are
responsible for designing, supervising and assessing educational programs, as well as instructing, assessing and evaluating individual students (School Act Regulation 17[1]). Non-enrolling teachers, such as resource teachers, act as case managers and are responsible for coordinating the IEP (ACT, 2016). Some student’s will have access to a teacher assistant, their responsibilities include working under the general supervision of a teacher, principal, or director of instruction, and assisting a teacher in carrying out their responsibilities and duties (School Act Regulation 18[1]).

In British Columbia, the special education policy mandates inclusion, where all students have equal access and opportunity to achieve their education goals (BC Ministry of Education, 2016). Students who are diagnosed with autism qualify for special education services, these can range from minor adaptations in an education plan to having a full-time one-to-one teacher assistant (BC Ministry of Education, 2016). Each school district has different policies around the allocation and type of services; for example, the Surrey school district has Applied Behaviour Analysis (ABA) support workers, who are trained to specifically work with students with autism. ABA support workers are paraprofessionals who can also be hired by the parent to work with the student in a home-based program (ACT, 2016). The decision for the type and level of support a student receives is largely decided at the school-level (BC Ministry of Education, 2016). The allocation of one-to-one support is typically coordinated by the case manager (sometimes called the resource teacher), with input from the classroom teacher and administrators (BC Ministry of Education, 2016).

Students who are designated as needing special education services have an IEP. The IEP is designed to provide modified learning outcomes to the regular curriculum, support services for the child and family, and if needed, adapted materials or assessment methods
A great deal of importance is placed on active parental engagement in the development of IEP (BC Ministry of Education, 2016). The IEP is considered a legal document, teachers are legally mandated to implement the strategies put in place by the IEP per the responsibilities as outlined by the School Act (School Act Regulation 17[1]). Ultimately, parent’s serve as the measure of accountability to ensure that their child is receiving the appropriate services and supports (Burke & Goldman, 2018; Howe & Boele, 2018).

These legislations and policies ensure that school professionals are just and ethical when they work with these vulnerable populations (Howe & Boele, 2018). Special education is the most litigious area of education within the mainstream culture (Fitzgerald & Watkins, 2006; Howe & Boele, 2018). Yet, there is a disparity when you examine advocacy efforts in marginalized populations, even though marginalized students account for much of students identified (Burke & Goldman, 2018; Howe & Boele, 2018). The laws meant to protect marginalized parents are inaccessible and may present as barriers to marginalized families (Bacon & Causton-Theoharis, 2013; Burke and Goldman, 2018; Jessop, 2018). The BC Ministry of Education (2016) recognizes parents are an integral part of student success, their knowledge and experience with their child bridges the support between home and school environments. To support families of children with special needs, school professionals need to approach marginalized parents and foster a relationship with an emphasis of partnership and community engagement (Burke & Goldman, 2018; Cobb, 2014; Epstein, 2018; Jessop, 2018).

**Family engagement in special education.** Extant literature consistently indicates positive student outcomes when parents are engaged in their child’s school performance.
(Castro, Expósito-Casas, López-Martín, Lizasoain, Navarro-Asencio, & Gaviria, 2015; Epstein, 2018). Educators must take family engagement into consideration when school planning, as the home and family environment have the greatest impact on a child’s development (Cumming, Marsh, & Higgins, 2017). A fundamental element to family engagement is a positive relationship between parents and their child’s teacher (Epstein, 2001; Haines, Gross, Blue-Banning, Francis, & Turnbull, 2015; Hodges, 2013). The relationship parents have with their children as well as their child’s teacher were the main factors impacting school engagement (Green, Walker, Hoover-Dempsey, & Sandler, 2007). These interpersonal relationships were a stronger predictor of engagement than both socio-economic status and parent perceptions of self-efficacy (Green et al., 2007; Hodges, 2013).

Teachers are the primary contact for parents in schools; this relationship greatly impacts the way parents perceive support and engage with schools (Cumming et al., 2017; Epstein, 2018; Frans, 2018). To gain a better understanding of the factors that influence a positive family-school relationship, Francis et. al (2016) conducted focus group discussions with parents. Participants included parents of children with and without a disability from schools that were lauded for their inclusive practices. A positive school culture of inclusion emerged as an overarching theme. School stakeholders displaying values related to dignity, openness, and acceptance, provided parents with a sense of community and belonging in their schools (Francis et al., 2016). This finding mirrors past theories and current literature; when engagement is a part of the school’s mission statement and site plan, it becomes ingrained as a part of all routines and operations that are established for the school (Epstein, 2001; 2018; Frans, 2018; Rose, Espelage, Monda-Amaya, Shogren, & Aragon, 2015).
For parents of children with special needs, the IEP meeting is often where they develop their perceptions of the special education process (Jackson, 2018). Frequently cited factors that contribute to perceptions between families and the IEP process included partnership, respect, communication, and confidence in the educator (Jackson, 2018; Jessop, 2018; MacLeod, Causton, Radel, & Radel, 2017). When families are viewed as partners in the IEP process, they are considered valuable members of the team and their opinions and suggestions are seriously considered (Epstein, 2001; Jackson, 2018; Jessop, 2018). Treating parents as equals fosters a positive relationship based on respect and empathy, which can positively impact parent engagement during the meeting (Jackson, 2018; Jessop, 2018). Parents who feel comfortable communicating with the members of their child’s IEP team, reported frequent opportunities to speak to the team both prior to, and during IEP meetings (Jessop, 2018). When parents felt that their knowledge was not valued, they reported that educators tended to downplay their ideas, leading them to feel marginalized and not competent in the care of their child (MacLeod et al., 2017). A poor family-school partnership may lead parents to feel disenfranchised and without a voice during the IEP process (Wagner et al., 2012; Zeitlin & Curcic, 2013).

There are different models of relationships between parents and professionals; extant literature praises and calls for educators and professionals to follow empowerment-based models that foster family engagement (Epstein, 2002; 2018; Robinson, 2005; Turnbull, Turbiville, Turnbull, & Zigler, 2009). The traditional professional-centered model highlights the teacher as the expert and decision maker (Robinson, 2005; Turnbull et al., 2009). This creates a sense of paternalism between parent and educator, it limits the parent’s autonomy, and negatively affects engagement (Bacon & Causton-Theoharis, 2013; Burke & Goldman,
2018). When families report negative experiences with their child’s school in the literature, their interactions with teachers generally follow this model. However, moving away from this model can be likened to swimming upstream. Special education is structured bureaucratically, the theoretical underpinning to a bureaucracy lies in functionalism (Skrtic, 1991). Thereby, special education presupposes a rational-technical framework, where an emphasis is placed on standardization of service and hierarchical, professional roles (Bacon & Causton-Theoharis, 2013). The medical model is institutionalized and used to bring rationality, order, and certainty to schools (Bacon & Causton-Theoharis, 2013; Skrtic, 1991). Following a historically bureaucratic structure, the system of special education is steeped in professional-based authority and reinforces similar positivist discourse (Skrtic, 1991).

**Special education and culture.** The mainstream Western model of disability is often situated in a medical context, suggesting that individuals with disability require treatment (Kalyanpur et al., 2010; Robinson, 2013). Members of Western culture that adopt this conceptualization may prioritize the importance and efficacy of formal supports, such as direct therapy and intervention (Robinson, 2013). Extant literature has shown that different social groups perceive disability in unique ways that are impacted their social, historical and cultural contexts (Boyd & Correa, 2005; Cobb, 2014; Harris, Goodall, & Andrew-Power, 2009; Harry, 2002; Kalyanpur et al., 2010). This difference in conceptualization has been shown to impact the priorities, goals, and parenting practices within that social group (Beauregard et al., 2014; Kalyanpur et al., 2010; Robinson, 2013). The unique considerations of working with families from diverse backgrounds can contribute to the amount and type of parental engagement (Cummings & Hardin, 2016; Harris et al., 2009; Kalyanpur et al., 2010).
There are vast differences in the values and expectations of children with disability between mainstream and minority cultures (Boyd & Correa, 2005; Cummings & Hardin, 2016; Harry, 2002; Kalyanpur et al., 2010). The Western concept of parent participation with their child with disability is often based on the middle-class advocate who holds high expectations of service providers, participates in formal meetings regarding their child, and involves litigation if necessary (Harry, 2002; Kalyanpur et al., 2010; Rosetti et al., 2017). Middle-class parents see the teacher as an equal; they use the same vocabulary as the teacher, allowing them to construct their relationship with the teacher with comfort to express their opinion (Harris et al., 2009). This model may not fit the context of minority parents of children with disability. The expectations of minority families surrounding educational practice may be impacted by their cultural norms, values, and expectations (Cummings & Hardin, 2016; Hodges, 2013; Rosetti et al., 2017). When values of the dominant culture are placed upon minority parents as expectations, a dichotomous relationship is formed (Boyd & Correa, 2005; Harry, 2002). The power dynamic in a dichotomous relationship, between the families and professionals, is skewed in favour of the professional having power over the family (Robinson, 2005; Stoner, 2003; Turnbull et al., 2009). In a hierarchic system, parents who see the professional as the expert, tend to take a passive role in their child’s education out of respect for the authority (Harris et al., 2009; Harry, 2002; Hodges, 2013; Kalyanpur et al., 2010).

Cobb (2014) analyzed the findings of 20 studies that examined parent involvement in culturally and linguistically diverse (CLD) families, through the entangled dimensions of the perceptions people hold, the relationships people have, and the systems they encounter. Diverging perspectives were found to adversely impact the way school officials interacted
with and treated CLD parents (Cobb, 2014). When school professionals were considered as positions of authority, CLD parents tended not to voice concerns or opinions during meetings despite having concerns (Cobb, 2014). The relationship a CLD parent has with a school professional was impacted by their perceptions of their interactions (Cobb, 2014). When school professionals used strategies that were not culturally responsive, such as argument by repetition, or direct and professionalized language, it adversely impacted the tone of future exchanges, the level of trust in the professional, and the power dynamic in the relationship (Cobb, 2014). Lastly, the systemic dimensions within special education, borne out of a Western model, privileged like-minded philosophies and languages, which served as barriers to CLD parents (Cobb, 2014). Professionals must take into consideration the immeasurable layers of complexity that impact engagement for diverse families are entangled within the dimensions of perspectives, people, and systems.

**South Asian families.** A South Asian parent’s conceptualization of their child’s disability is influenced by the unique constellation of their societal, cultural, and historical contexts (Heer et al., 2015). The knowledges, languages, and philosophies that a person is aware of and gives credence to influences the way they are positioned in, and by, social contexts, such as interactions with schools (Cobb, 2014). As such, South Asian families may experience unique stressors regarding their child’s diagnosis compared to Caucasian-dominant research populations (Grewal, 2010; Heer et al., 2012; Rizvi, 2017). These have been documented within the literature as community stigmas, stemming from the cultural shaming of children who have a disability, which can prevent families from openly discussing and accepting treatment (Daley, 2004; Grewal, 2010; Hatton et al., 2004; Ravindran & Myers, 2012). Conformity to social norms and societal expectations also serves as a barrier to help-seeking
behaviours of families with children with a disability (Daly, 2004; Grewal, 2010). It is important to note that group trends are not intended to be prescriptive to all South Asian families; each family is unique in their history, professionals should take culturally responsive approaches that are individualized (Shah, 1995; Rizvi, 2017).

Recent studies examining South Asian families’ experiences with a child with disability have shown some interesting trends. Initial challenges and struggles were noted to impact parents, their journey to accept the disability tended to move from fear-based avoidance into a more cultural or religious-based acceptance (Heer et al., 2012; Rizvi, 2017; Zechella & Raval, 2016). Research conducted on South Asian mothers’ perceptions of their child with a physical disability indicates that mothers take on both the medical and traditional models; mothers accepted Western medical intervention, but would also seek out traditional, homeopathic remedies based out of spiritual practices (Daudji et al. 2010). Challenges accessing service and communicating with service providers were commonly reported as a concern (Heer et al., 2015; Zechella & Raval, 2016; Walz, 2013). However, studies have indicated that South Asian parents have been actively engaged in their child’s education, even though navigating service delivery has been shown to be a barrier (Walz, 2013).

South Asian families may respond to a more relational approach to intervention (Ravindran & Myers, 2012). Services that are separated from the entrenched cultural and religious needs of South Asian families are not as effective as those that have been modified to recognize the unique characteristics of the population (Grewal, 2010; Jagetheesan et al., 2010; Shah, 1995). As the research on South Asian families is growing, a much more broad and diverse view of its members are being presented. Recommendations across the literature emphasize the need to tailor intervention within the context of that individual (Daudji et al. 2010; Heer et al., 2012;
Trust

**Theoretical components.** Julian Rotter’s (1967) explanation of interpersonal trust has served as the basis for many trust theorists. Rotter (1967) defined trust as, “an expectancy held by an individual or a group that the word, promise, verbal or written statement of another individual or group can be relied upon” (p. 651). The construct of trust is a cognitive phenomenon, based on the reliability and consistency between communication and action amongst adults (Rotter, 1967). Trust is developed over time; an individual’s disposition towards others can be generally trusting or non-trusting, but each trust decision is based on past interactions and present situations (Rotter, 1967). The development of trust, as described by Tschannen-Moran (2014), begins with an initial period of impression making and followed by a commitment period where the two parties explore one another’s trustworthiness. High levels of initial trust are still described as provisional and depend on several factors, including institutional policies that regulate the other party’s behaviour and the other party’s reputation (Tschannen-Moran, 2014).

Trust is an essential component to the development of a positive partnership between schools and families (Adams & Christenson, 1998; 2000). There are key elements within the definitions of trust defined across disciplines, including a level of vulnerability and an expectation of another person (Rousseau et al., 1998; Tschannen-Moran & Hoy, 2000). Rousseau et al. (1998) synthesized a view of trust and created a definition based on common elements across disciplines: “Trust is a psychological state comprising of the intention to accept vulnerability based upon positive expectations of the intentions or behaviour of another” (p. 395). Rousseau et al. (1998) asserts that trust is established slowly by building
interdependence. In studies regarding trust in education, trust is defined as the expectation that the school and the parent are working to provide the best level of support for a child with a disability (Adams & Christenson, 2000; Robinson, 2005).

Rempel, Holmes, and Zanna, (1985) created a definition of trust in their research on close relationships, that has been cited in the literature regarding trust between families and schools (Adams & Christenson, 1998, 2000). Within this definition, there are three dimensions of trust that move from concrete behaviours to abstract belief. The most specific and concrete stage of trust is predictability (Rempel et al., 1985). The predictability of the partner’s behaviour originates from past learning experience; trust is based on their specific actions (Rempel et al., 1985). Dependability, the second component of this model, involves the trust of another person's character rather than their actions. Vulnerability is a factor, as trust cannot be established without an opportunity for disappointment (Rempel et al., 1985). The third component is not dependent on past experience or the reliability of previous evidence; it is dependent upon the essence of trust in the future. Faith, the third component, is the belief in the relationship (Rempel et al., 1985).

Tschannen-Moran and Hoy (2000) created a definition of trust that is based on empirical and theoretical research studies across disciplines based on a review of the literature examining trust over the past four decades. Inclusion criteria for the articles examined in their multidisciplinary review were based on their relevance to the school context, such as trust in organizational settings. The authors found sixteen definitions of trust and identified five common themes within the trust literature as it related to schools. Trust is defined as “one party’s willingness to be vulnerable to another party based on the confidence
that the latter party is benevolent, reliable, competent, honest, and open” (Tschannen-Moran & Hoy, 2000, p. 356).

**Trust and special education.** Trust permeates throughout all aspects of education. It is the expectation that the principal, teachers, parents, and students will support each other; trust is developed when these expectations are fulfilled (Tschannen-Moran, 2014). Families and school professionals who view each other as allies have trusting partnerships, this contributes to positive outcomes for the students as well as the contributing stakeholders (Haines et al., 2015; Tschannen-Moran, 2014). Factors that foster this positive relationship include, professionals demonstrating empathy, sensitivity, compassion, and kindness towards students (Francis et al., 2016).

Parents were more likely to engage in their child’s education if they perceived that the school community welcomed them and cultivated a trusting relationship (Tschannen-Moran, 2014). Communication, respect, and commitment were described as key factors in promoting a trusting relationship (Francis et al., 2016). When teachers and staff demonstrated respect, by requesting and respecting parental knowledge, parents felt comfortable to communicate (Francis et al., 2016). Trust ensures the continued involvement of the parent throughout the child’s education (Blue-Banning et al., 2004). The partnership between families and schools helps build student success (Epstein & Connors, 1995; Underwood & Killoran, 2012). A shared responsibility between parents and educators provides students with opportunities for enhanced learning and academic support (Lautenbacher, 2013).

Parents of children with disability have reported not trusting their child’s education professional or trusting them conditionally (Angell et al., 2009; Stoner & Angell, 2006). Parents assume a certain level of trust in their child’s teachers, and trust develops
incrementally (Angell et al., 2009; Stoner & Angell, 2006). Trust between families and teachers examined in previous research have been based on perceptions of teacher competence (i.e., authentic caring, as well as their clear, frequent and honest communication (Angell et al., 2009; Balan, 2010; Esquivel et al., 2008; Stoner & Angell, 2006). The school climate, the services offered, and the amount of collaboration with parents have all been shown to impact parent perception of trust. (Angell et al., 2009).

In a qualitative study of eight, middle-class, Caucasian parents of children with autism, Stoner and Angell (2006) examined parent-teacher relationships and parental roles in education. The results provided explanations of the different roles that parents of children with autism take on; these roles changed based on the level of trust the parents experienced in their relationship with their child’s instructor and education assistants (Stoner & Angell, 2006). The parents in this study believed that the school staff were experts, but the parents also believed that they knew more about their child’s needs than the school (Stoner & Angell, 2006). These parents were sceptics and critical consumers of their child’s education and intervention; once a level of trust was established, the parents comfortably assumed a more supportive role and advocacy role with their child’s school (Stoner & Angell, 2006).

Research regarding the development of trust, conducted with predominantly Caucasian populations, has shown that trust must be earned for a parent to become a passive, supporter of their child’s teacher (Balan, 2010; Stoner & Angell, 2006). Caucasian, middle-class parents of children with disability often engage with their child’s schools to ensure the fair treatment of their child, litigation is commonly used to assert their child’s rights (Harry, 2002; Kalyanpur et al., 2010). Special education is consistently the most litigated area in education per American research (Wellner, 2012). Trust violations have been documented in
the literature to include: poor communication, lack of collaboration, poor listening skills, and an inability to adopt new perspectives (Wellner, 2012). The behaviour needed to support the development of trust in special education includes: relationship building, problem solving, and interpersonal communication (Wellner, 2009; Wellner, 2012). Wellner (2009) argues that a person must first have the capacity to trust another individual; then they must engage in effective communication to build and grow trust; and finally, employ cooperative and collaborative, student-centered, problem solving to assist in the development of trust.

**Trust and culture.** Trust is deeply rooted in cultural history, the way people conceptualize and create trust is bound within their cultural ethos (Choi & Han, 2011). Western society maintains a cultural ethos of individualism. Under this ethos, trust begins with the individual’s propensity towards trust; given that, trust is gradually built in interpersonal relationships through accumulated positive interactions (Choi & Han, 2011; Stoner & Angell, 2006; Rotter, 1967). Eastern societies, including East Asian and South Asian cultures, maintain a collectivist identity where emphasis is placed on the relationships built within the group (Choi & Han, 2011; Kong, 2013; Wang & Casillas, 2013). Trust has been shown in East Asian cultures to follow Confucian ideology, which posits that trust begins in relationships (Choi & Han, 2011; Kong, 2013). As social harmony is paramount, trust in others to maintain a positive relationship is innately assumed (Choi & Han). Confucian principals also insist a responsibility between the trustee and trustor, where both can rely on the other when help is needed (Choi & Han, 2011; Wang & Casillas, 2013). The differences in conceptualization of trust can impact the way families engage with their child’s schools.
Research on trust in special education based in a Western context, conducted with primarily Caucasian populations, may not apply to the unique challenges faced by culturally diverse populations. Parents of children with a disability from minority backgrounds have reported that they see the teacher as the expert, disagreeing with the professional may show a lack of respect (Boyd & Correa, 2005; Choi & Han, 2011; Kong, 2013; Lam & Kwong, 2012). Scepticism and autonomy can be relinquished with the elevated status given to the truth-telling professional (Kong, 2013; Lam & Kwong, 2012). This model of passive trust is opposite to the results described in Stoner and Angell’s (2006) study, where experiences of the middle-class Caucasian participants reflected mistrust and a greater experience of trust in themselves. Research has described South Asian parents of children with disability assume a more passive role in their child’s education and IEP process (Balan, 2010; Rizvi, 2017). In order to build trust in diverse parents of children with disabilities, school professionals must make efforts to understand the cultural context from which they conceptualize education and the role of the teacher (Kong, 2013; Matuszny, Banda, & Coleman, 2007; Shah, 1995).

South Asian culture, as it has developed over time in India, is entangled within the dominant religion’s constructs (Heer et al., 2012; Rizvi, 2017; Zechella & Raval, 2016). Deep rooted in current practices of teaching are the historic values that have been placed on teachers (Ratnam, 2013). Knowledge was originally caste-dependent, where only higher castes were allowed access; this created a hierarchical structure where power and authority were given to those with superior knowledge (i.e., teachers and doctors), thereby demanding respect from the lower class (Atreya, 2015; Ratnam, 2013). The teacher is known as the “guru” who, historically, was expected to impart knowledge to the student that would lead them to spiritual salvation (Ratnam, 2013). The teacher was looked up to as a God; the
student, or “shishya,” had implicit faith and devotion to their teacher (Ratnam, 2013). These values have been passed down generationally. The Indian school system has followed a modern colonial education since the mid-nineteenth century; however, its practices have developed out of deep-rooted traditions and cultural ethos (Atreya, 2015; Ratnam, 2013). The archetype of the “guru-shishya” relationship persists in present-day South Asian society; as evidenced by the morning prayers commonly a part of the daily rituals in schools, where the “guru” is described as a God (Ratnam, 2013).

**Literature Review Summary**

There is a paucity of research examining the role of trust in South Asian families of children with a disability. The literature suggests that culturally diverse families interact with schools in different ways from their Caucasian counter-parts (Harry, 2002; Grewal, 2010; Matuszny et al., 2007). Trust is an essential component to the development of family engagement with their child’s school (Angell et al., 2009; Balan, 2010; Esquivel et al., 2008; Stoner & Angell, 2006). Diverse families of children with disability may experience trust differently from the mainstream culture (Harry, 2002).

**The Present Study**

**Purpose.** The purpose of this research was to explore the phenomenon of trust for South Asian families with a child who has autism and their relationship with the school.

**Research questions.**

1. What are the experiences of South Asian parents with a child who has autism in the public school system in British Columbia?

2. What role do these families perceive that trust plays in the home-school relationship?
Chapter Three: Methods

Overview

The aim of this study was to better understand the lived experiences of South Asian mothers of children with autism in the school system, the role of trust within the home-school relationship was examined as a phenomenon. In order to achieve this aim, semi-structured interviews were conducted with South Asian parents of children with special needs. Qualitative methods and an Interpretive Phenomenological Analysis (IPA) approach framed the design and analysis of this study. In this chapter, the framework and design of the study, as well as the procedures, data analysis, and ethical considerations are presented.

Methodology

Interpretive Phenomenological Analysis. IPA offers a distinct approach to qualitative inquiry. It is rooted in both phenomenology, the study of an experience stripped from all biases to gain insight into a phenomenon; and hermeneutics, which emphasizes interpretation as a fundamental function of being (Larkin, Watts, & Clifton, 2008; Eatough & Smith, 2017). In IPA, understanding a phenomenon through a lived experience, as interpreted by an individual is sought. The phenomenon is coloured by the way that individual makes sense of their personal and social world (Eatough & Smith, 2017; Smith & Eatough, 2016). IPA posits that individuals and their worlds are socially and historically contingent, and contextually bound (Smith, 2004; Smith & Eatough, 2016). Since the individual is completely intertwined within their lifeworld, experiences cannot be examined out of context (Larkin, Watts, & Clifton, 2008; Eatough & Smith, 2017). While the aim is to clarify a phenomenon; the focus of IPA is to understand the experience as perceived through the individual’s lifeworld (Eatough & Smith, 2006; 2017). The lifeworld of an individual is
defined as the evolving order of thoughts and feelings, actions and events and in IPA researchers assume a chain of connection between an individual’s thinking, emotional state, and talk (Smith & Eatough, 2016). Based on hermeneutic principles, in IPA researchers examine the individual’s interpretation of reality in an attempt to gain insight into this contextual world (Eatough & Smith, 2017). This is a two-stage, double hermeneutic process. First, the individual attempts to make sense of their world; then, the researcher tries to make sense of how the individual is attempting to make sense of their world (Smith & Eatough, 2016; Smith, 2004).

For the purpose of this study, the perceptions and experiences of South Asian mothers of children with autism, specifically surrounding their experiences of trust in the school system and with school-based professionals, was examined. Participants engaged in semi-structured interviews to help the researcher understand their experience based on their socio-cultural context and their environment (Eatough, Smith, & Shaw, 2008; Smith & Eatough, 2016). IPA was fitting for the present study as it allowed for an in-depth analysis of a phenomenon (Eatough et al., 2008). The idiographic approach to understanding the phenomenon of trust, allows for the many complexities of human experience to be looked at holistically (Eatough et al., 2008). The aim of research using IPA is to understand the individual experience without prescriptive expectations based on preconceived assumptions, making this an ideal methodology to examine diverse populations (Eatough & Smith, 2017).

Past literature on the analysis of South Asian women, within a western context, emphasizes the importance of a holistic examination of their experiences within the broader social and environmental context (Bagguley & Hussain, 2014; Hatton et al., 2004; Rizvi, 2015; Shah, 1995). IPA employs thick description, which is a rich, detailed description of the
participant, their context, and the data collected (Eatough et al., 2008; Shenton, 2004). This served as an invaluable source of credibility as it provided enough detail for the researcher to understand the participant’s experience and the context surrounding it (Shenton, 2004).

In this study, the researcher worked with the individual to understand their interpretation of reality. The researcher also contributed to the data collected from the individual, as they were a part of the interview process (Smith, 2004). In IPA, the interview serves as a means of understanding the individual through a case-by-case analysis. The researcher uses the way the individual describes their experience to understand their construction of reality (Eatough et al., 2008). For example, the choice of metaphors used when the individual described their interactions with schools gave a glimpse into their image of themselves and the construction of their reality. The analysis incorporates the features highlighted above to produce an interpretation of the phenomenon of trust situated in an examination of each participant’s experiences with the school system. Once an in-depth account of each participant was created, patterns of convergence and divergence were examined across cases.

**Role of researcher.** Using an IPA framework, the researcher made efforts to leave their assumptions and judgments surrounding the subject matter, to prevent influencing the research findings (Eatough et al., 2008). The researcher is a member of the South Asian diaspora, and has worked as a behaviour interventionist with children with autism for seven years. To help ensure that past experiences did not influence the data collected, the researcher worked to maintain a neutral attitude during the interview process to ensure assumptions were not placed on the participant’s experience. A reflexive journal served as a method of tracking thoughts, feelings, and reactions to the interviews. This allowed the researcher to
reflect on any beliefs or biases that could have clouded their interpretation of the data. The researcher frequently debriefed with professionals in the field and peers regarding the interviews, which provided opportunities for fresh perspective and challenged assumptions that may have arisen.

**Participants**

Four South Asian mothers of children with autism participated in the study. A blended family (South Asian father and Latino mother of a child with autism) was also interviewed; however, after a discussion with the supervisor, the data was not included in the analysis for this study. Homogenous samples help to create a more robust understanding of the data (Eatough & Smith, 2017) as characteristics of this family and their backgrounds adding more heterogeneity to the sample they were not included in the analyses presented in this document. The sample size is consistent with the IPA approach. Qualitative in-depth interviews are often conducted with smaller sample sizes in order to preserve an ideographic emphasis in IPA (Smith & Eatough, 2016).

The participants identified as South Asian and were originally from India. The mothers had a biological child diagnosed with autism, and acted as the primary caregiver. All children of participants discussed in the study were enrolled in an elementary school in the lower mainland of British Columbia. In accordance with the Ministry of Education criteria, all children qualified for special education services under a government defined category designated for children with autism (BC Ministry of Education, 2016) according to the report of the parent. The children also had an IEP that reflected their personal learning goals in the
school. Two of the participants, Supreet\(^1\) and Nisha, spoke English as their first language and Punjabi as their second. Manisha’s first language was Hindi and spoke English as a second language. Sukh’s primary language was Punjabi and spoke English as a second language.

In an understanding the lived experience is sought; the psychological, cultural, historical aspects of each participant form the totality of their experience as something greater than the sum of its parts. A thick, or very detailed, description of each participant provides the contextual framework through which the analysis was examined. The specific participant data will be included as a part of the results in Chapter 4. Each participant is briefly described in Table 1.

Table 1

*Characteristics of Family Participants*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Sex</th>
<th>Highest Education Level</th>
<th>Country of Origin</th>
<th>Primary Language</th>
<th>Child’s Age in Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supreet</td>
<td>42</td>
<td>Female</td>
<td>Master’s</td>
<td>India</td>
<td>English</td>
<td>12</td>
</tr>
<tr>
<td>Nisha</td>
<td>38</td>
<td>Female</td>
<td>Bachelor’s</td>
<td>India</td>
<td>English</td>
<td>7</td>
</tr>
<tr>
<td>Sukh</td>
<td>36</td>
<td>Female</td>
<td>High School</td>
<td>India</td>
<td>Punjabi</td>
<td>10</td>
</tr>
<tr>
<td>Manisha</td>
<td>38</td>
<td>Female</td>
<td>High School</td>
<td>India</td>
<td>Hindi</td>
<td>7</td>
</tr>
</tbody>
</table>

Recruitment

Consistent with the policies and procedures of the University of British Columbia, this proposal received approval from the Behavioural Research Ethics Board (BREB) before data collection began. Participants were recruited through outside agency supports as well as the snowball technique (participants recommending others who might be interested in participation). Community-based agencies that support South Asian families with children

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\(^1\) All names of participants are pseudonyms in this write-up of the research.
with special needs, were contacted via telephone and in-person. Recruitment flyers were placed within their buildings, newsletters, and email listservs (Appendix C). The researcher volunteered at monthly support meetings for South Asian parent support groups, and spoke at community events intended to engage South Asian parents of children with autism explaining the purpose and procedures of the study. Ultimately, the snowball technique was the method used to recruit all the participants. Initial participants passed on the study information to other potential participants they knew. The researcher developed connections with members of the South Asian community who were in contact with different families that met the inclusion criteria. The snowball technique was well fitted for this study. Consistent with prior research, access to vulnerable populations was difficult (Hall, 2004). The recommendation and assurances from a person the caregiver trusted (the participant) helped to create a link into this community.

**Procedures**

**Semi-structured interviews.** When conducting an IPA study, semi-structured interviews are a commonly used data collection method (Eatough et al., 2008). In-person interactions during a semi-structured interview allowed the researcher the flexibility to follow a participant’s lead and to probe when necessary to gain a better understanding of their lived experiences (Eatough et al., 2008; Smith, 2004). Each participant served as a unique case where an interview was conducted, follow up questions were clarified over the phone as necessary at a later date. Consistent with IPA methodologies, the researcher examined the individual’s motivations, desires, belief systems, and feelings regarding their experiences surrounding trust with their child’s school (Smith & Eatough, 2016). The
researcher extracted different levels of the interpretation from the participant by probing deeper into their experiences and what they mean to them.

A set of questions was used to guide the interviews. Through a neutral stance, the researcher asked general, open-ended questions and probed when necessary (Smith, 2004). The interview questions were given to the participants prior to the interview (Appendix D). To limit social desirability bias, the researcher emphasized that the individual’s participation was confidential and voluntary, and reminded them that they could withdraw from the study if they felt uncomfortable (Shenton, 2004). Demographic information was obtained at the beginning when, the researcher asked the participant for background information (Appendix B).

Participants were first asked to share a favourite anecdote of their child to help ease them into the conversation and establish rapport, this also helped to orient the participant to thinking about their child. The interview guide was structured to first gain an understanding of the participant’s initial experiences with the school system. They were subsequently asked to share their experiences with teachers. Follow-up probes were used to extract as much detail about the experiences to help situate the researcher within each participant’s context. In order to gain an understanding of the manifestation of trust, specific questions surrounding trust were adapted from previous qualitative research studies examining trust and families with children with special needs place in their child’s school (Angell et al., 2009; Shelden, Angell, Stoner, & Roseland, 2010).

**Reflexive journal.** The researcher maintained a reflexive journal throughout the data collection process. During the interview, notes were taken on participant observation; the non-verbal cues and shifts in body language provided an additional level of interpretation
(Smith, 2004). The researcher also recorded their thoughts and feelings after each interview. This was used during the data analysis phase, the notes commenting on the participant’s tone and body language were added to the transcript to provide additional information.

**Data Analysis**

**Method.** In IPA, the researcher seeks to understand a phenomenon through an interpretive engagement with the data (Eatough & Smith, 2017; Smith, 2004). Following the theoretical roots of IPA, the hermeneutic circle is used to engage the researcher with the data in a dynamic and iterative way (Eatough & Smith, 2017). Considering aspects of the data as a whole and examining the parts, then examining the parts within the whole, through different lenses allows the researcher to see the data in different lights (Eatough & Smith, 2017). Through the iterative process, the researcher looks for possible meanings behind the data that reveal the phenomenon, these meanings are critically examined within the context of that person’s lifeworld (Eatough & Smith, 2017).

In this study, the interviews were transcribed and interpreted at different layers through a dual interpretive engagement (Eatough & Smith, 2017). The initial level of interpretation used hermeneutics of empathy, considering the individual’s experience and their sense of meaning surrounding (Eatough & Smith, 2017; Smith, 2004). Using hermeneutics of suspicion, the researcher critically engaged with the data at the second level of interpretation, by deciphering the hidden meaning implied within the literal meaning (Eatough & Smith, 2017; Larkin, Watts, & Clifton, 2008). Smith and Eatough (2016) emphasize that IPA provides flexible guidelines for the individual researcher to adapt to their research aims, especially within analysis. Per the general guidelines for analysis, the researcher familiarizes themselves with one case and creates initial themes, the themes are
refined as they are interpreted through subsequent cases, and finally compared across cases (Smith & Eatough, 2016; Smith, 2004).

The purpose of the study was to understand the experiences of South Asian mothers of children with autism in the school system, the role of trust within the home-school relationship was examined as a phenomenon.

**Stage 1.** The researcher familiarized themselves with the first participant’s data by reading the transcript multiple times and making initial notes. The repeated readings helped the researcher conceptualize the data through the eyes of the participant. Following hermeneutics of empathy, the researcher situated the data contextually, taking into consideration the participant’s social capital and support system. The researcher assigned brief, pithy phrases to summarize each data segment. The initial layer of interpretation provided rich understanding of the events and circumstances experienced by the participant as interpreted by the participant (Eatough & Smith, 2017).

Through hermeneutics of suspicion, the researcher examined the transcripts critically, and interpreted the meaning behind the individual’s lived experience (Eatough & Smith, 2017; Larkin et al., 2006). Consistent with the aims of IPA, the researcher sought to understand the lived experience of the participant. Eatough and Smith (2006) stated the evolving order of thoughts and feelings, actions and events make up the lifeworld of an individual. Smith and Eatough (2016) further validate this, stating IPA assumes a chain of connection between an individual’s thinking, emotional state, and talk. The researcher stepped back and explored the data across multiple layers, examining the way the participant perceived their world and how that impacted the emotions they attached to their experiences. This relationship was critically examined alongside the actions and results experienced by the
participant. The language the participant used provided insight into their self-schema, or the enduring beliefs and thoughts a person has about themselves, based on their memories of past experiences (Markus, 1977). Examining the data across the layers of perception, feeling, and action, allowed the researcher to engage in the hermeneutic circle. The parts that make up the lived experience were compared to the complete transcript, the self-schema of the participant, as well as the results the participant was experiencing.

With a thorough understanding of the data, the researcher organized concise phrases that captured the meaning of the data segment, and were abstract enough to allow cross-case analysis (Smith, 2004). These emerging themes were listed on a separate document, with evidence of the data below each theme.

**Stage 2.** The emergent themes were examined critically, reordered, and organized together based on the connections between them. Emergent themes without sufficient evidence were discarded. These clusters of themes, defined as broad themes, were assigned a name that represented that section of the participant’s experience. The emergent themes that made up the broad themes were identified as subthemes. The broad and subthemes were checked against the transcript to ensure they accurately reflected the data. The list of broad and subthemes created a skeleton structure of the data.

**Stage 3.** Stages one and two were repeated for each following participant’s transcript, using the broad and subtheme structure from the previous participant to help direct the analysis. The researcher searched for patterns of convergence and divergence in each participant. After completing all transcripts, the broad and subthemes were critically examined against the data, to ensure there was a coherent pattern within each theme. The
focus of analysis was based on the richness of the data collected across participants, and how well the subtheme helped to shed light on area of experience.

The reflexive journal provided insights into the participant’s body language and demeanor, the field notes were used in conjunction with the transcripts as a form of methodological triangulation (Shenton, 2004). To ensure credibility, the researcher recorded their conceptualization of the possible meanings that could be interpreted from the data (Shenton, 2004). The journal served as a source of data triangulation, and helped to explain the subjective progression of the construction of themes and the interpretation of the data collected (Shenton, 2004; Smith, 2004).

**Strategies to Ensure Rigour**

Several strategies were put in place to ensure the rigour of this study. Consistent with procedures developed for qualitative methods, the process of conducting the research was evaluated for trustworthiness (Shenton, 2004). To ensure the reliability of the analytical process, the researcher worked with a research assistant to establish intercoder reliability and intercoder agreement for the coded in-depth semi-structured interview transcripts (Campbell, Quincy, Osserman, and Pedersen, 2013).

**Trustworthiness.** The following steps were taken to ensure the trustworthiness of the research conducted (Shenton, 2004). The chosen methodology was established and well-suited to the aim of the present study (Shenton, 2004). IPA is a well-established methodology, there is a strong body of research in similar fields that have successfully used an IPA approach to examine and interpret various phenomena (Eatough et al., 2008). This methodology has been shown to accurately describe and interpret the experiences of the individual, allowing an in-depth exploration of the phenomena in question (Eatough et al.,
The researcher established good rapport with the participant by remaining accommodating and non-judgemental across all interactions, a safe space was created for the participant to feel comfortable. This helped to minimize the risk of receiving socially desirable responses from the participant (Shenton, 2004). During the interview process, the researcher also probed regarding common topics that came up for other participants. This process of corroboration compares the needs of similar individuals (Shenton, 2004).

*Methodological triangulation* provided different ways of understanding the phenomena, increasing the strength of the findings (Mathison, 1988; Smith, 2004). A semi-structured interview was the main form of data collection. It was also triangulated with notes taken on participant observation during the interview process in the researcher’s *reflexive journal*. The notes taken during the interview in the reflexive journal were added to the transcription and considered during the analysis (Smith, 2004). *Investigator triangulation* ensured that the researcher was not limited by personal biases and assumptions as the data was collected. The researcher’s supervisor was involved throughout the research process (Mathison, 1988).

Feedback and guidance were provided in the development of research questions and preparation for the interviews. *The researcher debriefed* with their supervisor, peers, and professionals in the field during the interview process, and throughout analysis. This helped with the iterative process and allowed the researcher to consider different perspectives of the data (Mathison, 1988; Shenton, 2004). Debriefing with others in the same field helped the researcher to develop and construct ideas about the data (Shenton, 2004).

**Analytical reliability.** As there is a paucity of research surrounding trust within South Asian families with children with autism, an inductive approach was taken to better understand the essence of the participant’s experiences. Inductive approaches to data analysis
are situated within the context of the participant, codes are data-driven and reflect interesting features of the data (Eatough et al., 2008; Smith, 2004). As this was an exploratory study, the themes were linked to the data themselves, they were not driven by theoretical expectations or the researcher’s preconceptions (Eatough et al., 2008).

Intercoder reliability and intercoder agreement ensured the reliability of the way the researcher conceptualized the data (Campbell et al., 2013). Intercoder reliability requires at least two independent raters to select the same code for the same unit of text (Campbell et al., 2013). Intercoder agreement requires that the raters are able to come to an agreement after a discussion of their coding discrepancies (Campbell et al., 2013). The researcher familiarized the research assistant with the project and coding scheme over several discussions. A sample of 10% of each transcript was used for the purposes of intercoder reliability. The excerpts of data were meaningfully segmented and coded by the researcher (Campbell et al., 2013). A copy of the excerpt was given to the research assistant, where the data remained segmented but the codes were removed (Campbell et al., 2013). The research assistant was given a detailed description of the broad and subthemes, as well as the coding scheme structure. After they independently coded the data, the researcher calculated the intercoder reliability of broad themes and subthemes using the proportion agreement (Campbell et al., 2013). The number of times a code was agreed upon, was divided by the total number of times that code was selected across both raters (Campbell et al., 2013). Initial intercoder reliability across coding of broad themes and subthemes was between 69% to 100%. A discussion of disagreements in coding were resolved to create intercoder agreement throughout the text. All differences were negotiated and a final agreement of 100% was reached for all coded discrepancies. A list of calculations is provided in Appendix E.
**Ethical Practice**

The Behaviour Research Ethics Board (BREB) at the University of British Columbia first approved of the research. Prior to participant interviews, the researcher explained the purpose and procedures of the study in a letter of consent. Participants were informed of the steps taken to maintain the confidentiality of their information. They were also notified they may withdraw their consent from the study at any time.

All identifiable information of the participant has been removed from the data and pseudonyms have been used to ensure participant confidentiality. Data stored electronically is password protected and encrypted, all physical data is stored in a locked filing cabinet in a laboratory office at the UBC Vancouver campus. Access to the data will only be granted to the researcher and the research supervisor.

**Summary**

The aim of this study was to understand the lived experiences of South Asian mothers of children with autism in the school system, the role of trust within the home-school relationship was examined as a phenomenon. An IPA approach was used to explore the phenomenon of trust through an in-depth examination of their experiences with the school system (Eatough et al., 2008; Smith, 2004). Participants were recruited through a snowballing technique. Semi-structured interviews allowed the researcher to understand the individual’s lifeworld (Eatough et al., 2008). The researcher transcribed the interviews and conducted different levels of interpretation, at the descriptive and interpretive level (Eatough et al., 2008; Larkin et al., 2006; Smith, 2004). Methods were used to ensure scientific rigour throughout the study, this helped to establish the credibility of the research conducted.
Chapter Four: Findings

Overview

The purpose of this study was to understand the lived experiences of South Asian mothers of children with autism in the school system, the role of trust within the home-school relationship was examined as a phenomenon. Interpretive phenomenological analysis was used to analyze the interview data of four South Asian mothers who had a child with autism. There were many shared and divergent aspects across the identities of the participants, these unique considerations provide the basis of understanding the lived experience for each mother. A detailed description of each participant is provided as a contextual consideration to help frame the findings.

In this chapter the findings from the study as identified by the broad themes that arose from the analysis is presented. Three broad themes were identified across all four participants’ experiences within the school system. When discussing the role of trust in their relationships, a total of three broad themes were identified across participants. In addition to the themes, two contextual lens’ were found to split the participants into two groups, Recognized Authority and Unrecognized Authority. These are presented alongside the thick description of the participants, as a contextual consideration. The themes are presented within the context of each research question. Per IPA research guidelines, each theme and subtheme were prevalent across at least three participants, to ensure sufficient density of the findings (Smith, 2011). In instances where a theme is not dense, the findings presented are sufficient and idiographic (Smith, 2011). A summary of the themes and subthemes for the study are highlighted in Table 2, below.
Table 2

Prevalence of Themes that Emerged in The Study

<table>
<thead>
<tr>
<th>Broad Themes</th>
<th>Subthemes</th>
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Contextual Considerations

Participants.

Supreet. Supreet is a first-generation immigrant who was raised in a traditional Punjabi household in a predominantly South Asian community in the UK. She went to college and became a teacher in the UK. After marriage, she immigrated to a large city in the BC lower mainland and became a stay-at-home mom. She has two neuro-typically developing children in high school. Her youngest child is twelve years old and was diagnosed with autism at age two. Supreet described the initial experience of the diagnosis as
grief. However, she quickly turned to action and spent all her free time researching and understanding the disorder. She worked with her husband to ensure they provided every possible treatment to support their daughter. Supreet managed a comprehensive treatment plan, which included a behaviour intervention team as well as a regimen of biomedical interventions, such as a strict gluten and casein free diet and supplements.

Once her child started school, Supreet went on to further her education, getting a diploma in special education. This led her to work as a resource teacher within a school district. In this role, Supreet worked with teachers and parents to help support children with special needs in school. Supreet went on to complete a Master’s degree in Special Education to help her better understand the students she was working with. She is an active volunteer with an autism community program, working as a parent volunteer with a South Asian parent group. She frequently speaks in the community describing her experience as a parent with a child with autism and the resources available to parents in Punjabi.

**Nisha.** Nisha and her husband live with their son in an outside urban township in the lower mainland of BC. Their extended family live nearby; Nisha describes their relationship as close-knit. She and her husband own and operate a successful business from their home. When their son was diagnosed at age two, he experienced delays in language and motor development. During the interview, Nisha described the emotional experience of hearing her son say, “I love you” for the first time, when he was four years old.

In an effort to learn as much as she could about the disorder, Nisha researched a great deal of information through an autism community support centre. She believed in their work so much, that she took a position to work for the organization as an administrative assistant. Her background in managing a business helped her in her role with the organization. She
helped many minority parents who have children diagnosed with autism learn about the services that are available to them. She has helped translate information sheets into Punjabi and provide them to members of the community. She is also a member of a South Asian parent group, organizing and setting up monthly support group meetings for South Asian parents of children with autism. Through her extensive knowledge, she has helped parents navigate the school and government structures to gain access to funding and services.

**Sukh.** Sukh immigrated to a large city in the lower mainland from Punjab, after her marriage in 2011. She completed her high school education in India, but did not learn to speak English confidently. Shortly after moving to Canada, she gave birth to her son. A preschool teacher at Strong Start informed her of the cognitive delays her son was displaying, she referred the family to a speech therapy consultant. The speech therapist confirmed early signs of autism, and their family doctor referred the child to a provincial health centre for diagnosis. Their child was diagnosed at three years old. Sukh reported a great deal of grief and confusion surrounding the diagnosis. Immediately after the diagnosis, she recalled health professionals giving her a lot of information, but she was not able to retain or understand any of it. She asked if there was a medicine he could take as a cure, but the professionals told her behaviour therapy was their only option. After receiving the diagnosis, her mother-in-law blamed her for her child’s disability. Her husband became distant, refusing to provide any financial, emotional, or respite support.

Sukh began working with a behaviour consultant who spoke Punjabi and helped translate the necessary information for her. Sukh remained optimistic and held a hope that her child would be cured after therapy; she realized later this was a permanent problem and subsequently lost all her confidence and grieved again. After starting school, she saw her
child’s progress from the behaviour therapy and felt lucky to work with a team that was kind and helped her navigate the system. The behaviour consultant guided Sukh to access her social worker who has acted as an advocate. Sukh describes herself as a single parent; her son has needed full-time attention and support since birth. She frequently reported feeling alone without a family network or people to help share her burdens. Sukh staying home to support her son has prevented her from cultivating a circle of support in her community, she does not have many opportunities to practice her English. Without active employment, she reported struggling to pay for the therapy and support her son requires.

**Manisha.** Manisha is a dedicated mother, she and her husband married in Gujarat and immigrated to a large city in the lower mainland in 2007. She completed English as a Second Language classes and worked in a South Asian enclave in the city. Manisha describes her life as changing once her only son was diagnosed with autism when he was two and half years old.

Manisha described the diagnosis as difficult to accept in the beginning, her husband did not accept the diagnosis as real. One year after the diagnosis, Manisha reported that she eventually was forced to accept it. Her son was getting worse day by day. He could only say the words mom or dad and refused to respond to anyone. A support worker from a local agency for children with developmental disabilities told her that she had no choice but to accept the diagnosis and place her son in a special preschool. Manisha reported that she made up her mind and decided to send her son to a preschool designed for behaviour therapy for kids with autism.

Circumstances allowed Manisha to stay at home and help support their child for an extra three years after her maternity leave, despite the financial implications for their family.
Progress was noted after beginning behavioural therapy at his preschool. Eventually a behaviour consultant joined as a part of a home team, their son has steadily progressed since. Manisha attributes her son’s success to God’s grace. As a practicing Hindu, she frequently goes to the temple to give offerings, such as flowers and fruit, to receive blessings for her son.

**Summary of participant context.** As highlighted in the descriptions above, the unique knowledge, philosophies and histories of each participant coloured their experiences. All four of the mothers shared similar demographics, they were South Asian with a child with autism in elementary school in the Lower Mainland of British Columbia. Yet, there was a divide in the way they related to their child’s diagnosis and perceived their experiences with the school system.

**Contextual Lens.**

**Overview.** The participants reported similar themes and subthemes across the research questions; however, the way they described their experiences and the way they described their interactions with the school professionals varied. Across the findings, these differences were described as a contextual lens through which the parent approached the system, as well as the way the system responded to the parent.

**Recognized authority.** The contextual lens of Recognized Authority arose out of the differences in discourse and perception that were noted in the interview data from Supreet and Nisha. The lifeworld of these two participants included advantages that afforded them access to education, social standing, and the financial freedoms to easily focus on their child’s therapies. As described in the participant descriptions, both Supreet and Nisha were born and raised in traditional South Asian families, but they grew up in a Western society.
They attended schooling in English and went on to pursue higher education. Their careers were directly associated with understanding autism and the school system.

These mothers approached challenges faced in their child’s school as though they were the authority in the matter. They had background knowledge about the school system, understood their rights, and used the appropriate language to assert themselves. Supreet expressed her distaste when a teacher did not invite her to an IEP meeting, per the legislation of the School Act (ACT, 2016). She went on to describe how she set up a meeting and spoke to the teacher about the appropriate procedure:

Her integration teacher met with the classroom teacher and drafted a new IEP and sent it home... Like, well hello? I'm a parent... Did you forget to call me? Are you going to call me after the fact? That doesn't work.

Anyway ... [Supreet scoffed]

We met subsequently and we talked about it and stuff and I made it clear that that was not to happen again. I talked about how I wanted it to go from future, in the future, I said, the, the way it should work is you ask me do I want to have a meeting ... Then I'd just say yes or no.

These parents had the confidence to challenge school staff and access their needs from school professionals in higher positions, if they were not getting the desired outcome. For example, Supreet found that a speech-therapy service was available through the school district and requested it for her child from the integration teacher. The teacher denied the request because she didn’t believe that it was beneficial, to which the mother stated:

I wasn't happy with, with that at all. I didn't like the way that she responded to a parent request. And so, I contacted the lady who held, holds the license
for the Surrey school district Fast Forward. She's a speech and language pathologist. She came by my house, met with me, [Child’s] dad, met with [Child] and set us up despite the integration teacher's lack of knowledge of it, really. And the results were amazing.

These parents described negative experiences with school professionals, but they asserted themselves in a way that established their authority with that professional. After contacting the school district to request a change in support teachers, Nisha received a negative email from that teacher demanding fake policies: “She had sent me an email saying that any correspondence that goes to the district needs to go through her.” This mother skillfully responded in a way that asserted her authority:

Yeah. I said to her, to put it bluntly, I was pissed off. I’m like you have no right to tell me who I can speak with. I didn’t say that back to her, but what I said was, “I’m confused as to your concern with my correspondence with the district as this started while you were on leave and at the direction of the principal and the mainstream support teacher at that time.”

The parents understood the language of the system and used it to position their social status in their relationships with school professionals. The school system, in turn, seemed to recognize their authority, as they were reported to respond to requests more favourably. As evidenced in the reaction of the aforementioned support teacher, as described by the mother:

She back pedaled and said “No, no there’s no concern” … I don’t know what’s happened since then. I don’t know if inside the school district, somebody said something to her. Now she supports my son the way she’s supposed to have done.
**Unrecognized authority.** The contextual lens of Unrecognized Authority described the language and perceptions that were noted to be unique in Sukh and Manisha’s interview data. In these participant’s stories, Sukh and Manisha reported the challenges they had with their beliefs and perceptions about autism and how that related to their limited knowledge about the disorder. Both mothers reported never learning about autism in India. Sukh laments this fact when she described the diagnostic process:

> Our education from where we are, we don’t know what is special needs, and how to react with the problem. We never learned about special needs.

> We don’t know what autism is.

Having been raised in India, these parents explained that disability was not spoken about. They reported that families typically did not seek to diagnose autism, this is consistent with the literature describing the stigma surrounding mental health disorders (Balan, 2010). As referenced by Manisha, “In India, they have, but they never diagnose with this. Kids have autism there. But it is found more in Canada and America.” The previous knowledge, philosophies, and histories of these mothers regarding autism were closely tied to the cultural stigmas of India.

These mothers experienced additional barriers on top of the grieving process some families go through when they discover their child has a disability (Balan, 2010). Including isolation, Sukh describes her experience as suffering alone:

> It’s harder for single parents. My husband is uncooperative, my mother in law is not happy with me. They blame me for [Child] and don’t support me. I have many problems in my family. Family only tortures me. I have no help from elsewhere. I am not expecting money from them…
Financial burdens impacted the type of services the families accessed as support. The sacrifices that these mothers made to stay at home and dedicate their lives to their child impacted their ability to cultivate a social network for support. These mothers faced unique barriers when they interacted with the school system. They had to contend with their stigmas surrounding disability, the lack of financial and emotional support from their networks, as well as their lack of understanding of a Western school system.

When they approached challenges in their child’s school, they generally assumed that the professional understood what their child needed. For example, when asking Manisha if she ever had a negative experience with a teacher, she explained that the teachers knew what was best for her son: “No… I've never had, no. The teacher, they teach our kids, right? So, I don't think so.” In situations where the parent was looking for more services, they tended to remain timid and not voice their needs. Manisha also described her struggle trying to get a support worker for her child after multiple instances of bullying:

So, this year they made me little bit upset. Upsetting if he has some issues, we need to work, so he need the assistance, right? So, if I keep sending an emails to teacher, it will be worrisome or bothering for them because they are teaching, they are teacher.

These mothers were more self-conscious about bothering the teacher. The teacher was frequently reported as busy. Cultural factors may prevent the parents from asking for additional supports. In situations where the parent disagreed with the school and was trying to voice their concerns, they may have struggled to find the right way to ask for services, as poignantly described by Sukh:
We, South Asian have a problem of expressing ourselves. South Asian people have hesitations/shyness. We don’t take too much help from different people. Other people they have the language and they know how to read, they can fight for the rights they need.

Expressing disagreement with a school professional required these mothers to use their second or third language to challenge a professional, who they also believed to be the expert. When a school professional acted in ways that the parent disagreed with, they didn’t have the right words to stand up for themselves. One parent described the difficulty she had in expressing herself at an IEP meeting:

Yes. it was the meeting of IEP. I told them that he gets bored at school.

They didn’t listened to me. I was crying, because they were blaming me. I think it was December before or December. It is very hard for parents. They [school professionals] do not listen. They only work with the children at school then they don’t care about the child afterwards.

These parents appeared disadvantaged in meetings with professionals because they did not have a clear understanding of the discourse, the system, or the rights they were entitled to. The way these parents reported their interactions with teachers, they described the school professional as being in a position of power. In the experiences described, the parent was not able to express themselves in a way that was recognized by the school professional. When the power dynamic favours the professional, a hierarchical relationship is formed. The authority of the parent is dismissed and remains unrecognized.

Summary of Contextual Lens. The participants described their experiences and their interactions with the school professionals differently. Across the findings, these differences
were described as a contextual lens through which the parent approached the system, as well as the way the system responded to the parent. Parents described as having Recognized Authority were able to speak to school professionals and advocate for their child in ways that the school professional understood and recognized. These parents tended to receive services they advocated for. Parents described as having Unrecognized Authority, did not know how to navigate the system or use language to fight for the services they wanted for their child. They advocated for their child, but did not advocate for them in a way that was recognized by the school professional. See figure one below for a description.

Figure 1. Contextual Lens of Recognized Authority and Unrecognized Authority.

Research Question One: What are the Experiences of South Asian Parents with a Child with Autism in the School System?

Overview. The purpose of this research question was to better understand the experiences of South Asian parents with a child with autism in the public-school system in
British Columbia. Overall, a total of three themes and twelve subthemes emerged. The parents all had experiences that related to the school system, which included the process of seeking services for their child. There were also common experiences that related to positive and negative interactions with teachers. The subthemes within positive and negative interactions were discovered to be reciprocals of one another. Where a parent described a positive interaction, they included a positive aspect of collaboration, such as a willingness to meet. When describing a negative interaction, they reported negative aspects of collaboration, such as not responding to emails. A diagram of the findings from research question one is represented in figure two below.

![Diagram of findings](image)

*Figure 2. Experiences of South Asian Parents of Children with Autism in Schools.*
Theme 1: Interactions with the System. This theme describes the experiences the participants had in their interactions with the school system regarding enrollment, applications for supports for their child, and bureaucratic structures in schools. This does not include the interactions parents had with teachers at the classroom level. Four subthemes were identified as: Fear of the Unknown, Bureaucracy, Advocacy, and Sacrifice.

Subtheme 1.1: Fear of the Unknown. All the participants noted fear surrounding their child’s future in school. This was typically reported prior to the child starting school. Not knowing what to expect from the school system, or how their child would be supported was commonly expressed across participants. Supreet went as far as setting up a meeting with the district principals of special education to gain clarification about what to expect, “that the meeting really was to alleviate my fears about [Child] entering kindergarten about the kind of support she was going to get.” There was a concern about the child getting lost in the system, or simply pushed through without the supports that they needed. As described by Nisha:

I feared that he wouldn’t understand what was being asked of him. That he would get lost in the system was my fear. He’s just going to get pushed along and he’s not going to get the support he needs or understand the instruction that’s being given to him.

Supreet described a fear of not knowing how her child would fare in school regarding their academic and social development, “I think I was just worried about everything. You know, how she was going to be academically. How are things going to work? How things are going to work out for her socially ... Cognitively.” The unknown future left parents feeling anxious. This extended to the unknown of what would happen to the child after leaving the
school system, as described by Manisha when considering the supports their child would receive in school. “So, in the long run, what will be the consequences, right? Every time he will be leaving his school. So, I'm always worried about him.”

**Subtheme 1.2: Bureaucracy.** Common across all participants when describing their interactions with the system, were their frustrations with bureaucracy or structures that were in place by the school system or government. Parents frequently cited a “keeper of the keys” or a school professional who was in charge of allocating services that the parent wanted for their child and could not access. Supreet reported that the professional who oversaw applications to a speech-therapy program did not put her child’s name forward because they didn’t believe it was a beneficial program. “I spoke to [Child’s] integration teacher about it who sent me an article or printed off an article from Wikipedia telling to, to kind of poo-poo it.” These experiences were frequently associated with a lack of transparency regarding the process of allocation or why their child didn’t qualify for services. As described by Nisha:

> We were asking for full time support for him for grade one and we had started initiating that in the spring and we were told that he wouldn’t get it. Without trying we were told this off the bat. Our mainstream support teacher oversees all of the support staff. We were told that he wouldn’t get anything.

Parents also reported a frustration in the shortage of resources that prevented their child from receiving supports they felt their child was entitled to. Manisha reported her concerns:

> So. This time, this is my worry, some of it. He doesn’t have any assistance although he’s eligible for that. I spoke with the principal, they said our
resource teachers are working as a teacher because we have a shortage of teachers. But if you have a shortage of teachers, that doesn’t mean if he needs the support and you have the support teacher, you are using them as a teacher, then he is deprived of this opportunity, right?

Parents also reported concerns regarding the supports that were missing from the school system altogether. Sukh described her frustration with the lack of school support in helping her child during recess and lunch hour: “There should be arrangements in every school for children to play. It is the responsibility of school to provide them all kind of learning and playing instruction as well.”

**Subtheme 1.3: Advocacy.** All participants advocated on behalf of their child, they spoke with teachers, principals and sometimes sought support from outside agencies to ensure that their child would receive the supports they needed. However, there was a difference in the methods and responses between parents with Recognized Authority and Unrecognized Authority.

Supreet and Nisha described experiences advocating for their child by contacting school professionals at the district level to get the appropriate services for their child. Nisha reported an experience where her son was crying every day and was afraid to go to school because of negative interactions with a strict lunch supervisor. After reporting this to his teacher and not seeing an improvement, she went to the principal:

I videotaped my son in the car to show the principal how upset he was. I said this is not normal for my kid. He’s usually quite a happy child. He’s not like this and I said it’s very concerning to us. If this continues, I’m not
sure we made the right decision or picked the right school. And this is our first year.

In a similar experience, Sukh reported that her child was crying every day and refusing to go to school because of negative interactions with the support teacher in his classroom. However, when she attempted to speak about this with the classroom teachers, she reported being dismissed. That experience prevented her from asking higher authorities for help. To have her voice heard, she accessed her social worker to advocate on her behalf. When asked if she spoke to the Principal or Vice-Principal, she responded: “No, I didn’t meet with them. The school was not listening me. I met social worker she visited the school, I’m not sure who she spoke to. I would speak to her and she would email the school and speak to them.”

**Subtheme 1.4: Sacrifice.** All the participants reported making sacrifices to support their child, such as not choosing to not work. However, the financial and social impacts of their sacrifices differed across the contextual lens’ of Recognized and Unrecognized Authority.

Nisha found out from the district that her son was not getting into the school she applied for at the beginning of June before the Kindergarten year started in September. She phoned the school directly and found out he could get in if their family lived in the area, or catchment. “We basically bought a house within a month to get him into the school, to get him to the catche [catchment] student.” This was a huge financial sacrifice for a family to make for their child. She reported that she had some financial support from her family and extended family, which allowed them to do this.
Supreet did not work and stayed at home to support and manage her child’s services. She reported being fortunate that her husband’s income provided them with enough financial freedom to pay for the supports needed. Supreet began working once their child was well adjusted in school.

Manisha also reported staying at home to help support her child: “I didn’t work for, like after my maternity leave. I did not care. Like, if one is working, only one parent. I didn’t work for a least four hours, at least four years. So, four years, sorry. Because I just want to worry about him.” In Manisha’s case, their family could only afford to be a single-income family until her child was four years old. After which, she reported working long hours to help make up for income loss. Similarly, Sukh also reported staying at home to support her child. She emotionally described the burden as being alone,

I am alone here... I cannot work… I can work only for few hours a week.

Government also does not help, he’s 10 years old, and no help. [Sukh began crying] When will we get help?

**Theme 2. Positive Interactions with Teachers.** The participants described common experiences when describing the elements of a positive interaction with their child’s teachers. Four subthemes were identified as key features to a positive interaction with their child’s teacher: Child-Related, Teacher Competency, Communication, and Collaboration.

**Subtheme 2.1: Child-Related.** The participants frequently spoke about their child’s well-being when describing a positive interaction with their teacher. One of the initial indicators for parents was if their child liked the teacher. When the child communicated, or gave the indication that they felt comfortable or happy around their teacher, parents were
more likely to speak about that teacher positively. Nisha describes how she can tell her son liked his teacher:

Just in the way [Child] respects her and deals with her. I can tell from that that he’s never complained. He’s never said anything about her. He doesn’t like going to school because it’s hard, but when I ask him what he thinks about his teacher and stuff like that I know that he likes her. I can tell and I think that makes a huge difference.

Manisha describes her interaction with her child’s teacher as positive when she saw that her child was happy when his teacher was at school: “[Child’s Teacher] was sick, 2-3 days I guess, he was really sad. … But when his teacher was back, so he was really happy, he told me, ‘My teacher came back, she did this.’ Because she appreciated [Child].” When parents perceived the teacher as caring about their child’s well-being, they described the teacher as empathic, nurturing, or kind to their child. “She will take extra responsibility. Maybe she loves [Child] or she really wants him to eat. So, that’s a good thing, right?”

The participants also reported positive interactions with their child’s teacher when they felt that the teacher was invested in the child’s success. Supreet described a teacher as being invested when they held the appropriate expectations of her child, “…just accepting and pushing her in the ways that she needs to be pushed.” Also, when they witnessed their child had progressed in a positive way (academically, socially, or behaviourally), as evidenced by Sukh:

At starting school, I felt myself as a lucky mother… [Support teacher] also brought positive changes…I met her in school, we saw how nicely she was
teaching [Child], I asked if she could work with him at home. I was happy that my child learns better in her company. I was happy.

**Subtheme 2.2: Teacher Competency.** The subtheme of teacher competency arose as a factor that the participants reported when describing teachers they had positive interaction with. Nisha praises her child’s current classroom teacher when describing her experience, “Then this year his teacher is really good. She has been teaching for a number of years. She’s won some teaching awards from what I’ve heard. She seems to really care.” Experience included an understanding of the appropriate methods of teaching children with autism, specifically. Manisha describes her appreciation when her classroom teacher employs techniques that encourage her son to participate, “She gives him really positive reinforcement to do that, and then the special helper stuff sometimes. So, he’s very excited. ‘I want to go to school early, I will do special helping.’” Sukh has worked with the same support teacher over three years, she frequently spoke very highly of this teacher.

She was very experienced, she taught him well, often got him outside, and he listened her, more than myself. She had a better method of teaching… She brought special things for him, special pencils that make it easier for him to write. She already had experience of working with autism.

In the same vein, parents reported teachers as being competent when they were described as having knowledge about autism. Supreet described having a special connection with her integration teacher:

Her current integration teacher has been in Special Ed for years, 15, 20 years. Has a child, grown child, with autism spectrum disorder. Well that's it, that's part of my community, right? So immediately there's a ... Okay,
we're, we're bonded here. Right? You're in Special Ed, so am I. Both integration teachers. Both children on the spectrum. You've got way more experience than I'll ever have, right? Uh, you're um just a wealth of knowledge.

**Subtheme 2.3: Communication.** Common across all the participants, the way a teacher communicated with the parent greatly impacted that parent’s perception of their interaction. Parents appreciated when the teacher communicated with them about their child’s progress in school. They appreciated hearing about their child’s challenges and successes. During either impromptu or formal meetings, parents reported an appreciation when teachers provided honest and accurate updates on their child’s progress. As Supreet describes, “They've been honest to me about any challenges she has had, which I appreciate because I can work on those.” This sentiment was confirmed by Sukh, “They were telling everything about the child, his progress etc. I was happy when she tells me about things he’s doing good in. She says that he is good at Math and shows me that he can do math sheets.”

An important feature related to positive communication involved parents describing feeling respected or that their opinion was valued. When Nisha chose to take her son out of school in November for a break to recharge, she checked in to get the missing classwork from his teacher, and was impressed by the response:

She said, no, he needs a break. You’re right. Give him that break. I have nothing to give you. I was really impressed by that because she recognized it, where more teachers are like you’re pulling this child out of school when Christmas holidays are coming up. There wasn’t any of that from
her. She understood it and she said go with it. Go ahead and give him that break.

Similar to respect, positive teacher communication was built when a parent felt that the teacher was empathizing with them, or treating them kindly. Sukh described this as feeling understood, “They were realizing my problems, and they understood me. Sometimes when he would be late to school, or if I was having a problem with him, they would understand me.”

**Subtheme 2.4: Collaboration.** The subtheme of collaboration was stressed by the participants as a valued aspect of positive interactions. Collaboration moved beyond the style of communication, as it involved the parent and teacher working together on a curricular-based decision for the child. Supreet warmly recalled a collaborative meeting she had with her classroom teacher, “What took place there that day was an example of a very positive meeting. We met for about an hour and we were able to share information both ways and it was positive in the sense that they had some excellent ideas.” When describing collaborative experiences, parents reported that their child’s teacher demonstrated they were open and willing to meet. This often looked like the parent communicating with the teacher at the door, as described by Manisha: “But his grade one teacher was really good. So, I always communicate with her when I was going to pick her if I get the chance, or drop him off.” Supreet reported a similar appreciation, “[The teachers] have always been to, to, been willing to give me time to meet with them.”

If the parent had any concerns about the child, the teacher listened to what the parent said and took that information into consideration. The teacher reportedly worked with the parent to find solutions and ways to support the child. Manisha had a concern surrounding
her son not eating his lunch after the school had to cut-back lunchtime supervision assistants.

At a parent-teacher meeting, the school staff informed her they cut-back on these supervision assistants because there were less reported concerns during lunchtime. She expressed her concern:

…So this time… School’s having a nightly meeting, like there are very few challenges so we don’t need assistance [school cut lunchtime supervision]

Then I said, “I have some challenges. Like safety and lunch.” They said, “Teacher can look over his lunch.” She [the teacher] said, “I can take that responsibility.”

Manisha came back to speak about how much the teacher taking on a personal goal meant to her, reporting that she felt that her son’s teacher didn’t just show care at a surface level, but truly cared for her son.

Because school said we don’t force the kids to eat because that’s not the part of the job. But they said if you have challenges, we’ll see… But I just requested them, so the teacher just accepted this challenge … She doesn’t show [care]. She really cares.

Parents also reported appreciation when the teacher was willing to work with or meet with outside agencies to help support the child. For example, Nisha described a quality she liked in her son’s classroom teacher, “If we ask her to do anything, fill out forms for his different appointments or different therapies, she's always willing to do it. There's never any of this, I can't be doing this. I am too busy. So, we really appreciate that.”

**Theme 3: Negative Interactions with Teachers.** Negative Interactions with Teachers were commonly described by the South Asian parents in this study. The common
elements of negative interactions were described in the subthemes as: Child-Related, Lack of Competency, Negative Communication, and No Collaboration.

**Subtheme 3.1: Child-Related.** The participants frequently referenced their child when describing a negative interaction with a teacher. Teachers were perceived negatively when an interaction between the teacher and child resulted in their child becoming upset or crying. Often, the children were reported as having limited language skills to describe what was happening. Parents reported seeing their child upset, as well as their child’s feelings towards school, as an indicator. Sukh described her discovery of her son’s negative experience with his teacher: “He started getting more and more irritated slowly. Started hiding himself to safe corners. He started missing the school, he wouldn’t want to go to school at all.”

The parent reported not knowing what was happening in the classroom with the teacher. A fear for their child’s safety and well-being arose. As reported by Sukh, “If my child goes to school weeping how I can feel easy. I was not able to see, what was happening in school.” Manisha reported a similar concern regarding a bullying incident with her son, “He’s just being hit like badly; two, three times. When I am at work, I always think about ... if he’s safe, oh God.” This fear resulted in parents feeling helpless to support their child. Nisha describes this in relation to her child crying due to a negative incident with a lunchtime supervisor:

> I think my fear of him not being able to communicate that something was happening to him or being done to him or said to him and he can’t share that with us, I think I was just worried and so upset. It just felt, how am I supposed to help my son? How am I supposed to help my child when he can’t tell me what’s happening to him?
**Subtheme 3.2: Lack of Competency.** When participants had negative interactions with teachers, they commonly reported that the teacher lacked the competency required to complete their role. The teacher was reported as not having the qualifications or experience necessary to know how to work with their child effectively. Children with autism have developmental delays, research has shown they respond better to structure and routine; without structure, they can become easily overwhelmed (ACT, 2016). Parents reported feeling frustration when their child’s teacher did not know how to support their child. Nisha reported:

> The EA was like, “Oh I don’t understand why he’s upset or what he’s doing,” but she didn’t know how to handle him, or what to do, or how to support him; and I found that really frustrating. So, she had no idea about using visual schedules, or breaking down tasks for him in the amount she was supposed to. That part was really frustrating.

Sukh described a similar frustration, where her child’s teachers were not adjusting their method of teaching to best support her son:

> They put many things in front of him to make him happy; however, he gets madder. They don’t explain to him what he’s doing. They just place the things in front of him and tell him to do them.

Similar feelings were expressed, when parents described experiences in which teachers and support staff were not doing what was required of them in their role. Supreet felt disrespected when her integration teacher ignored the laws that required her to invite parents to discuss their child’s IEP. “I don’t think that IEPs drafted without the parents being invited in is respectful at all.”
**Subtheme 3.3: Negative Communication.** Interactions where teachers used a negative style of communication, impacted how the participants perceived that teacher. Participants disclosed experiences where they felt the teacher spoke to them disrespectfully by using bullying and blaming language. Sukh detailed how her child’s classroom and support teacher blamed her efforts, during an IEP meeting regarding her son’s challenges at school:

> But for nothing, she did not cooperate, saying to me that, “You are not helping him.” I said he is not doing work by you who are well experienced, how can he do it by me who am his mother? Asking me in the meeting, also that he does not come up with his homework done.

The teachers were also described as speaking to the parent in a way that undermined the parent’s intelligence. Nisha reported the negative interactions she had with her support teacher to the district. When this support teacher discovered this happened, she reportedly told Nisha that her correspondence with the district had to go through her. Nisha describes:

> I told them [the district] we didn’t want to work with the mainstream support teacher from the school…We don’t find that she’s helpful. She [the mainstream support teacher] came back in September and she had sent me an email saying that any correspondence that goes to the district needs to go through her.

When a parent described their opinions or input as being dismissed by the teacher, they consequently felt unsupported or disrespected. The parents in this study have reported examples of their child’s teacher using a position of power over the parent. In Sukh’s example, the teacher was reported to use language that blamed the mother. Nisha described a
teacher who manipulated facts to ensure the parent wouldn’t independently access higher authorities.

**Subtheme 3.4: No Collaboration.** Negative aspects of collaboration, as described by the South Asian parents participating in this study, involved the teacher not working with the parent in supporting the child in school. This included the teacher ignoring the parent’s emails, or requests to meet. Manisha inquired with her classroom and support teacher, via email, regarding concerns about her child coming home from school with visible signs of physical incidents with his peers.

I know my son, he’s very gentle, he doesn’t do the same thing as they would be, like other kids do that. But he’s just being hit like badly, two three times. So, that’s the email I have sent to [classroom teacher] and [support teacher]. I did not get replies from [support teacher], maybe she’s away or she just ignore me, my emails.

The No Collaboration subtheme includes examples of the teacher not working with the parent to co-create goals for the child. For example, when an integration teacher and classroom teacher broke the law by sending an IEP home to be signed, without inviting Supreet for a meeting. During the interview, Supreet communicated her disappointment with furrowed brows and an audible scoff. Parents also provided examples of teachers refusing to work with outside agencies to gain learning opportunities for supporting the child. Equally emotional, Sukh was exasperated when she described this situation:

Our behaviour consultant spoke to the EA and gave her programs and things to do in the classroom, but the EA refused to do any of them.
Nisha had the same experience; she used the word frustration multiple times during her interview. Especially, when she was describing school professionals who did not make efforts to support her child:

Our behavior consultant went into the school and she had recommendations and they were like, oh we can’t do that. Without making an effort. She’s worked with him. She’s seen him grow. She has some experience that could be valuable in helping him, but they weren’t open to her suggestions which I found really frustrating.

**Research Question Two: What is the Role of Trust in the Relationship Between South Asian Parents with a Child with Autism and their Child’s School?**

**Overview.** The purpose of this research question was to better understand the role of trust in the relationship between South Asian parents with a child with autism and their child’s school. Overall, a total of three themes and five subthemes emerged. Across all South Asian parent participants in this study, a description of Innate Trust was provided as an underlying level of trust in their child’s teachers, as they entered the school system. The culmination of the participant’s experiences in schools, including interactions with the school system and interactions with teachers, contributed to either the maintenance of trust or the violation of trust. Despite the violations of trust, the parent participants in this study described a continued faith and belief in their child’s teachers or future teachers. A diagram describing this process is represented in figure three below.
Research Question 2: The Role of Trust in South Asian Parents’ Relationship with Teachers and the School

Figure 3. Role of Trust in South Asian Parents’ Relationship to Teachers and School.

**Theme 1: Innate Trust.** Innate Trust was described by South Asian participants, when they spoke about their trust for their child’s teachers and school. A philosophy of reverence for teachers has endured throughout history. It was described by Nisha as:

> I think in the South Asian community that’s quite common. We are very accepting of whether it’s a physician anyone with any kind of authority to just accept what they are telling me. You’re believing in what they’re telling you. Having faith that that’s the way it is.

Sukh also described this cultural expectation of faith in school professionals. “There may be a number of South Asian families that simply accept what is given to them. Like this is what there is. This is what is in your plate. You have to eat it otherwise, you will remain without food.” In this study, the South Asian families described entering the school system with a level of Innate Trust. Manisha explains how much trust means to her in her relationship with her child’s teacher:
How we will make the trust? Our kids trust in ourselves, right? My mom and dad. So, we trust in God, too. So, we have to make trust. Trust should not be shakable. We should have trust, right? If we trust in doctor when we are sick, we trust that he will cover us. When he will do surgery, when we go for deliver a baby, we trust him, he will say have the baby, or good baby. So, after surgery everything will be fine. We trust him like a God, right? So, trust is everything.

This concept was strong part of Manisha’s identity and philosophy. Teachers deserved a great deal of respect. In a previous question, when asked if she had ever had a negative experience with a teacher, Manisha quickly reported that she could not have a negative experience with a teacher: “No… I've never had, no. The teacher, they teach our kids, right? So, I don't think so.”

All the parents reported initially trusting the teacher and the school without having a specific reason why. As Manisha responded, when asked if there was any specific reason for her trust, “Not specifically. I just trust them.” Supreet expressed a similar sentiment when asked the same question:

Well I've just trusted them. I've trusted them with her education, with her development, you know her social and emotional development, her cognitive development, her academic development. ... That's, those have been trusting relationships ...

Both Manisha and Supreet described their experiences as generally positive. They experienced negative interactions with teachers in the past. They also expressed their frustration when faced with bureaucracy in trying to get services. Manisha related negative
interactions with teachers, when her classroom and support teacher did not collaborate with her when she was trying to get support for her son. Supreet described two negative experiences with support teachers that did not collaborate with her; she described the challenges as a lack of competency on the part of the teacher. When asked about the proportion of negative relationships compared to positive, she responded, “Yeah, much less. It's basically been a very, very positive relationship. And it's, I think back and I think it's only been with the integration teachers and not all of them...” Both parents had trust when their child began school, and maintained trust throughout their experiences with the consistent positive interactions with the teachers.

Sukh and Nisha both reported starting with trust in the teachers and school system. Sukh described her initial experiences as happy:

The parents have to have a belief that you can happily send the kids to school, the teachers are going to teach the kids nicely. People have a confidence in school... Earlier I was very happy, had full trust.

Nisha reported that she began with a trust in the schools and her teachers, she described trust to be innate:

I think trust for me would be just having faith that if somebody says something to you, you can take it for face value. I don't have to question if you mean it, or your ulterior motive.

As they experienced greater amounts of negative interactions with teachers, as well as bureaucracy, their initial levels of trust became conflicted. Despite the negative interactions, Nisha remained hopeful: “I’m not focusing to these things. I don’t think it helps me get ahead
or it’s not going to help my child. You have to put faith into the system and try and trust what’s being done.” Sukh frequently spoke of having no choice but to trust the teachers:

I do not know. I have no choice other than to trust her, yet my experience is not so good. Teachers are just like mothers and fathers. They spend more time with children then the mothers and fathers do…

When asked if she had trust left in the school, she responded, “I have trust; they may help me next year. I have a belief and trust that next year they will be able to understand him.” Respect and trust in teachers are inlaid in the philosophies of South Asian culture. While this can create an innate trust for parents as their child enters the school system, that trust can either be maintained through positive relationships, or conflicted through negative relationships and bureaucratic structures.

**Theme 2: Maintenance of Trust.** While the participants began with a level of Innate Trust, their experiences and interactions within the school system impacted their levels of trust afterwards. The theme Maintenance of Trust consists of two subthemes, Positive Interactions with Teachers and Reliability.

**Subtheme 2.1: Positive Interactions with Teachers.** All parent participants reported positive experiences with their teachers. These positive interactions contributed to their maintenance of trust during their time in the school system. Sukh had a very positive relationship with a support teacher, “At starting school, I felt myself as a lucky mother. Behaviour consultant was very nice and helpful. [Support teacher] also brought positive changes.” The elements of positive interactions included, seeing the child’s progress over time, the competency of the teachers, the style of communication, and the collaboration with
the parent. In asking for the specific attributes that made that relationship trusting for her, Sukh described:

He got a lot of improvement. I witnessed the positive changes. His teacher was making me updated with his progress. He had a lot of challenges. He gave a tough time to [support teacher] also. He would bite her and scratch her and even leave bruises on her. But she treats him like a mother. She teaches other children also with kindness. I was happy when she tells me about things he’s doing good in. She says that he is good at Math and shows me that he can do math sheets.

When asked how Manisha could tell her child’s teacher was trustworthy, she described seeing emotion in the teacher’s face and the extra goals the teacher took on to collaborate with her.

Because I went to two times parent-teacher meeting and IEP meeting. And I can just see her expression when he improves in academic levels and how she explains what she’s doing and the challenges. She has accepted to work on his lunch. So, it’s working well.

Nisha reported that she felt trust in her relationship with her son’s current teacher and described the important aspects of that relationship to be respectful communication and collaboration.

I respect her and I think she respects our opinions as well. She doesn't just dismiss any of our concerns which I really appreciate. If we come to her and say he's come home and said this, she'll say that's strange. She'll say let me see if that's what I see.
When questioned about the specific behaviours that made her child’s teacher trustworthy, Supreet said that she couldn’t witness the teachers acting with her daughter, but felt they were trustworthy based on her interactions with them.

... But I mean in terms of being in a meeting we're just talking, right, so there's no kind of behaviours ... It's things that they say. Right? I'm not there to observe the next day what they actually do but, well, you know, the mere fact that they're willing to meet ... They want to meet for an hour. They're interested. They have the insight into [my daughter]. They have ideas and suggestions or if I have an idea and suggestion that they're willing to put that into place. All of those things.

**Subtheme 2.2: Reliability.** Parent participants reported that they found the teachers they had good relationships with to be reliable. The parents deemed the teacher as being honest and reliable when speaking with them, they believed what the teacher said and did not have to question it. Nisha reported that she can depend on her classroom teacher:

>If we ask her to do anything, fill out forms for his different appointments or different therapies, she's always willing to do it. There's never any of this, I can't be doing this. I am too busy. So, we really appreciate that.

The teacher followed through on their claims to parents. While she couldn’t witness how her teacher acted with her daughter, Supreet perceived they were trustworthy based on her interactions with them. She described her child’s teacher as following through on his claims:

>Yep. I may not know how, but the fact is he's willing to ask, right? If you wanted to but she doesn't really need supporting. Was he taking the interest
in- willing to ask if she needed it? Would he do so? Did he follow up?

Actually, he did. There was some stuff he did follow up. He did make the
e-mail. He did speak to whoever he needed to speak to. He did call me
back, or e-mail me back. He did all the right things.

The parents were confident in and could rely on the teacher or school. As Manisha
described, “That’s where trust comes from, right? If they’re not reliable, then how I can trust
them?” Sukh explained that her trust in her support teacher was not without cause, “I am not
giving undue value to [support teacher] the only thing is that she can teach my child
efficiently. She teaches in schools, she is experienced, has good method.” The teacher
consistently acted in ways that were beneficial and supportive of the child.

**Theme 3: Violations of Trust.** This theme consists of three subthemes that were
described as trust violations from the parents, including: Bureaucracy, Negative Interactions
with Teachers, and Wariness.

**Subtheme 3.1: Bureaucracy.** The participants reported that experiences of
bureaucracy negatively impacted their levels of trust. The parents expressed concerns that
their child was not receiving the appropriate or enough services, and lamented that the school
has a shortage of resources. Manisha exclaimed:

That’s the one thing to do. So, they should have more teachers. So, if they
have a shortage, then they have to deal with this. It’s not the family who is
depriving of this opportunity for their kids. Hire more staff, right?

This was corroborated by Sukh, “Maybe I can understand that they had limited
resources this year. But I can still keep the belief that they will be able to support him next
year, if not then how much more can a parent keep on believing?”
When a school staff acted as a barrier to receiving services, they were seen as a “keeper of the keys.” Parents described the keeper of the keys as unsupportive, and frustrating to deal with. A lack of transparency in service delivery kept parents out of the decision-making process, leaving them feeling frustrated with the system. Nisha had experiences where she did not trust the teacher after they prevented her child from accessing services that she felt would benefit:

I don’t understand how they justify how they help kids. I don’t understand it and maybe that’s something that I need to learn and educate myself about. It’s very difficult because it’s not. And they’re not sharing how it works, so if I don’t know, then I’m going to assume that you don’t have my child’s best interests at heart and you’re just… If I don’t complain, if I don’t say anything, that’s fine, we’re happy with that. We’ll just keep it at that level.

Parents were not informed of the services available to them, they described feeling lost trying to navigate the system. Nisha described this:

I think because no one tells you these are the resources that are available but unfortunately this is how they’re allocated. If you really want them your child gets wait listed or it depends on … There’s none of that honestly where the information … I find that really frustrating. They won’t disclose what resources are available to your child at all.

**Subtheme 3.2: Negative Interactions with Teachers.** The parent participants reported negative interactions with their teachers as a part of violations of trust during their time in the school system. The elements of negative interactions that impacted parents’ level of trust
included the impact on the child’s well-being, the competency of the teacher, a negative style of communication, and the lack of collaboration with the parent. When asked if the parents trusted the specific teachers they had negative experiences with, the parents reported that their trust was damaged. As Supreet described, “It's only ever happened with two integration teachers that she's had. Um, I don't feel ... I didn't feel there was any trust then.” Nisha reported her distrust with the support teacher she worked with:

How do you trust them without them showing you that they can support you and that they really care about my child because he's not just another kid or another number. In their eyes he is. To me he's not.

Sukh described multiple negative interactions with her child’s current classroom teachers, she reported, “No, I don’t think I can trust her. How can you, when feel like your child is not happy, cries at school?” Her child’s well-being impacted the way she felt about the teachers. She reported her challenges with the competency of the teachers and their lack of collaboration. However, a negative style of communication, where the teacher was reported to use a bullying and dismissive tone towards the parents impacted the parent’s level of trust the most. As Sukh described:

Initially, I was happy. She is an Indian teacher. It was easy for me talk to her. Then things went opposite. She started blaming me. When I started inquiring about [Child], they turned it around on me. Like [Child] leaves books at home, does not complete homework, and misses things etc. I told them that wasn’t the problem, it’s not about books, I wanted to know why he was crying, he wasn’t going to school. But they were not ready to make efforts.
**Subtheme 3.3: Wariness.** Parent participants reported that they found the teachers they had negative experiences with, tended to not follow through on their claims to parents. Nisha described multiple negative interactions with her support teacher, and found that it impacted her ability to trust in the system: “I think it was just nobody was forthright. It didn’t seem there was honesty there. That you were given information but there was no follow through.” That same parent goes on to describe the difficulties of working with the school and being able to trust that they would provide services, “I don’t take anything at face value. If you tell me something’s going to happen, until it happens, I’m not going to believe you.”

A feeling of wariness was described when the parents interacted with the teachers they had lost their trust in, due to previous negative interactions and bureaucracy. Supreet described this, “Yeah. Because you do, you feel wary of the person afterwards. But yeah it's been ... But she's had a few integration teachers, that was just two of them.” The parent did not believe they could rely on the teacher/school. The parent deemed the teacher as being dishonest when they spoke to them, the parent does not believe what the teacher says and does not expect delivery of claims until they see it.

**Summary**

A total of six broad themes were identified across four South Asian mothers of children with autism in elementary school in the Lower Mainland. Two additional contextual lens’ were identified that split the participants in two groups. One group of participants approached problems in the school system with the knowledge of the intricacies of the system and understood how to work the system in a way that yielded the best results for them. The other group of parents did not have a clear understanding of the school system or
the language to clearly articulate their problems with the school system, therefore their authority remained unrecognized with the system.

In response to the first research question, three themes provided an understanding of the experiences of South Asian mothers in the school system. These themes included their interactions with the system when trying to advocate for services for their child, as well as their positive and negative interactions with teachers. Features of positive and negative interactions involved levels of collaboration, styles of communication, levels of competency, and the way their child reacted to the teacher. The second research question addressed the role of trust in the relationship these families had with their teacher. Trust is a unique construct in South Asian culture. Historically, teachers have been likened to mothers, fathers, and Gods. While this is an antiquated notion, it remains ingrained in the culture as a philosophy. The thought of trusting a teacher is innate. That trust is either maintained through consistent positive interactions with teachers, or it is violated and lost through consistent negative interactions with bureaucracy and teachers.
Chapter Five: Discussion

Overview

The aim of this study was to better understand the lived experiences of South Asian mothers of children with autism in the school system, the role of trust within the home-school relationship was examined as a phenomenon. Several noteworthy findings were revealed in the data. Certain findings were particularly interesting, including the contextual lens’ through which the parents approached problems in the school system and the sense of innate trust of the South Asian parents in the present study. These areas are explored below.

Themes in the Context of Previous Research

Role of trust. Trust was described by South Asian parents in this study as being initially innate. Innate trust in the child’s teachers and the school system was described as obvious and unquestioned. The parents reported that they had no choice but to put their trust in their child’s teachers and to have faith that the teachers would do their best to support their child. Western culture typically describes trust as developing over time, an initial provisional trust is granted to the other party based on an individual’s disposition to trust (Tschannen-Moran, 2014). A disposition to trust can be high or low depending on past experiences; a high disposition to trust may lead an individual to give several chances to another after experiencing untrustworthy behaviour (Tschannen-Moran, 2014). However, this is still different from innate trust, where a parent’s disposition to trust is not based on their individual experiences, but is built to be a part of their cultural ethos (Choi & Han, 2011; Kong, 2013; Wang & Casillas, 2013).

In South Asian culture, a great deal of respect is presented to teachers. Historically, they have been referred to as “gurus” and likened to be at the same level of respect as
mothers, fathers, and Gods (Grewal, 2010; Ratnam, 2013; Ravindran & Myers, 2012). This is described in a famous poem by Saint Kabir, “Teacher and God both are here, to whom should I first bow? All glory be unto the teacher, path to God who did bestow.” Culturally, since the early Vedic Period (2000 Before Common Era), there has been a sense of paternalism, where the teacher is automatically considered the expert and deserves the utmost respect (Ratnam, 2015). Insight into the historical practices that colour societal values provides a glimpse into a part of the rationale behind the innate trust of teachers for the South Asian participants in this study.

The parents described the experience of innate trust in their child’s teachers as they entered the school system. This trust was either maintained through positive interactions that left parents feeling they could rely on teachers, or violated through challenges with bureaucracy and negative interactions that left parents feeling wary of teachers. Descriptions of the maintenance and violation of trust were in line with what has been reported to build and violate trust in parent-school relationships in the literature (Angell et al., 2009; Jessop, 2018; MacLeod et al., 2017; Stoner & Angell, 2006). The four mothers in this study all reported feeling trust in the beginning. They all reported negative experiences in their interactions with the system and their interactions with teachers. However, the frequency and type of negative interaction ultimately impacted the way they described their trust with the school and teachers at the time of the interview.

All parent participants reported varying levels of trust after their experiences in the school system. Each parent described trust in a unique way, as shaped by their personal background. Manisha and Supreet reported their experiences with the school system to be mainly positive. Both reported negative interactions with the bureaucracy of the system when
trying to get services, and a lack of collaboration with their classroom teachers where the parent’s wishes were not recognized. However, these incidents were perceived as minimal compared to their positive interactions with teachers. Their trust in the school system and teachers was maintained. Manisha reported the greatest level of trust in the teachers compared to the other parents. She likened her trust in teachers to her trust in God and medical doctors. She described interactions with teachers that were negative, but did not perceive the teacher as being wrong. From her perspective, she has never had a negative experience with a teacher. Supreet reported two events as being negative throughout her child’s schooling. She described being wary of the teachers she had the negative experiences with, but overall reported always trusting her child’s teachers. Supreet reported having full faith in the teachers when she sends her child to school.

Sukh reported multiple negative interactions with her child’s current classroom and support teacher, and Nisha reported a greater amount of negative interactions with bureaucracy when seeking services. They were left feeling wary of particular teachers after frequent negative communication, including the reported use of bullying or blaming language. Research has described the power imbalance between parents and teachers as favouring the school professional (Harry, 2002; Goss, 2017; Jackson, 2018). This hierarchical difference in power may lead to the use of bullying and blaming language, as described by parents in their interactions with teachers (Bacon & Causton-Theoharis, 2013; Goss, 2017; Jackson, 2018). In a survey of parental experiences in special education, sixty-four percent of parents reported not feeling respected by school professionals, and twenty-six out of forty-two teachers were reported to have blamed the parent for their child’s academic problems (Mueller & Piantoni, 2013).
Sukh reported having a lot of trust with her teachers and the school until her child entered the current school year, where he reportedly had negative interactions with his classroom and support teacher that left him frequently crying and refusing to attend school. Sukh described struggling with teachers who would not collaborate, she reported feeling bullied and blamed for her child’s behaviour. This lasted for eight months before she enlisted the help of an advocate to speak to her child’s teachers. Collaboration is frequently cited as being a key factor to the development of trusting relationship between parents and schools (Cobb, 2014; Jessop, 2018; Lam & Kwong, 2012; MacLeod et al., 2017). Parents in special education have frequently reported that their school team does not consider their input when making decisions about the child (Jackson, 2018; Jessop, 2018; MacLeod et al., 2017).

Nisha reported that she felt trust in the school system when she began the process of getting her child enrolled, but as the enrolment process developed she felt disappointed with the bureaucracy of the system. She reported having “restored faith” when her child started school, but described many subsequent negative interactions with the school system. She frequently felt as though there was a “keeper of the keys” that prevented her child from receiving the services and support she felt he needed. This echoed findings from Goss’s (2017) qualitative study examining the barriers to parental involvement of 14 parents in an urban school district. Participants reported feeling kept in the dark about the decision-making process for discipline policies and service delivery (Goss, 2017). Frustration is commonly reported when parents describe not understanding why decisions are made in different ways in special education (Jackson, 2018; Jessop, 2018; MacLeod et al., 2017).

Sukh and Nisha reported more frequent violations of trust, this may have led to a breakdown in their initial innate trust. Their trust was described to be conflicted at the time of
the interview. The parents reported having a continued hope and belief in future teachers, but had lost trust with the teachers they had negative interactions with. Sukh described a continued trust and faith in the school system and teachers. At the time of the interview, she reported having no choice but to trust her child with his current teachers, but having a belief and faith that the teachers next year would be better. The multiple negative interactions with the system that governs service delivery had left Nisha questioning the school system: “We all want to be able to just go through the motions and get the support with the understanding that people genuinely want to do good.” Ultimately, she felt that she had to put her faith into the system and described herself as trying to trust: “You have to put faith into the system and try and trust what’s being done.”

The way that the parents in this study described trust, is different from studies examining trust in special education whose participants are mainly Caucasian. Stoner and Angell (2006) examined the role of trust in teacher relationships from the perspective of eight, middle-class Caucasian parents of children with autism. They found that all the participants reported not having trust in their teachers initially (Stoner & Angell, 2006). Their research reflected much of the extant literature that describes parents spending more time involved with their child’s teacher initially and having trust once they felt that the teachers had proven themselves to be trustworthy (Angell et al., 2009; Macleod et al., 2017; Stoner & Angell, 2006). In a qualitative study examining perspectives of the IEP process, the majority of parents reported the importance of having a teacher you could trust and the importance of establishing a trusting relationship (Jessop, 2018). However, one Caucasian parent in the study was described as having innate trust in her classroom teacher because she was confident in their expertise (Jessop, 2018). This drives the importance of the individuality of
each parent’s contextual lens, and the importance of tailoring work with parents to be culturally responsive.

Contextual lens. There were many similarities in the four participants within this study. They were all South Asian mothers of children with autism in elementary school in the Lower Mainland of British Columbia. Yet, there were distinct differences across all the participants. Each mother came with her own unique history. A shared cultural background provides a blueprint that each member of its diaspora colours with their individual experiences. Sukh and Manisha had similarities in their experiences; their histories impacted the way they approached problems in the school system. This was different from the way Supreet and Nisha approached problems with their child’s teachers.

Supreet and Nisha are South Asian; however, as members of the diaspora, they have the advantages of having been raised in Western society. They understand the medical model that governs service delivery in Canada. Empowered with a sense of awareness of resources, these parents knew how to advocate for their children in ways that school professionals recognized. They knew what language to use; they knew who to contact in the district to get their voices heard. This finding is similar in Jessop’s (2018) qualitative research examining parental perceptions of meaningful engagement in IEP meetings of seven Caucasian mothers and one African-American mother in a suburban demographic of Nebraska. Parents in this study reported feeling a sense of determination in knowing their rights and understanding the school system (Jessop, 2018). As a parent described in Jessop’s (2018) research, having a background working in the school system armoured them in their meetings with school professionals. Both Supreet and Nisha sought to become experts in autism after their child’s
diagnosis and both took positions as advocates in an agency that supports families with children who have autism in schools.

Extant literature has reported parents feeling as though their credentials have been minimized by educators (Bacon & Causton-Theoharis, 2013; Cobb, 2014; Goss, 2017; Jackson, 2018; Jessop, 2018; MacLeod et al., 2017). In a study that examined IEP experiences from 35 parent advocates who were active in an online Facebook group, MacLeod et al. (2017) reported the urgent plea for educators to consider the parent as an expert and equal participant when collaborating on IEP goals. The parents in this study considered themselves the expert and felt that educators tended to respond negatively if they questioned their judgement (MacLeod et al., 2017). Common across research that describes parents as being forceful advocates in the school system, are participants who are typically not culturally and linguistically diverse from Western culture (Bacon & Causton-Theoharis, 2013; Burke & Goldman, 2018; Cobb, 2014; Jackson, 2018). Culturally and linguistically diverse families may face more barriers to engagement than families that are a part of the mainstream culture (Bacon & Causton-Theoharis, 2013; Burke & Goldman, 2018; Cobb, 2014; Epstein, 2001; Ennis-Cole, Durodoye, & Harris, 2013).

The knowledge, languages, and philosophies that make up a parent’s lifeworld impacts the way they understand and approach situations (Cobb, 2014; Eatough & Smith, 2017; Smith & Eatough, 2016). A parent’s education, primary language, and creed impacts the way they are positioned in a society, as well as the way members of that society consider them (Cobb, 2014; Goss, 2017; Panofsky & Vadeboncoeur, 2012). This ultimately influences the parent’s interactions in social contexts, such as interactions with schools (Cobb, 2014; Panofsky & Vadeboncoeur, 2012). It is an advantage to understand the medicalized discourse
in special education, as well as the bureaucratic structure of the school system; these are resources not all parents have access to (Bacon & Causton-Theoharis, 2013; Cobb, 2014; Panofsky & Vadeboncoeur, 2012). Research has shown three common perceptions of middle-class parents that afford them access to these resources: a presumption that they are entitled to have the institution accommodate their child’s specific needs, they are comfortable speaking their opinion and concern to people in authority, and they will climb the hierarchy of authority to achieve their interests (Harry, 2002; Jessop, 2018; MacLeod et al., 2017; Panofsky & Vadeboncoeur, 2012). School professionals, in turn, easily recognize the middle-class parent participation, which allows the parent to negotiate a level of status and power (Bacon & Causton-Theoharis, 2013; Cobb, 2014; Harry, 2002; Panofsky & Vadeboncoeur, 2012).

It follows that a parent who does not have access to the resources afforded by middle-class parents, may be disadvantaged in social interactions with school professionals (Cobb, 2014; Goss, 2017; Panofsky & Vadeboncoeur, 2012). These resources include understanding of the structure and discourse of special education; as well as other social resources, such as financial mobility and supportive social networks (Cobb, 2014; Harry, 2002; Panofsky & Vadeboncoeur, 2012). Sukh and Manisha experienced greater barriers in their interactions with the school system, their resources were limited in comparison to the other participants. They were both raised and educated in India and moved to Canada after marriage. Their support network in Canada was described as limited. Sukh reported being alone and living as a single parent, with occasional help from her mother-in-law. Manisha reported managing her son’s treatment alone, stating that her husband has difficulty accepting the diagnosis. Their highest level of education was high school and their second language was English. They both
described struggling to manage their child’s treatment financially. An understanding of how social inequalities can impact parents, will help educators to understand ways to better foster engagement and comfortability with the school system.

**Implications for Educators**

Trust is an essential component in the relationship between parents with children who have special needs and their child’s teachers (Angell et al., 2009; Haines et al., 2015; MacLeod et al., 2017; Stoner & Angell, 2006; Tschannen-Moran, 2014). South Asian cultural ethos, as developed from deep-rooted and historic practices, demands respect and faith in teachers (Ratnam, 2013). An innate trust can impact and change the way a family engages and approaches the education system. Educators may tailor their approach in their interactions with South Asian parents when they are cognizant of what trust could look like for South Asian families.

Each South Asian family has their own unique philosophy and history that colour the perceptions, feelings, and actions that make up their lifeworld (Eatough & Smith, 2006; Smith & Eatough, 2016). The contextual lens that was described in this study, highlights the diversity of experience and perspectives within South Asian culture. In line with previous research, it is essential to not make assumptions or cast stereotypes over a South Asian parent, but to tailor intervention within the specific context of the individual (Daudji et al., 2010; Heer et al., 2012; Rizvi, 2017; Zechella & Raval, 2016).

The contextual lens highlighted that some parents are advantaged in their interactions with the school system, because they are aware of the knowledges, languages and philosophies of special education in Western society. To support the parents who may not have the background knowledge to navigate the system, it may be helpful to meet with
parents to gain an understanding of what they know about the system of special education. This would also provide an opportunity for educators to understand how that parent conceptualizes disability and learn about the ways that parent may support their child in ways that are unique to their culture. Asking the parent what their expectations are of the educator, and the educator describing their role in the child’s education, will help to establish understanding. A clear description of the way services are triaged in special education can help parents to better understand why or why not their child is receiving what they perceive to be beneficial for their development. Finally, encouraging parents to connect with outside agencies may help them to better understand the school system and advocate for themselves.

It is not possible to reach a level of cultural competence for any ethnic minority, as individuals who are a part of that culture each have a unique identity that may or may not take on common traits of the culture (Heer et al., 2015; Jones, Lee, Zigarelli, & Nakagawa, 2017; Rizvi, 2017; Zechella & Raval, 2016). It is imperative to take a culturally responsive approach, where educators take the time to recognize the beliefs of parents and adapt interactions and interventions in ways that respect that family’s values (Jones et al., 2017). Research provides us with a framework to understand families and inform our practices. However, broad strokes cannot be brushed over the intricate details that make up an individual’s identity.

**Implications for School Psychologists**

School psychologists are unique members of the school community. They are regarded as leaders and agents of change within the school. A school psychologist can help by encouraging school staff to take into consideration the unique cultural factors that can impact a parent’s engagement and the ways that the teachers can be culturally responsive to
the needs of the families. A staff presentation on how to be culturally responsive can be a broad training opportunity for teachers to consider differing ways parents approach special education. Providing one-to-one consultation with teachers who are looking for support in working with their families can be a way of maintaining that training over time.

The school psychologist can also offer presentations to parents of the community demystifying the special education system, and describing the process through which services are delivered to students. The presentations would need to be held at accessible times for parents who may work during the day, and offer child-care for parents who may not have access to that resource. The school psychologist has the potential of being an ombudsperson between parents and educators, acting as an ally for parents who may feel their child is having a disservice.

**Limitations and Strengths of the Study**

**Limitations.** The present study has contributed to the literature on trust in South Asian families with children with autism in school. However, there are limitations in the study. As this was a small n qualitative study, the findings cannot be generalized to large populations. The study was originally intended to understand South Asian parent perspectives; however, only mothers participated in the research. While in the current study voice is given to the perspectives of South Asian mothers; the perspectives of fathers, and others, are needed for a holistic understanding of the parent/family perspective. Homogeneity of the sample is a key feature in IPA research (Eatough & Smith, 2017). While all the mothers were a part of the South Asian diaspora with a child with autism in elementary school in the Lower Mainland, there was heterogeneity in their experiences. Two of the mothers were raised in Western societies, had a University education, and represented a
higher socioeconomic demographic. The other two mothers were raised and completed their high-school education in India. They immigrated to Canada after marriage and represented a lower socioeconomic demographic. The differences in demographics between the two groups of participants appear to have impacted the study findings, creating differences in the contextual lens’ of the participants. Greater restrictions surrounding participant selection may have helped to minimize the differences in demographics.

**Strengths.** Despite the limitations, there are strengths in the study that highlight its significance. The history and practices that have developed and passed through generations in India create a unique perspective for South Asian families, especially when they interact with educators. Extant literature has typically examined trust in special education from the Caucasian perspective (Angell et al., 2009; Jessop, 2018; Stoner & Angell, 2006). In this research the experience of trust for South Asian families, an under-represented population in the trust literature is highlighted. Another strength is the use of IPA as a methodology, which frames the goal of the research to gain an in-depth account of the individual’s experiences (Smith & Eatough, 2017). The need to consider the individual’s perspective was a highlighted feature of the present study; therefore, IPA was well-suited as a methodology. The role of the researcher has proven to be a strength in this study. As a South Asian woman who has been raised in a traditional family, the researcher has personal experience of the cultural values that dictate innate trust in educators. The researcher had insight into the unique needs of South Asian families through her experiences of working with South Asian families of children with autism, and her outreach work surrounding the stigma of mental illness and disability in the South Asian community.
Future Directions

There is a paucity of research on the experiences of trust in minority families in special education (Jessop, 2018; Stoner & Angell, 2006; Tschannen-Moran, 2014). An understanding of the perspectives and experiences of trust across minority families in special education will help service-providers to open their eyes to the perspectives of different families. Concerns have been reported in the literature about the challenges of engagement of minority families in special education (Harris et al., 2009; Harry, 2002; Hodges, 2013; Kalyanpur et al., 2010). Trust is known to be a key feature of parent engagement (Angell et al., 2009; Jessop, 2018; MacLeod et al., 2017; Stoner & Angell, 2006; Tschannen-Moran, 2014). As the role of trust has been shown to be unique to the previous literature in the present study, it gains to understand the role trust for other cultures. This may help to better understand the barriers to engagement in special education for different families, and inform culturally responsive approaches to support engagement.

Future research should consider addressing the limitations described in the study above. Further research examining the role of trust for a greater number of South Asian parents, including South Asian fathers, will help with generalizability. Given the role of the extended family in South Asian culture expanding the interpretation to all family members involved in the schooling of the child would be valuable. This study examined the experiences of South Asian parents with a child with autism specifically, it would be interesting to find what the experiences are for South Asian parents who have a child with different disabilities. An understanding of the teacher perspective of working with South Asian families will give voice to the other half of the conversation and experiences described by parents. Future research should also consider measuring the differences in experiences of
South Asian parents in special education across different demographics, including how recently the family has immigrated. Parents who have been raised in Western society and have an intimate understanding of the bureaucratic structure of the special education system, may have different experiences from parents who are new to the country. This will help to provide further information on the contextual lens’ as found in this study.

**Conclusion**

In this study, the lived experiences of four South Asian mothers of children with autism in the school system, and the role of trust within the home-school relationship was explored. It is a small step towards understanding how trust differs across cultures. The findings demonstrate the importance of taking a culturally responsive approach when working with South Asian families in the school system. The importance of positive interactions with teachers were highlighted to include positive child outcomes, competency, a kind and empathic style of communication, and open collaboration. The reliability of positive interactions with teachers contributed to a maintenance of trust. Negative interactions with teachers was shown to include negative child outcomes, a lack of competency, and no collaboration. A negative style of communication was shown to have the largest impact on trust. The lack of transparency and bureaucratic nature of service delivery was reported by all participants to impact trust. The findings from this study add to the literature on South Asian families in the special education system, highlighting the unique experience of trust for South Asian families. It is hoped that future research will expand the literature on trust for culturally diverse families.
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Appendix A: Preliminary Interview Protocol

I asked participants to share a story about their child. This was to get participants to open up about speaking about their family and prime them to think about their child.

1. Tell me about your child’s school.
   a. Tell me about your first interaction with your child’s school. What happened and how did it make you feel?
   b. Tell me about a typical interaction between yourself and your child’s school.

2. Tell me about your relationship with your child’s teacher. How would you describe it?
   a. Is it a positive relationship? Negative? In what ways?
   b. Do you feel as though your child’s teacher knows how to best support your child?

3. What does trust look like for you? Can you describe a relationship in your life that you have with someone you trust?
   a. Tell me about an experience you have had where you felt trust.
   b. Tell me about an experience you have had where you did not feel trust.

4. Do you trust your child’s teacher/school?
   a. Do you feel as though your child’s teacher is honest with you?
   b. Can you depend on your child’s teacher?

5. What do you need to improve your relationship with your child’s teacher/school?

6. What do you need to feel supported and safe in your child’s school?
Appendix B: Background Questionnaire

Nationality, Race/Ethnicity:
As a South Asian person, which country is your family from? _________________________

Where were you born?
Born in Canada
    o Please specify province or territory: _________________________

Born outside Canada.
    o Please specify country: _________________________

Of what country(ies) are you a citizen? Indicate more than one country, if applicable.
    □ Canada, by birth
    □ Canada, by naturalization
    □ Other country. Please specify _________________________ (space to fill in)
    □ Other country. Please specify _________________________ (space to fill in)

Family:
How many children do you have? _________________________

What is your relationship to your child?
    _____ Biological Mother
    _____ Biological Father
    _____ Grandmother
    _____ Grandfather
    _____ Aunt
    _____ Uncle
    _____ Other

How many people currently live in your home?
    _____ Number of adults including you
    _____ Number of children and youth aged 19 or younger

Are there other adults who provide a caregiving role for your child?
    _____ Yes _____ No

What is their relationship to your child? _________________________

Please describe the current employment status for each of the following caregivers currently living in your home:

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>You</th>
<th>Other Caregiver (Specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working full-time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working part-time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time student</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part-time student</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not employed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C: Recruitment Letter

South Asian Families with Children with Disability:  
The Role of Trust in their Relationship with Schools  
SCHOOL REQUEST FOR HELP WITH PARENT RECRUITMENT

Principal Investigator: Laurie Ford, Ph.D.,  
Department of Educational & Counselling Psychology  
& Special Education  
Phone: XXX-XXX-XXXX  
Email: XXXXX@ubc.ca

Student Co-Investigators: Shalini Arya  
Department of Educational & Counselling Psychology  
& Special Education  
Phone: XXX-XXX-XXXX  
Email: XXXXX@ubc.ca

________________________
________________________
________________________

Dear Principal,

We are writing to see if you will help us locate families to take part in our research study. We want to learn more about parents experience with their child’s school, particularly about how they believe trust is involved in that relationship. Your helping us locate families to take part in the study is very important to help us better understand experiences concerning the relationship between schools and South Asian families who have a child with identified special educational needs. This letter is intended to introduce you to the study and to describe what it would mean for the families to take part and for you to help us.

What is the purpose of the study?

The purpose of the study is to learn about what trust means to South Asian parents who have a child with identified special educations needs in their relationship with schools. Trust is an important part in parents developing a good relationship with their child’s school. The aim of this study is to better understand what trust looks like for South Asian families with children with special needs, and their relationship to their child’s school. There is not much research that has explored the relationship South Asian parents who have a child with identified special needs have with their child’s school. There is also no information on how South Asian parents experience trust in their relationship with their child’s school. We hope the results of this study will help us better understand effective ways to foster a trusting relationship for South Asian parents who have a child with identified special education needs and their child’s school.
What is involved if the parents take part in the study?
The research study involves taking part in a one-to-one interview with the researcher. The interview will take approximately 60 to 90 minutes and will be conducted at a time and place the parent and the researcher agree on. There may be a need for a brief follow-up interview to expand on or clarify information from the first interview, if so, this will take no more than 60 minutes. With their permission, the interviews will be audio-recorded and transcribed. Your identity will remain confidential, but parts of your interview and/or direct quotes from the interviews may be used in Ms. Arya’s thesis without sharing any identifying information. If you would like, a summary of the results will be sent to them once the study is completed.

Taking part in this study is voluntary and they refuse to take part or withdraw at any time. More details will be given when they provide their informed consent prior to the interview.

How are we asking the school to help us?
If you are willing to help us, we will give you recruitment letters to give letters to the resource teacher or other teaching providing service to parents of students receiving special education services at your school. We are particularly interested in working with parents who are South Asian and have a child receiving special education services. We will give you the number of letters you think you need in an envelop and ask you to send the letter home with the student with their other materials at the end of a school day. That is all you need to do. If the parents are interested, they will contact us directly with any questions or to let us know they want to take part.

If you are willing to help us by sending our letters home with families, please contact Shalini Arya by email or phone number listed at the beginning of this letter.

Sincerely,

Laurie Ford, Ph.D.  
Associate Professor  
Principal Investigator

Shalini Arya, B.A.  
M.A. Student in School Psychology  
Co-Investigator
Appendix D: Parent Consent

South Asian Families with Children with Disability:
The Role of Trust in their Relationship with Schools

PARENT CONSENT

Principal Investigator: Laurie Ford, Ph.D.,
Department of Educational & Counselling Psychology
& Special Education
Phone: XXX-XXX-XXXX
Email: XXXXX@ubc.ca

Student Co-Investigators: Shalini Arya
Department of Educational & Counselling Psychology
& Special Education
Phone: XXX-XXX-XXXX
Email: XXXXX@ubc.ca

Dear Parent/Guardian/Caretaker,

Please read the following information carefully. This is a request for you to take part in the study that we are doing. If after reading this letter, you would like to take part in this research study, please sign one copy and return in the envelope provided (or in person at the time of the interview). Keep the other copy for your records.

Purpose:
The purpose of this research study is to explore the phenomenon of trust for South Asian families with a child with a disability, within the families’ relationship with the school. We are talking with parents and caregivers of students with a disability to better understand: 1) their experiences as a South Asian parent or caregiver with a child with disability in schools, 2) the role these families perceive that trust plays in the home-school relationship with their child’s school.

Research Study Participation:
1. Taking part in the study means that you will take part in a one-on-one interview about your experiences receiving services for your child with identified special educational needs including your relationship with the school, your experience with meetings with school personnel, your experience getting information about your child from school personnel, and the process of working with school staff to plan an educational program for your child.

2. The interview will take place at your home or another location mutually agreed upon that is quiet and works well for you. The interview will take approximately 1 to 1.5 hours. We may ask for you to take part in a second interview by phone or in person if we both agree. The second interview will take more than 1 hour.
3. The interview will be audio-recorded and notes will also be taken. The researcher will then transcribe the interview, from the audio recording.

4. If you agree to take part in the study, we will ask you to answer a short background questionnaire following the interview.

5. After the interview is transcribed the researcher will contact you to give you an opportunity to review the transcript for accuracy, clarification, and need for any changes. This may take up to 60 minutes and will be done in person or by phone, your choice, with the interview transcript sent to you in advance via password protected file.

6. We are not aware of any risks if you take part in our study. However, if you feel uncomfortable, you may choose to stop at any time. If any of the questions in the interview make you feel uncomfortable, you may chose not to respond to those questions. You are welcome to contact us with any questions.

7. Taking part in the study means that you agree to the information being used for the purpose of reporting the results of the research in presentations or publications. This information will help to provide more information about the needs of South Asian families with children with special needs in schools. However information identifying you directly will not be included.

8. The information you give us is confidential. **No individual information will be reported and no participant will be identified by name** in any reports about the study. The information will not be shared your child’s school or teachers. The information collected will be stored in a locked filing cabinet and with electronic files password protected and encrypted at the university office of the researchers. The only people who will have access to the information you give us are the researchers working on this study.

9. As a thank-you for your time and any transportation expenses, each person who takes part in the study will receive a $10 gift card to a local business. The researchers will also provide child-care on site if it is needed.

10. If you have any concerns or complaints about your rights as a research participant and/or your experiences while taking part in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at the University of British Columbia at (604) 822-8598 or if long distance, email at RSIL@ors.ubc.ca or call toll free at 1-877-822-8598.

11. If you are interested in taking part or would like to learn more about the study and what is involved, you may contact us by phoning the research project office at XXX-XXX-XXXX or by sending us an email at: XXX@ubc.ca
Consent to Participate in this Research Project

By signing below, it means you consent to take part in this research study. When you sign below it also means that you have received a copy of this consent form for your own records.

___________________________________
Your Name (Please Print)

___________________________________
Your Signature Date

Additional Questions
If you would like a summary of our results upon completion of the study, please indicate below and provide your email and mailing address so we can send you a copy.

Full Mailing Address (include city and postal code):

Email: ____________________________ Phone: _____________
Appendix E: Intercoder Calculations

Table 3

*Intercoder Reliability and Agreement Calculations*

<table>
<thead>
<tr>
<th>Broad Themes</th>
<th>Intercoder Reliability</th>
<th>Intercoder Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interactions with the System</strong></td>
<td>80% to 100%</td>
<td></td>
</tr>
<tr>
<td>Fear of Unknown</td>
<td>4/5 = 80%</td>
<td>5/5 = 100%</td>
</tr>
<tr>
<td>Bureaucracy</td>
<td>5/5 = 100%</td>
<td></td>
</tr>
<tr>
<td>Advocacy</td>
<td>4/4 = 100%</td>
<td></td>
</tr>
<tr>
<td>Sacrifice</td>
<td>3/3 = 100%</td>
<td></td>
</tr>
<tr>
<td><strong>Positive Interaction with Teachers</strong></td>
<td>75% to 100%</td>
<td></td>
</tr>
<tr>
<td>Child-Related</td>
<td>4/5 = 80%</td>
<td>5/5 = 100%</td>
</tr>
<tr>
<td>Teacher Competency</td>
<td>3/3 = 100%</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>6/8 = 75%</td>
<td>6/6 = 100%</td>
</tr>
<tr>
<td>Collaboration</td>
<td>4/4 = 100%</td>
<td>6/6 = 100%</td>
</tr>
<tr>
<td><strong>Negative Interaction with Teachers</strong></td>
<td>86% to 100%</td>
<td></td>
</tr>
<tr>
<td>Child-Related</td>
<td>6/7 = 86%</td>
<td>6/6 = 100%</td>
</tr>
<tr>
<td>Lack of Competency</td>
<td>6/6 = 100%</td>
<td></td>
</tr>
<tr>
<td>Negative Communication</td>
<td>3/3 = 100%</td>
<td></td>
</tr>
<tr>
<td>No Collaboration</td>
<td>7/7 = 100%</td>
<td></td>
</tr>
<tr>
<td><strong>Innate Trust</strong></td>
<td>7/7 = 100%</td>
<td></td>
</tr>
<tr>
<td><strong>Maintenance of Trust</strong></td>
<td>63% to 100%</td>
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</tr>
<tr>
<td>Positive Interactions with Teachers</td>
<td>16/23 = 63%</td>
<td>23/23 = 100%</td>
</tr>
<tr>
<td>Reliability</td>
<td>3/3 = 100%</td>
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</tr>
<tr>
<td><strong>Violation of Trust</strong></td>
<td>73% to 100%</td>
<td></td>
</tr>
<tr>
<td>Bureaucracy</td>
<td>5/5 = 100%</td>
<td></td>
</tr>
<tr>
<td>Negative Relationships with Teachers</td>
<td>11/15 = 73%</td>
<td>15/15 = 100%</td>
</tr>
<tr>
<td>Wariness</td>
<td>6/6 = 100%</td>
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</tbody>
</table>