HOW PARENTS OF CHILDREN WITH AUTISM ACCESS SERVICE: THE RECOLLECTION OF EIGHT FAMILIES

by

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Abstract

Autism Spectrum Disorder has an increasing prevalence in children; diagnostic tools have become more refined and children are diagnosed younger. Parents of children with ASD learn to cope with challenges. It was hypothesized that many parents in the lower mainland of British Columbia are self-educating instead of learning from healthcare professionals. It was also hypothesized that parents are unaware of the resources available to them after receiving a diagnosis, and are therefore seeking help for their child and assembling services in much the same way they self-educated themselves. Eight families were interviewed about their experiences post-diagnosis. It was observed that families varied greatly in emotional response and were provided with information from a physician. However, few actually used the information provided to achieve a service assembly. This qualitative research revealed that families experience relational strain and parents desired a resources to guide, support, and educate them throughout their autism journey.

Keywords: Autism Spectrum Disorder, relationship strain, parent and family education, qualitative method.

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CHAPTER ONE: INTRODUCTION

Rationale and Context of the Current Study

The prevalence of Autism Spectrum Disorder (ASD) has increased substantially over the last 12 years. In British Columbia as of 2007, one in 209 children aged 0-18 were diagnosed with ASD. From census statistics available in 2015, that number rose to one in every 68 children aged 5-18 (Government of British Columbia, 2016). Elsewhere, the prevalence of ASD is reported as one in every 64 children within Quebec, one in every 79 children in New Brunswick, and one in every 57 children in Newfoundland and Labrador aged 5-18. Data as of 2015, averages one in every 66 children across Canada aged 5-18 are being diagnosed with Autism Spectrum Disorder (Government of Canada, 2018).

This increase in rate of children in BC receiving an ASD diagnosis may result from breakthroughs in better diagnostic tools and increased awareness of the indications and behaviours of ASD. As reported prevalence of ASD increased over time, there was a concomitant rise in research into how parents and families cope with receiving such a diagnosis, and how ASD affects families: the individuals within the family, the family as a whole, and external family relationships (Kasari & Sigman 1997; Glasberg, Martins, & Harris, 2007; Hastings, 2008; Dabrowski & Pisula, 2010; Giallo, Wood, Jellett & Porter, 2013).

Many studies look into the difficulties and challenges of raising a child with ASD, and many more look into therapies and interventions that are most effective in treating and shaping behaviours for children with ASD.

The government of British Columbia in partnership with the Ministry of Children and Family Development (MCFD) has established helpful funding and resources for families. With the help of MCFD and local Child Development Centres, children and families with an Autism

Spectrum diagnosis have resources available to them such as: speech language pathologists, occupational therapists, physiotherapists, respite-care, counsellors, and others.

After receiving an Autism Spectrum Disorder diagnosis, parents are provided with a folder or binder with information pertaining to autism. This folder contains resources, definitions, and a list of contacts that parents need to obtain funding (e.g., a social worker). Despite informational material being provided for parents post-diagnosis, this resource is often not the first resource parents turn to.

Purpose Of this Study

The purpose of this study was to determine how parents educate themselves about Autism Spectrum Disorder, how they discover resources, and who they turn to when they have questions about ASD related issues. If parents are not using physician provided information to gather resources for their child, where are parents receiving their information and education?

It has been shown that grief and stress have been strongly linked to parents who have a child with ASD (Meirsschaut, Roeyers, & Warreyn, 2010). Families find themselves in a heightened emotional state after receiving an Autism Spectrum Disorder diagnosis and are provided with information by their diagnostic clinic. This study examined whether families are using the resources available and/or provided to them, or whether there is a gap in knowledge, resources, and aid, after receiving an ASD diagnosis all the way to what the parents viewed as a completed service assembly.

CHAPTER TWO: LITERATURE REVIEW

According to British Columbia's Data Catalogue, the prevalence of Autism Spectrum Disorder (ASD) is growing (Data BC, 2016). In 2007, 1 in every 209 children between the ages of 0-18 were diagnosed with ASD; more statistics from the Government of B.C. census data show in 2015 that 1 in every 84 children were diagnosed with ASD within British Columbia. This data, compared with data from Census Canada from the year 2000 onward, reveal that children receiving an ASD diagnosis has increased steadily. In order to more clearly understand the significance and relevance of this study, this chapter will review relevant literature pertaining to autism and its impact on the lives it touches. This chapter will examine the history of Autism Spectrum Disorder, parental coping of raising a child with ASD, and the evaluation process of ASD. This chapter will explore familial responses to receiving and living with a child with an autism diagnosis (both parent and sibling), and what the effects of ASD are on these individuals. Lastly, this chapter explores education and information made available to parents and families, as they seek support and knowledge about their child.

History of Autism Spectrum Disorder

Kanner and Asperger. In 1943, Leo Kanner, an Austrian psychiatrist and physician, was the first to distinguish that what was being called early childhood schizophrenia and/or dementia, was actually autism. Kanner borrowed this term autism, which is defined as "an absorption of self" (Wolff, 2004, p. 7), or "withdrawal from the external world" (Scott & De Barona, 2007, p. 446), from the Swiss psychiatrist Eugen Bleuler. Kanner believed autism correctly defined these children's behavioural characteristics and used the term to categorize children by their specific deficits and behaviours: obsessiveness, repetitive actions, lack of social relations (even during early infancy with family and others), and unusual cognitive abilities

(Scott & De Barona, 2007). A year later Austrian pediatrician Hans Asperger did a case study on four children he termed to have “autistic psychopathy” fitting Kanner’s behavioural deficits. Hans Asperger further defined Kanner’s understanding of autism to be more of “the shutting off of relations between self and outside world” (Scott & De Barona, 2007, p. 7). Hans Asperger’s case study of the four children noted several distinguishing features not previously noted in that of Kanner’s autism. Asperger found that the children in his study showed impairments in speech, lack of empathy, difficulty forming relationships with peers, and difficulty in reciprocal conversation. He also found that these children “developed extensive knowledge in a specific area of interest” and referred to these children fondly as “little professors” (Scott & De Barona, 2007, p. 7).

Autistic Psychopathy. Throughout the 1950’s and the 1960’s the definition of “autistic psychopathy” for childhood mental illness became commonly used, and the terms childhood schizophrenia and childhood dementia were now diagnoses used more infrequently. This began the search for the cause of autistic psychopathy. Autistic psychopathy was understood to be a psychological disturbance thought to be caused by external and environmental influences. It was difficult to find common external influences on children as young as three who came from various backgrounds, with different socio-economic-statuses, different cities, and different heritages. This caused the medical community to look for a common denominator in these children; however, the external influence on a child who is only three years of age is limited. Yet all of these children did have one thing in common: they all had a mother. For nearly 15 years the majority of doctors held mothers responsible for causing autistic psychopathy in their children through uncaring and apathetic parenting. Doctors referred to mothers of children with autism as “refrigerator mothers” (Wolff, 2004; Scott, 2007). These mothers were deemed cold and the cause of their child's disorder. It wasn't until 1964 that Bernard Rimland challenged the theory of cold mothers, finding proof of a biological connection to the disorder. This forced doctors to look for other causes of the childhood disorder, and the notion of "refrigerator mothers" fell out of use.

Autism Spectrum Disorder. Throughout the 1970's much research into possible genetic causes took place through the studies of twins, to demonstrate that there is reason to believe a genetic link is one of the elemental causes of autism. Much of this research helped redefine autistic psychopathy as a developmental disorder and not a psychosis (Wolff, 2004). Yet it wasn't until the 1980's when diagnostic criteria for autistic psychopathy was established, and Kanner's and Asperger's "autistic psychopathy" were distinguished as Autism Spectrum Disorder (ASD) and Asperger Disorder (AD). What separates these two types of autism is language and cognitive abilities. In ASD, both language and cognitive abilities were impaired or delayed, whereas children with AD were not impaired in these areas (Scott & De Barona, 2007). In 1987, both Autism Disorder and Asperger Disorder were described for the first time in the DSM-III, providing criteria for diagnosing and identifying characteristics of behaviours.

There were very slight differences between an Asperger Syndrome diagnosis and a high functioning Autistic Disorder diagnosis. Children with Asperger Syndrome tend to have language development earlier; social difficulties and motor delays are not typically noted until the child is older, at 4-5 years of age (Howlin, 2003). However, these early differences have been shown to decrease with age (Gilchrist et al., 2001; Ozonoff, South, & Miller, 2000) and assessments based on current functioning of the child have been unable to reveal any major differences between AS and ASD (Howlin, 2003). In 2012 the separate diagnosis of Asperger Disorder and Autism Spectrum Disorder was abolished with the release of the DSM-5, which categorized both AD and ASD as being within: Autism Spectrum Disorder (Wing, Gould, & Gillberg, 2011). It should be noted that the authors were reviewing a prepublication version of the DSM-5.

Today, Autism Spectrum Disorder is defined as a “neurodevelopmental disorder characterized by impaired social interaction, difficulties with verbal and non-verbal communication, and restricted or repetitive behaviours” (AutismBC.ca). Problems with social interaction, narrowed interests, repetitive routines, and difficulties with communication, have defined autism since its admittance to the Diagnostic and Statistical Manual of Mental Disorders (DSM) in the 1980’s (Rhoades, Scarpa, & Salley, 2007; Cederlund, Hagberg, Billstedt, Gillberg, & Gilberg, 2008; Boyd, Odom, Humphreys & Sam, 2010). Research suggests that the spectrum is stable over time for the majority of diagnoses, however there are dramatic differences in functioning levels across ASD groups (Cederlund et al., 2007).

The unique presentation of those with ASD exists along a continuum. Differences vary widely between person to person within ASD. This diversity in brain function has brought about a relatively new label for those with atypical neurological development: neurodiversity. Neurodiversity focuses on differences and respects human difference (Armstrong, 2011). This term is used to positively describe those whose brain is unique in its functioning, and to respect human difference, normalizing human variation. Though neurodiversity is to be celebrated, Autism Spectrum Disorder is still considered a neural impairment. Over the past 25 years, ASD has emerged as the most common disability condition in children (Newschaffer et al., 2007; Boyd et al, 2010).

It has been found that there are two primary reasons for the increase in diagnoses in children: (a) children are being diagnosed at a younger age and (b) children with milder characteristics are being diagnosed (Wolff, 2004; Lord et al., 2006; Hertz-Picciotto & Delwiche, 2009). Additionally, ASD can be diagnosed co-morbidly with multiple disorders such as: intellectual or cognitive disabilities, language disorders and Asperger's disorder (Boyd et al., 2010). Consequently these factors contribute to an increased number of children being diagnosed with ASD. The growing number of children being diagnosed with Autism Spectrum Disorder has caused an ever-developing awareness amongst teachers, doctors, and the general public of ASD and its characteristics (Wolf, 2004). Autism and its expressive behaviours and peculiarities has increased in public awareness through the use of books, blogs, YouTube channels, and television.

As parents of children with autism begin to share their stories, and the voices of some of those who have autism are finally able to be heard, the strength of their advocacy and dialogue has caused an increase of intervention innovations, education, and care for those who are diagnosed with ASD (Wolf, 2004).

Intervention methods. As previously discussed, statistics released by Statistics Canada show that the number of ASD diagnoses are increasing. As the diagnostic tools become more refined, so too do the intervention methods to help these children and families. One common type of therapy a child with ASD receives is Early Intensive Behavioural Intervention (EIBI), as it is the most studied type of therapy (Matson & Smith, 2008). Early Intensive Behavioural Intervention (EIBI) is based on the principles of operant conditioning, focusing on deficits in language, imitation, academics, self-care, and social skills all taught through the use of backward chaining, reinforcement, extinction, and prompt/prompt fading (Duker, Didden & Sigafoos, 2004; Sturmey & Fitzer, 2007). While there are many types of intervention/behavioural modification therapies available to families with a child with autism, some have been shown to be more effective than others (Eikeseth, 2009; Reichow & Wolery, 2009; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). However, interventions are often dependent on the medical and educational services available to the parent and family. Some communities may only offer center-based therapies, while other communities may be able to provide private therapies, and extra supports to the child and the family through other services such as respite-care, speech pathology, and occupational therapy. Regardless of the intervention type, children with ASD who receive interventions have been shown to have positive adjustments behaviourally. Smith (1999), Wolff (2004), Rhoades et al. (2007) and Dawson et al. (2012) showed that without regard of a child's functionality, and of intervention type, early intervention changes a child's developmental trajectory; and starting these therapies as early as 18 months has given evidence to lead to better long-term outcomes (Gordon-Lipkin, Foster, & Peacock, 2016). Children with ASD who receive EIBI have been shown to outperform children cognitively who receive other types of behavioural modification treatments (Eikeseth, 2009; Reichow & Wolery, 2009; Peters-Scheffer et al., 2011). Nevertheless, all clinical-based early intervention methods may guide improvement for neurodiverse persons, and a combination of services and approaches to meet various needs of the child may aid in this incline growth (Gordon-Lipkin, Foster, & Peacock, 2016). Although it has been concluded that early intervention has meaningful benefits for children on the autism spectrum, it is important to remember that this disorder encompasses a wide range of abilities. Much research has also shown that there are still large individual differences in response to treatments and some children may always need a specialized service (Matson and Smith, 2008; Rogers and Vismara, 2008, Eikeseth, 2009; Dawson et al., 2012.). Early intervention has proven to be crucial to a child who is diagnosed with ASD, and parental participation is considered fundamental to help the child maintain and generalize skills learned through early intervention. A vital question remains—How can a parent of a child with ASD possibly keep up with the stresses of family, work, a child with a special need, and now therapies?

Parental Coping

Parental coping after receiving an ASD diagnosis has been researched more intensively over the past decade as the prevalence of ASD increases. Research is demonstrating that children with a diagnosis, regardless of the diagnosis (bi-polar, schizophrenia, Autism Spectrum Disorder, Downs), not only affects the individual but also their families and primary caregivers.

Parental grief may start long before parents seek out professional help to receive a diagnosis. Parents of children with ASD have been shown to be at a significantly higher risk of experiencing psychological distress and difficulties than parents of children with other disabilities or no disabilities (Kasari & Sigman 1997; Bromley, Hare, Davison, & Emerson, 2004; Glasberg, Martins, & Harris, 2007; Dabrowski & Pisula, 2010). It is believed that the maladaptive behaviours of autism are the primary link between ASD and parental distress (Benson, 2010); and that is merely the regular every day parenting of a child with ASD. The diagnosing process can sometimes compound the feelings of anguish that parents experience.

Autism Spectrum Disorder Evaluation

A comprehensive ASD evaluation can include a visit, or multiple visits by a multidisciplinary team consisting of physicians, psychologists, and sometimes other providers such as speech language pathologists, social workers, occupational therapists and/or genetic counselors (Gordon-Lipkin, Foster, & Peacock, 2016). “Each specialist brings different expertise to aid in diagnosis and recommendations” for the child (p. 852). These evaluations are time-consuming, with frequent appointment scheduling and clinical testing; and then comes the added stress of waiting for appointments. As of October 5th, 2017, in British Columbia the approximate wait time for a public autism assessment is reported to be 40.7 weeks (PHSA, 2017). A comprehensive ASD evaluation takes time due to its “absence of quantifiable biochemical or neurological markers” (p.10). A diagnosis is reliant on observations of behaviour—both formally and informally (school, playgroup, home, etc.), developmental historical information about the child, and consideration of parental concerns (Pilowsky, Yirmiya, Shulman, & Dover, 1998; Filipek et al. 2000). This process can be time consuming (Cassidy & Morgan, 2006). The evaluation is just one hurdle to be completed in the autism journey. Once the evaluation is completed, parents may find themselves unclear about future steps and in need of clear advice as to how to proceed after a diagnosis (Keenan et al., 2010). The added concern caused by the knowledge of early intervention being most effective for their child, the continued delay in receiving a diagnosis, together with little to no guidance of clinically based intervention therapies for their child—parents experience the compounding distress of continuous hurdles over which they have no control (Keenan et al., 2010).

Family Response to Diagnosis

Behavioural Intervention therapies for a child with autism affect not only the child, but also the parents. As parents learn that their child can respond to therapies, and parental abilities to manage their child’s problem behaviours are enhanced, parents begin to feel hopeful and successful, giving the parents a feeling of self-confidence and efficacy (Sofronoff & Farbotko, 2002; McConachie & Diggle, 2007; Singer, Ethridge, & Aldana, 2007).

Parental response to diagnosis. Parents have been shown to vary considerably in their response to their child’s autism and how they cope with the challenges and burdens that come along with an ASD diagnosis (Benson, 2006; Benson & Karlof, 2009).

Parents who have children diagnosed with ASD have heightened grief and stress as they process the loss of future hopes, wishes and aspirations, loss of the individual as they have known them, and a loss of relationships as the disability disrupts not only family dynamics but also friendships and other social groups (Godress et al., 2005). Parents of children with ASD have been shown to experience greater stress than parents of typically developing children, and more stress than parents of children with other disabilities (Dabrowski & Pisula, 2010; Ingersoll & Hambrick, 2011). If parents do not employ healthy coping strategies there is a great increase in individual, marital, and family burden (Stuart & McGrew, 2008). Consequently, these parents are more likely to quit their jobs due to childcare issues than parents of children diagnosed with other disabilities (Harper, 2013). Ingersoll & Hambrick (2010) encourage providers of behavioural interventions to "screen for parent mental health problems, and make appropriate referrals when necessary". The child diagnosed with ASD is not the only one who needs support in a family.

Through all this distress, parents do not need to feel like there is no hope for them. Interventions are available for parents as well as their child. Counselling, family therapies, and help from health care professionals can aid parents in managing feelings of depression and anger often associated with parenting a child with autism (Benson & Karlof, 2009; Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003). There are interventions available that seek to aid in coping and cognitive strategies promoting mindfulness and positive acceptance of their child (Blackledge & Hayes, 2006; Singh et al., 2006; Lloyd & Hastings, 2008; Benson, 2010). Allowing a parent to talk about the fatigue and exhaustion they are feeling in a safe space, helps them to understand what factors are contributing most to their fatigue and how they can best manage themselves and their family (Giallo, Wood, Jellett & Porter, 2013).

Sibling response to diagnosis. Siblings of children who have ASD also feel the impact of parental or family stress and exhaustion. Siblings face changes in family roles, structures, activities, and a shift or loss in parental attention (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). Despite all these changes, siblings have been shown to fare better than their parents in the shift of family dynamic. Typically developing siblings have expressed a positive view on their relationship with their sibling with autism (Rivers & Stoneman, 2003) and through observations are believed to be well adjusted socially, despite the stresses they face (Pilowsky et al., 2004). Even though this resilience is affirmed, the use of support groups and counselling sessions can provide added benefit to siblings of children with ASD (Rivers & Stoneman, 2003).

Supports. Research has also revealed the importance of social support such as support groups, respite care, and counselling. Social support or outside help such as respite has shown to reduce stress and improve quality of marriage (Harper, 2013; Godress et al., 2005). Clinical intervention for families and children helps alleviate grief and burden (Stuart & McGrew, 2008) and good communication between healthcare provider and parents improves parental perspective and stress (Rhoades et al., 2007; Schneider at al., 2009). Siblings, when provided with clinical support and a supportive environment, were able to have an increased understanding of their brother or sister’s disability, which was shown to increase positive perceptions and fewer negative sibling interactions (Rivers & Stoneman, 2003; Smith & Perry, 2005). All this research has shown that parents and families can have positive gains, personal growth, and improve personal relationships in spite of having a child with autism (Hastings & Taunt, 2002; Pakenham, Sofronoff & Samios, 2005).

Information Deficits. Knowing this, there still seems to be a lack of information given to parents of children who have recently been diagnosed with ASD. Keenan, Dillenburger, Doherty, Byrne and Gallagher (2010) sought to document the experience of parents receiving an ASD diagnosis for their child. Seventy-seven percent of the participants “felt that at the time of diagnosis the advice from statutory providers was not sufficient for their child and family” (p.393). Many of these parents felt as though their concerns and perspectives were not considered by the healthcare provider. Keenan et al. (2010) brings attention to this problem as parents can become more knowledgeable in some areas than professionals, as these families take on parent training and a data based home therapy program for their child. Parents felt that their interactions with healthcare professionals were difficult to understand and did not provide the help they needed. Parents desired professionals to communicate with “the same manner and respect as they would interact with their dealings with other professionals” (p.232) and the need for barriers to be broken, to work alongside professionals to help make the best decisions for their child and take away the “underlying feeling that it’s them again us” (p.232). The importance of a good relationship between professionals and parents can be imperative to the mental health of a family. Parents have been shown to be more willing to attend support groups if referred by their diagnosing clinician (Mandell & Salzer, 2007).

This divide between parents and healthcare professionals may be detrimental to families, and may have various causes. For example, this disconnect may exist because of limited training given to healthcare professionals regarding disabilities. This limited training may cause healthcare professionals to be reluctant to diagnose ASD for fear of emotional reaction from parents, therefore impeding families from obtaining much needed help. The divide between healthcare providers and parents, and limited time spent with patients by physicians, can inhibit parents from receiving he information they need (Rhoades et al., 2007; Stuart & McGrew, 2008; Schneider et al., 2009).

Parents desire to have a relationship with their physicians. To have a relationship and feel cared about, parents must experience care, trust, respect, and intentionality (Schat, 2016). In a relationship with a physician ethical care is involved. Schat (2016) refers to Noddings (2013) noting ethical care is for professionals, not for parents or patients. Professionals may not always *feel* natural about caring, but they can make an ethical and skillful decision to care. This unique relationship of caring helps to bridge the disconnect families may feel while going through the receiving of an ASD diagnosis. This type of ethical caring creates a positive outcome of providing the feeling of empathy, a deeper understanding of how professionals see their clients, and a willingness for patients to follow recommended guidance.

A positive developmental trajectory between age and intervention is evident; the younger the child is when receiving intervention has shown to significantly improve a child’s cognitive abilities over time. And as discussed earlier, some therapies are better than others. However, if parents are not educated, especially in a sense of “support and guidance about appropriate empirically supported services and treatment options” (Rhoades, Scarpa, & Salley, 2007, p. 2), it is difficult for a parent to help their child in the best way possible. There seems to be an information gap that exists in the area of parental education for parents of children with autism spectrum disorders (Schultz, Schmidt, & Stichter, 2011).

Education is vital and important in many aspects of North American culture. For most jobs people must first have education or on the job-training to have success within their working environment. If education toward job success is important to the culture, then it could follow that parents with children with ASD should also receive an education to give them the best chance to succeed in their so-called “job” of parenting an exceptional child. Parenting a child with the unique needs of ASD can be challenging for parents and caregivers. If parenting a child with ASD came with education and extra training, parents could be more prepared for handling tasks and situations that arise within their environment. Specific parenting techniques can positively alter a parent-child relationship and nurture the child with ASD― and the entire family (McConachie & Diggle, 2007; Soresi, Nota, & Ferrari, 2007). Studies have revealed that parent training not only increases skills but renews confidence and reduces stress (McConachie & Diggle, 2007). As parents enter the world of ASD and become more informed and hopefully educated, it can allow them to speak freely about the truths of day to day life with ASD.

As noted above, ASD awareness has grown in modern western culture and daily life. Additional examples of this cultural awareness can be seen in several shows on television which depict persons with Autism Spectrum Disorder, such as: *Atypical*, *The Good Doctor*, and *The Big Bang Theory*. Even a children’s program such as *Sesame Street* now has a Muppet named Julia who is on the spectrum and helps teach guests, children, and other Muppets how to interact and befriend someone on the spectrum. This awareness has allowed for much public discussion about best treatments and interventions. Unfortunately, this type of open forum also allows for misinformation to germinate and take root. “Desperate parents can be seduced by untested and often expensive treatments which later prove to be ineffective” (Wolff, 2004). The importance of educating parents to avoid such persuasion can be significant, as the abilities and potential of children on the autism spectrum have a large range, as do the interventions offered (Wolff, 2004; McConachie & Diggle, 2007). “Some of these [therapies] are still untested and others remain popular despite their proven ineffectiveness”(Wolff, 2004, p. 206). Parent education serves multiple functions: it informs parents, teaches them new skills, and can help supplement child interventions (Wolff, 2004; Brookman-Frazee, Stahmer, Baker, Ericzen & Tsai, 2006). Parent education has been shown to improve child outcomes (Simpson, 2005). With the growth in attention that ASD is receiving from the media, and the increasing presence of ASD within schools, there is a need for effective, evidence-based intervention for ASD, and that can only be achieved through education (Lord et al., 2005). Therefore, the question remains—How are parents being educated, if not through their healthcare providers?

Literature Summary

This study explores whether parents are receiving optimized support, as existing literature suggests, after receiving an Autism Spectrum Disorder diagnosis for their child, or whether the actual experience between diagnoses to service assembly is wanting. It is hypothesized that parents in the lower mainland of British Columbia are self-educating using books, media, the Internet, and word-of-mouth resources, instead of learning from health care professionals. It is also hypothesized that parents are not aware of the resources that are available to them after receiving a diagnosis, and are therefore seeking help for their child and assembling services for their child in much the same way they self-educated themselves. It will be argued that this type of self-education and service assembly can lead parents to *not* receiving the best help for their child, getting help that is not clinically based, and causing more stress and frustration for themselves, their family, and their relationships.

CHAPTER THREE: METHODOLOGY

Method

A qualitative method was used for this study; it situates the researcher as listener and allows the researcher the ability to address issues through hearing the stories of people (Schneider et al., 2004). Qualitative research can be transformative to participants as they explore and give special attention to a specific relationship or moment in time. This method seeks to answer questions about “what is happening?” and “why or how it is happening” (Shavelson & Towne, 2002). This methodology gives voice to the perspective of the participant and how they view their world (Cho & Trent, 2006; Schneider et al., 2004), and allows researchers to gain a holistic view of a social phenomena and their dynamics (Attride-Sterling, 2001; Cho &Trent, 2006). The qualitative method attempts to access the *human story,* to understand human lives, unmask human feelings, and give face to the human participants of the research (Dickson-Swift et al., 2007). This research method was chosen specifically to give voice to family and parental experiences after receiving an Autism Spectrum Disorder diagnosis.

The qualitative method, however useful, may still be controversial. Qualitative research blurs the lines of objectivity and subjectivity (Brantlinger et al., 2005). This type of research may be used more to document than discover, and therefore is seen as an inductive approach to research, reasoning from specific to general. It is important to remember that qualitative research is exploratory in nature, as it is founded in an interpretive paradigm. This type of paradigm allows researchers to gain knowledge in an area of which little may be known (Liamputtong & Ezzy, 2005).

Despite the doubts, the qualitative research method “is a systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context” (p.195). Qualitative researchers must ensure their collection of data is empirical, credible, and trustworthy (Brantlinger et al., 2005; Mertens, 2015). Qualitative designs do produce science-based evidence that have been shown to inform policy (Brantlinger et al., 2005). Hearing stories and saying them out-loud can change lives. It can give voice to the marginalized, silenced, or the struggling. The qualitative method gives voice to the humans whose stories are rarely told, and yet are so common.

Through the use of an open-ended interview this research can engage with participants naturally and generate rich narrative descriptions within a real-world setting. The perspectives of the participants is the foundation for this research. As researcher, I felt privileged to have heard their stories, and hope to use their narratives to explore subjective human experience to better explain this time interval between receiving an ASD diagnosis and receiving help in families' lives.

Sampling Procedure

Research took place using participant families from cities across the lower mainland and Fraser Valley of British Columbia, Canada. This study used a criterion sampling method that sought families who had a minimum of one child with Autism Spectrum Disorder and had a completed service assembly.

Recruitment of participants was achieved through a sample of convenience by way of word of mouth, Facebook, email, and a forum post through the website www.featbc.org. In total eight parents replied to volunteer. Only six had a completed service assembly, however the other two families, who did not have a completed service assembly, were included in the study as they were deemed highly informative and worthy of being studied by the principal investigator.

All families recruited participated in one face-to-face interview of approximately 20-90 minutes in duration. All interviews occurred in an environment of their choosing that was comfortable to the participant. Six interviews took place within the participant's home, one took place at the participant's place of work, and one took place at the interviewer's home at the request of the participant.

Interviews took place between October 2017 and March 2018. All interviews of the participants were transcribed, analyzed, and sorted into themes. After analysis of these interviews, direct quotes from participants pertaining to main themes and key issues were extracted and emailed individually to each family. Participants were asked if they agreed with how they were portrayed and if the study could use direct quotes, as they were deemed worthy of use. Upon permission from all participants data analysis commenced.

Stakeholders

Stakeholders are anyone who can affect or be affected by this research, therefore the stakeholders of this study are the interviewees and current and future parents of children with Autism Spectrum Disorder (ASD). The interviewees shared their stories, providing the foundation of this research, and resulted in them having an interest in the study's outcome.

Both the interviewees and parents of children with ASD share an investment in this study. If any change in services to families occur as a result of this study, those services will directly affect these stakeholders.

These families shared their stories, hoping to bring attention to issues currently existing for families who journey with autism. The stories of each of the participating families are presented in the following chapter.

CHAPTER FOUR: FINDINGS

The purpose of this study was to examine the experience of parents between receiving an Autism Spectrum Diagnosis to a completed service assembly. Data were collected through one-on-one interviews of eight families who have children with Autism Spectrum Disorder. It was found that two families had not yet achieved a successful service assembly. However, all eight families were included in the thematic analysis of the interviews and data collection, as all interviews were deemed worthy of the study and highly informative.

Participant Demographics

Eight families shared their story with the interviewer. An overview of some of the demographic information is presented in Table 1. Note that names have been altered so as to protect the identity of participants. Subsequently each narrative of the participant family will be summarized.

Table 1

Summary of Participants

Participant	Marital Status	Number of Diagnosed Children	Age of Child(ren)	Number of Siblings	Year of Diagnosis	Time From Diagnosis to Completed Service Assembly
Caroline	Married	2	6	1	2015 and 2016	9 months
Florence	Married	1	13	2	2008	6 years
Daniel and Helena	Married	1	14	1	2009	Have not yet attained a service assembly
Victoria	Single	1	6	2	2014	2 months
Nancy	Married	1	8	1	2015	3 ½ weeks
Janet	Single	1	8	0	2012	4 years
Curtis	Married	1	18	2	2003	Have not yet attained a service assembly
Lisa	Common Law	1	4	5	2016	3 months

Note. Age (in years) of child(ren) is at the time of interview

Caroline

Caroline is married and the mother of three children. Caroline has twin boys and a younger son. Her oldest twin boys are both diagnosed with ASD. Both Caroline and her husband work full time and live in Surrey, British Columbia. Caroline's twin son received his ASD diagnosis in 2015, while the other twin was diagnosed in 2016. From diagnosis to completed service assembly was nine months. Caroline's twin sons are six years of age.

Florence

Florence is married with three children, two daughters and a son. Her youngest, her son, is diagnosed with ASD. Florence works part time from home, and her husband works full time.

Florence and her family live in Abbotsford, British Columbia. Florence received her son's diagnosis in 2008. From diagnosis to completed service assembly was six years. Florence's son is 13 years of age.

Daniel and Helena

Daniel and Helena are married with two children. They have a son who is diagnosed with ASD and a younger daughter. They both work full time and live in Abbotsford, British Columbia. Daniel and Helena received their son's diagnosis in 2009. At the time of this study, Helena and Daniel had not yet attained a completed service assembly. Daniel and Helena's son is 14 years of age.

Victoria

Victoria is a single mother of three boys. Her middle child is diagnosed with ASD. Victoria works full time and lives in Abbotsford, British Columbia. Victoria received her son's ASD diagnosis in 2014. From diagnosis to completed service assembly was two months. Victoria's middle son is six years of age.

Nancy

Nancy is married and has two children. Her oldest son is diagnosed with ASD and she has a younger daughter. Both Nancy and her husband work full time and live in Mission, British Columbia. Nancy received her son's ASD diagnosis in 2015. From diagnosis to completed service assembly was three and a half weeks. Nancy's oldest son is eight years of age.

Janet

Janet is a single parent with one child. Her daughter is diagnosed with ASD. Janet works full time and lives in Surrey, British Columbia. Janet received her daughter's ASD diagnosis in 2012.

From diagnosis to completed service assembly was four years. Janet’s daughter is eight years of age.

Curtis

Curtis is married with three children. His oldest daughter is diagnosed with ASD. He has a younger son and a younger daughter. He works full time and his wife is a stay-at-home caregiver. They live in Abbotsford, British Columbia. Curtis received his daughter’s ASD diagnosis in 2003. Curtis never attained a completed service assembly for his daughter. Curtis’ daughter is 18 years of age.

Lisa

Lisa is married with 4 children and 2 step-children. She has three daughters and three sons. Her youngest daughter is diagnosed with ASD. Lisa’s partner works full time and Lisa, due to illness, is a stay-at-home caregiver. They live in Maple Ridge, British Columbia. Lisa received her youngest daughter’s ASD diagnosis in 2016. From diagnosis to completed service assembly was three months. Lisa’s daughter is four years of age.

Themes

Analysis of the eight transcripts revealed 11 themes that arose as common experiences amongst families. Each of the themes is discussed more fully below. The themes were:

- The feeling immediately (minutes up to 1 day) after receiving an ASD diagnosis
- Events following receiving diagnosis
- Family strain
- Marital strain
- Sibling strain

- Fears; both present and future
- How parents educated themselves about ASD
- How parents sought and received information about ASD services
- What services and supports families feel they needed/wished existed
- Questions parents had and still have
- What parents would tell their past self

The Feeling After Receiving an ASD Diagnosis

After receiving an ASD diagnosis, parental response varied greatly across the eight participant families. Three parents revealed they had positive feelings upon receiving their diagnosis. These three parents found comfort having the confirmation of what they felt they always knew or suspected. Representative statements include the following:

> *So to finally have that confirmation of: you know what? It is. I was almost exhilarated. I was like flying—wahoo! Like a crazy kind of feeling.*
>
> -Lisa

> *I mean, for me…I'm just going to describe a feeling, for me the feeling was total relief…I just felt so relieved because I felt like—finally I'm going to get some help.*
>
> -Caroline

> *Actually it was a lot better than before I got diagnosed because before we got the diagnosis that was a lot harder because at that point it was - "Sorry, you're going to have to excuse my son's behaviour. He might have autism." That was tough. Or maybe he's just being this way for some other unknown reason. It was a very difficult time because he was non-verbal except for one word. So he wasn't having his needs met at all and not*

> *communicating meant crying, whining, screaming sometime—to try to express himself. So, that was stressful. Once we knew this is because of autism it was acceptable. It was easier to accept it in your head. Oh—this is why he's being like that, this is how we're going to get him help for this. It's okay...So I was really grateful for the diagnosis and I felt a lot better.*
>
> -Victoria

Despite receiving an explanation for previously unexplained behaviours, receiving an ASD diagnosis was not a positive experience for the other five families interviewed.

> *I mean, I was sobbing, I could barely stand up. I went to the bathroom and I vomited. I mean, it's just, and then they just hand you a binder and it's on your way you go!*
>
> -Janet

> *…I think I started crying on the way home, possibly during this meeting*.
>
> -Nancy

> *So we got the diagnosis. And I went home. And the next day I was rocking in a corner saying "I'm not Ok, I'm not OK."—and I had to go to the doctor to get an Ativan prescription and those kinds of things because I was freaking out. It's just so overwhelming*.
>
> -Nancy

Receiving news of an autism diagnosis brought other emotions as well.

> *As a parent that's scary. You just got a new diagnosis, your child has a disability. It's all just brand new and it's very difficult…*
>
> -Victoria

> *We're both numb, we're thinking, what's he going to say and so he gives us this diagnosis, this pamphlet of all his findings and then this little booklet. Here's a number, this is where you can go for help. Basically, all the best. And ya, we go to the car and I look at my husband and it's kind of like what now?…we're just so numb and you're just in such a fog. I remember going to Subway and trying to eat a sandwich and thinking we need a bit of time before we go home because emotionally you just felt so drained and it's like what now? It just felt very hopeless.*
>
> -Florence

> *And then there was guilt too. I know for me there was a lot of guilt.*
>
> – Daniel and Helena

Emotional strife was expressed by six of the families interviewed after receiving the diagnosis for their child. Some families said that an emotional response was delayed, and that they experienced grief some time later after receiving the diagnosis.

> *It was later where you take those breaths and those crying moments for yourself.*
>
> -Lisa

> *It was a later onset, but I was already not in a good place to begin with. And then…a couple of days after diagnosis I am rocking in the corner (…) I was just… completely panicking.*
>
> -Nancy

> *I think at the moment part of your brain is hoping that it's 'no,' but there was a part of us that already knew. And you're still fighting that when you're at that point in your life, okay, you hope it's something different. But then it takes a while to just digest it and that took us quite a while.*
>
> - Daniel and Helena

These families expressed feelings of emotional distress and an overwhelmed mental state. However, receiving an ASD diagnosis did not change their child.

> *…reminding ourselves that our son was no different than he was the day before or the morning we left him at home, but, here, now, we have this paperwork.*
>
> -Florence

ASD redefined these families as "normal" in their home. This new label to characterize their family was the first step in their journey. Moving forward were the next steps after receiving the diagnosis.

> *It was awful. I remember taking J [her son] to school the very next day and just kinda like dropping him off at preschool and going—okay we got it. And some people were like: Oh good! You get the funding! But I didn't feel like there was really anything to celebrate. Because it was like, okay, now what?*
>
> -Florence

Events Following Diagnosis

All eight families had the same experience after receiving an ASD diagnosis for their child. Each family received a packet of information in the same meeting where they received a diagnosis. The information package was described as either a red folder or a white binder, and every family spoke of the intimidating nature of receiving these materials.

> *… that binder is very overwhelming. It's full of words that parents don't understand unless they've been through it. It's full of acronyms that you don't understand unless you've been through it.*
>
> -Victoria

> *…just looking through the pamphlet of, go here, go, like, there just wasn't a lot to grasp from. And just no, I felt like there wasn't any care or sensitivity. Here you go, this is what your son has. He's on the autism spectrum. He'll get some help, apply for some funding, apply to here. Call this place and all of it was French to me.*
>
> -Florence

> *One thing the system did is they, you kind of get your diagnosis, and at least at the time we did, they shove a huge stack of paper and go: "Here you go"—Right? Various support things, things you could apply for, various services, it was a pretty information dense kind of thing. Like your—maybe talk to this person, talk to this person—but it put all the onus on us to go and get those services.*
>
> -Curtis

> *And they gave us probably a 58-page breakdown of what autism was.*
>
> -Lisa

> *You leave with this diagnosis as a parent and there is just not enough information to really make decision for your child, because ultimately you are their advocate. How do I know ABA is going to be OK? How do I know Reggio style might be the correct. There's*

> *so many different things.*
>
> -Lisa

> *Somebody made a comment right after diagnosis that you tend to, it's not a learning curve when you get a diagnosis, it's a learning cliff—because you have to go straight up. Or straight down. So you hit this wall of information and this is what you have to do. So I tried to go straight up.*
>
> -Nancy

Information was provided for all eight families interviewed, however the overwhelming nature of how and when the information was provided brought varied responses from these parents. Some parents entered what they termed a "desperation phase," as represented by the following:

> *I was...I can't even tell you the level of desperation. Like, I just can't even tell you, because like, it's so bad. It's like constant screaming, constant crying, no sleep. EVER. I don't even know how I made it through. I wanted to kill myself.*
>
> -Caroline

> *I think, I think, I really truly think, most parents enter this in a desperation phase, I really think that that is…I mean I can't speak for anybody else. I mean, I had two. I didn't care at that point. I was just like "Please! Somebody help me! Just somebody!" And when you finally get somebody that says "I'll help!' you glom onto them like instantly. It's like saviour that appears in front of you...and you're just like…I don't care at that point. Someone has offered help. And you'll take it. And I think that that could be*

> *what the problem is*.
>
> -Caroline

> *…you're so desperate and you just look to these people who are supposed to be the professionals to guide you and help you.*
>
> -Janet

This "desperation phase" provoked parents to move quickly into finding help and services for their child. They looked for services that would accept them as soon as possible and knew little else of what these services offered and did for their child.

> *They manage your funds. You don't have to do anything but sign on that dotted line when you're distraught and don't even know what year it is. So, I did. I went in to [clinic] and was looking for them to fix my daughter because I didn't know anything about it or what took place.*
>
> -Janet

> *But I wasn't really feeling like they were listening to me. They sort of seemed to me, like, I would talk about the things that I needed the most, but they didn't seem to work on those things at all, they sorta create their own program…Maybe they have the same program for everybody, and they start to work on certain things with their kids. But that's not what I needed...And no matter how many times I was trying to get them to listen to me, nothing would change. They wouldn't change their programs. They wouldn't... They wouldn't really listen to me.*
>
> -Caroline

Other parents in desperation sought help for themselves first.

> *Drugs!*
>
> -Nancy

Two parents, Janet and Caroline, discovered that finding help quickly, did not mean getting the help they felt they needed. The decision to find help was a common difficulty for all families. Though all parents were provided with a pamphlet, brochure, folder, or binder full of information, and directed to the Autism Community Training website, all interviewees struggled with next steps.

> *But again, you are finding out this for the first time. So it was a little overwhelming. Like I said, at first it was exhilarating, then it was like: Lisa, I can't handle this. So it was get the book, get out, go home. Like I said I got on the computer right away, I looked up the ACT. The first thing I started doing was, I knew I did not want the facility, I knew I wanted B [daughter] to be in the house, was I started going-well who do I pick? How do I go about this?*
>
> -Lisa

> *And think, okay, who do we call? We had had some help from the Fraser Valley Child Development Centre. They had already worked with J [son] and us in the preschool so there was a few things going. (...) And started looking at what to do. So the first thing that popped out of that little booklet was, there was a program that was called the [name of program] program. It basically, once the funding got allotted to us, it basically took almost all the funding so you had to enroll and commit full time.*
>
> - Florence

These decisions about finding a therapy that was a good fit for their children led Florence, Janet, Caroline, and Daniel and Helena, to using many different services until they were satisfied with a completed service assembly.

Caroline, Janet, and Florence interviewed and used more than four different autism specific services before they found a service assembly they were satisfied with. Caroline used and left three different services within four months searching for help that she felt would best aid in her twin boys' growth and development. These three families felt desperate and exhausted continually searching for a service assembly, however not all families found a service assembly they were satisfied with.

Daniel and Helena interviewed and used more than six different autism specific services and are currently not using any services. This family has tried many different therapies available to them and have tried intermittently over nine years to find a service that would be a good fit for their family. Unfortunately, they have been unable to find a service assembly that they are satisfied with and that meets their needs.

These four families searched for services by themselves using the materials and websites provided for them, and through the suggestion of friends. These stories stand in stark contrast to the three families interviewed that had someone to guide them through to completed service assembly.

Victoria had a friend who had a child who was recently diagnosed with autism, who came beside her telling her what services were best for her and felt fortunate to have her.

> *Luckily at that time I had a friend whose son had already been diagnosed so she said bring the binder, come straight to my house, we can go over everything. So I was very fortunate to have that person. Because otherwise that binder is very overwhelming*.
>
> -Victoria

> *Based on my friend's recommendations. She was using a home based team and that's the way I wanted to go also.*
>
> -Victoria
>
> *I did exactly follow in their footsteps. I did do a little bit of my own looking into a center based facility and did not like what I saw in the least bit compared to what the home program had to offer. It was not for me at all. I'm sure it's for some people, but not for me.*
>
> -Victoria

Nancy had an occupational therapist visit from the Child Development Centre the day after diagnosis, who provided her with guidelines and extra information to help guide her service assembly.

> *We actually had an appointment scheduled the day after diagnosis, so they show up, and I have my red folder on the table. And they're like: "OK! You have news!" So, instead of having the meeting they were gonna have, they started telling me about different services and what not. And emphasizing I need to go see the social worker immediately. And it's so overwhelming, and they give you this lovely little check list and it's like: This is what you have to do, and step one, is to go to MCFD [Ministry of Children and Family Development] and contact the social worker. But they went through it with me and they're talking about you know centre based programs and individual based programs.*
>
> -Nancy
>
> *And I went in and saw the social worker again the next day to try to get an idea. And she made some comments…it's difficult with a child who's high functioning, because*

I wasn't sure if we were autistic enough. You know, so she's talking about all these resources and respite and this kind of thing, and I was like: "Oh—I don't know if I need that"—type of thing. And it's just so overwhelming.

-Nancy

I remember her talking and she was telling me. And she said I might want to consider group based and there was [autism facility], and then she made a comment about [private consulting] that was really…She didn't say anything specific but she said that um…that's not a recommendation she's gonna make for reasons she's not going to tell me. And, but, there was these other, or if I wanted to do that I could just look individually. (...) And that one-on-one meeting with the Fraser Valley Child Development Centre with me and the occupational therapist who came to my house, the OT was like—I know this other lady who has a child with autism and it might be really helpful to talk to a parent. And she connected me with this lady. And it took a week or two for her to be off vacation, but when she came back we had a talk. And she was just again telling me, be in control of your funding, get a good understanding, make sure it's people you trust.

-Nancy

I got a list of the local consultants with a little comment [from her social worker]: I would look into these ones but I'm not telling you why.

-Nancy

Lisa connected with other parents at a child development centre meeting who shared recommendations and personal experiences to help guide her service assembly.

> *So we sat down with the coordinator from [facility], she basically went through, if I wanted to continue with the facility itself. You know, how it's going to work, how the funding worked, um, gave us a book, and sent us on our way. That was about it. So I got home and got onto ACT, onto the website. And it's not the greatest in the world.*
>
> -Lisa

> *I got a hold of [child development centre worker], she told me there was this wonderful group that was, it's a parent group for children with ASD, and other mental health disorders. We're really lucky that there's a parent group and somebody to come and talk about…what was it…I think it was the social worker actually at that point, was coming into talk about the avenues and ways you had to go about funding and how it was all going to go. So it happened to be about a week after B [daughter] had got her diagnosis. We went and did that right away. I spoke to the social worker right after, I had papers going.*
>
> -Lisa

> *So I met a social worker, I met some parents, they gave me notes of certain consultants to possibly use. One that came extremely recommended was [consultant]. So of course, I went, read up on her a little bit. I kinda, really sorta, after that meeting, decided ABA was probably going to be the best approach with B [daughter].*
>
> -Lisa

These contrasting experiences of families who had someone to act as a guide to their autism journey not only eased stress, but drastically shortened the time it took to find a completed service assembly these three families were satisfied with. Lisa, Victoria, and Nancy only hired one autism specific service, and were satisfied with their service assembly.

One of the participating families took a very different approach to receiving an ASD diagnosis for their child. Curtis was concerned about having future children and did genetic testing following their diagnosis.

> *You know something's wrong and nobody can tell you why. It's pretty rough. You know, at the time we only had her, right? And I wasn't willing to have another child if the risk of this happening again was going to be significant. So that was, kind of a nice closure there. It meant we could kind of move on with our lives a little bit. It was just a freak mutation. I don't have it. My wife doesn't have it. Our other kids have turned out without it. So it was just one of those evolutionary, out-of-luck draws.*
>
> -Curtis

With the confirmation of their daughter having a genetic mutation that caused her ASD, Curtis and his wife did not seek any behavioural therapies or consulting services, only respite, physical therapy, and occupational services offered by the child development centre.

> *But here's a spectrum disease that's mostly genetic in its foundation and people are again looking for that closure and that fix even more so. So they can have a normal child.*
>
> -Curtis

> *I think some of that. It's an obvious limiter, there's no cure, right? There's…so it's just a matter of the fact that she's going to learn slower, she's going to develop slower, and some things she won't be able to do.*
>
> -Curtis

Family Strain

Having a child with a special need is a cause of great strain within a family. Research, as previously discussed, has shown that autism specifically can cause families stress, grief, and be a burden to the family as a unit.

> *Up and down. Really really up and down. It's just…it's just...uh…it's been tough. It was really tough. I had a lot of crying moments. You know, I have a big family, so at that point I still had two teens in the house plus T [son]. So, you know, I have one that is in grade 10, I had one graduating, and I had T, and then going through everything with B [daughter]. So I was pretty stressed out…Yup, four kids at home, and one with autism.*
>
> -Lisa

> *January 2016 I finally went in and started to see a psychologist. Because I was just too much, all over the map. Personal reasons, relationships, autism diagnosis, trying to raise teens, trying to keep everybody united and on the same page. Explaining to family what autism was, it's because when you are trying to explain to them, it's very difficult.*
>
> -Lisa

> *Right. So, it's, ya. And you know my family didn't really know much about it either. I mean they really don't have a clue about the autism. So, much more now, they are much more supportive. They see it now, it's a lot more apparent now, they are a lot more helpful now but really for about 4 years it was just K [daughter] and I trying to figure this out.*
>
> -Janet

> *Super stressed. I think it was a bit of a relief to know it wasn't just us being shitty parents and caregivers. But on the other hand, none of us really knew what that meant to have an autism diagnosis and what that was going to look like. Um, the other thing I hadn't really been expecting was feeling kind of a grieving process through the whole thing. 'Cos you're having to kind of reconcile your own expectations and hopes for your child and then realizing that expectations are out the window.*
>
> -Nancy

> *You'd never heard a louder cheer when we stopped putting basically diapers on a six year old. You know, when you're having to dance a 65 pound 6 year old, in your arms, to try and get her to go to sleep, and you spent the last half an hour, dancing around the living room, trying to rock her to sleep, and then you lay her down and 30 seconds later she wakes up. Those are the times you want to kill yourself. Right, cause it's months on end. It's not just the one time. Or—oh their sick, or whatever. That's a part of parenting. It's the 6 months of after every dinner she throws up.*
>
> -Curtis

Families that had a support network did not however appear to experience less stress or strain on their family.

> *It's not been easy. It's been, pretty stressful. Fortunately we did have a lot of family support at the time. I would not want to do that right now, again. I would not want to start this process over right now.*
>
> -Curtis

The diagnosis itself and the behaviours of the child are one difficulty that all these families faced, the added stress of services coming into your home was another cause of increasing strain to Lisa's family.

> *Because it's still very overwhelming for parents and everybody. You have all these people in your house, they're sitting around, they're starting all these programs, and your like: "What are you doing with my child?!" You know? I didn't understand the data collecting, I didn't understand any of this. And they're there to work with your child, they're not really sitting down explaining the whole—this is how it's going to go—it was a very brief. There wasn't a lot of information [to the parent].*
>
> -Lisa

Research suggests that autism spectrum disorder is stable over time for the majority of diagnoses; however, the behaviours that occur and are expressed by individuals do not remain stable or permanent across the life span. As children grow and develop, their behaviours change. Families interviewed found themselves continually learning and moulding to fit autism and the constant change of its behaviours.

> *Ya, I think the strain is when we feel like now again a new phase, now being a teenager, that he is still struggling so much, but in new ways and then the family takes that on because it takes everybody trying to catch up and learn and now again being in this new area of like, okay, what help do we need now? What else can we add? What more does he need? And looking through that, yes, it's exhausting lots of time. He's fun, he's so fun, but there's that part of what more can we do for him? And what are we possibly missing and always second guessing what other therapy should we be trying?*

What should we be doing that I'm not finding?

-Florence

It's been a pretty insane learning experience, I mean, lots of positives, lots of negatives. For me, ya, it's been, compared to K [daughter], it's, ya, it's just been, it's been, interesting. I think for both of us too, it can get frustrating at times and you feel helpless. So when you're in that state mentally, you just feel defeated. And then there are those moments where he gets that 'aha' moment and you're like 'okay—this is working' and then you kind of go that direction until you hit another wall. The thing is, just because it works for one family you try that and it's like, it's not working for him.

-Helena and Daniel

Parents experienced strain in trying to educate their significant others, children, and extended family on autism.

Big time [strain on the family]. Because again, there's not a lot of understanding around it. So now, I'm the one taking all the education trying to understand it and teach it to everybody. So there's a strain because, especially between me and C too, because C really didn't understand it.

- Lisa

Ya, I would say it was definitely very stressful, very exhausting, trying to always make time for the other kids and stuff. And getting them on board, trying to educate them at the same time, his 2 sisters about what J[son]'s going through and stuff. So definitely at times just feeling like barely in survival mode. But at other times we tried to keep as much of a normal family as possible. Go on vacations, go on outings, do things the best

> *we could as a family and this was how it was*.
>
> -Florence

Families were under great amounts of stress trying to keep their family together and educated, however the stress and pressure of raising a child with ASD also strained the relationship with their significant other.

Marital Strain

Seven of the eight parents interviewed were in a long-term monogamous relationship at the time of diagnosis. Six of these families described this time as stressful on their relationship with their significant other. One family expressed that this stress was caused by a limited amount of time to be together.

> *It's all a bit of a fog now. I would say it's okay. I would say we didn't feel like we had the time to really give to each other. After he was about 5 years old, it's just been like, okay, tag teaming you know. Okay, relieve each other here, there. It's okay, it could be stronger, cause I feel like parenting him is 80% of it at all the time still. That leaves little for the other part of life*.
>
> -Florence

For other families, strain on their relationship with their spouse or common-law was caused by differing ways of dealing with stress.

> *It was stressful at times. It was up and down I think. I think for me, I have a different personality than Daniel too. Daniel can brush things off whereas I really let something fester inside of me and I deal with depression too I think. And the lack of sleep compounded things as well when he was younger. I never blamed Daniel for any of this*

> *but it's just a struggle and then it puts a strain on all of my relationships really.*
>
> -Helena

> *Yes, that was stressful for sure. Lots of fighting, but not about the diagnosis or about E [son] but just a generalized stress over the household because there were 2 other children involved the other one also diagnosed with learning disability and anxiety. And he's going through anxiety as well. The autism diagnosis in itself wasn't stressful but definitely just as a whole it was stressful.*
>
> -Victoria

> *So he wasn't really seeing what I had to go through every day. And that was making me very resentful because, you know, he'd just come in and say "It's not that big of a deal—it's not that big of a deal." I'm like, "Yeah! It's not that big of a deal for you! It's a big deal for me!" And so, we were having this back and forth thing and he would say, "Well, why don't I stay at home then, and you go to work!" And we're like constantly fighting, on this very minimal time that we're together.*
>
> -Caroline

For other families, the most stress-inducing part of receiving a diagnosis was the change in personal role and family dynamic. Parents took on the mentality of a student as they tried to educate themselves on autism, and discover the needs of their child. Siblings are asked to be more understanding of their sister or brother who has autism. And parents are continuously trying to balance a family, a routine, and relationship with their children and their partner.

> *The autism diagnosis in itself wasn't stressful but definitely just as a whole it was stressful. Having to make decisions that are going to impact your child's entire future.*

Stressful.

-Victoria

So, again, our household is a little unique compared to others because we are dealing with blended families on top of just our own two between C [common law] and I. And there was just a lot on our plate. The great thing about C though is he wanted to learn. He wanted to understand. So that was good, but still this strain getting us through it. And this strain on the relationship. It's hard. It's—where's your role, what's your responsibility, it changes, it's different, it's…you're having to compensate for a child who does have autism. Also trying to be understanding for the children who don't have autism. That is a huge thing within itself. How do you balance everything?

-Lisa

It was a super stressful time to begin with. Part of my anxiety is I get super ragey. And he [husband] is a nice safe person for me to lose it on. And he's a lot bigger than me. And I'm not going to hurt him if I'm freaking out [laughing]. It was a time of transition. It was the first year after moving from a place where I had an 8 minute commute and he had a thirty minute commute, to both of us having an hour/hour and a half commute, my parents taking care kids, so we are interacting with my parents more. My kids have a complete change in their routine. A [son] had had a year where...his first year here he kept saying: " I wanna go back to 303, this isn't home, I wanna go home, this isn't home, I wanna go home" so it was a very a stressful period already.

-Nancy

…it was stressful for you because we just didn't know sometimes what to do. I still don't know sometimes what to do.

-Daniel and Helena

Having a child with an autism diagnosis takes a lot of time and energy for these parents. This change in family dynamic adjusting to a child with ASD not only affects parents, but also siblings.

Am I paying enough attention to the other kids who don't have autism? Stressful. Are they going to understand what their brother is going through? Are they going to look out for him? Thinking about the future, thinking about his future, that's stressful.

-Victoria

Sibling Strain

Research has shown that siblings of children with special needs tend to be resilient. Children have shown to be accepting of their siblings with special needs and that was shown within the families interviewed.

I think he just thought that's who his sister was. She screams a lot that was about it.

-Lisa

I'm fortunate in that both my other children are "normal" and healthy and mature for their ages in a lot of ways. Especially when it comes to dealing with their sister.

-Curtis

Though children are more quick to show acceptance to their sibling with ASD there is still strain and stress caused on the sibling-parent relationship.

> *For M [biological daughter] and H [biological son] we were already dealing with the blended aspects of a stepfather so that was hard within itself there. But if you're talking general with the autism, H really adapted close to her, they actually started quite a unique little bit of a bond. Whereas I found my daughter M pushed away…It did really put a strain on my relationship with her. I used to spend quite a bit of time with M where, now we have appointments [for B], we have engagements [for B], you're doing all these things. So it made it…it definitely put a little bit of a strain on her for sure.*
>
> -Lisa

Siblings were accepting of their brother or sister with ASD, however, tension still existed within the sibling relationship and was regularly observed by parents.

> *I know that for M [son] and K [daughter] there's tension, there's friction. I think K is very much a mother hen. She's become very much a mother hen because she's grown up with a sibling. Difference is she wants to help him but he doesn't want the help. And so she sometimes is like the mom and we have to intersect and say, "You know that's not your job," but she wants to do it and that bothers him. Or he sees her excelling too academically and he's 2 years older and that bothers him as well right. And then socially too. She's an extrovert, she's like a social butterfly. He's an introvert. He's very much like me. He likes to do things on his own and he's shy and I can relate to that. And so he sees her and she's got friends.*
>
> -Daniel and Helena

> *It’s a juggling act. Especially with other “normal” kids. Because, sometimes the behaviour rubs off on them. And then they, and of course they start asking questions, then they start reacting poorly, especially when she has a meltdown or something like that and starts screaming and yelling, and banging on stuff.*
>
> -Curtis

One family found themselves learning how to celebrate all achievements.

> *That’s the thing – we’re all celebrating it and then M is like ‘I didn’t get any awards’ right and then you’re like—so there’s a lot of that and it’s tough. Because he sees it and he holds it back. And she’s got sleepovers and playdates and it’s like hamburgers on the grill and we’re just watching a movie while she’s out and about so I think deep down it’s like man...It’s for us too to learn to celebrate him as well and I know for me I’m trying to find those pieces for him to feel that he is special because he is, and important. And again, our psychologist has stressed that with us. You have to find things that he loves to do and encourage him and praise him and make him feel equally important in comparison to his sister.*
>
> -Helena and Daniel

Another family is learning that what were once acceptable roles and dynamics in the family is not constant over time. Neuro-typical siblings develop and grow over time as well and needs of each individual in the family change over time.

> *I think if anything, now years later, we got more diversity and things going on where I have to take his feelings into account.*
>
> -Lisa

Fears: Both Present and Future

Receiving an ASD diagnosis changes the family dynamics as well as the expectations parents may have for their children. Typical milestones in child development are adjusted, usual achievements in school are delayed or never achieved. Two families expressed a sense of grieving as expectations for their child were changed and their future became unknown.

> *The other thing I hadn't really been expecting was feeling kind of a grieving process through the whole thing.'Cos you're having to kind of reconcile your own expectations and hopes for your child and then realizing that expectations are out the window. Milestones…Screw your neuro-typical milestones and your stupid deadlines… 'cos…I remember getting really excited when he lied to me for the first time, because I was like, "Holy Cow!" because this is something he hadn't been able to do before. Right?! So, that reconciling took a while too. I was just acknowledging—Ok my son has a language disorder, and he struggles with communication and stuff, so putting him in a French immersion kindergarten is probably not the best option....And there was this process of just coming to terms with my own expectations, and we need to make a big adjustment.*
>
> -Nancy
>
> *For me, I was like, I don't know, it's a whole process and you go through different phases. I mean, we've come a long way from when he was diagnosed. Every phase has its things. I think for us, it was stressful.*
>
> -Daniel and Helena

One parent discovered changing expectations for their child brought out fears both present and future.

> *Thinking about the future, thinking about his future, that's stressful. That was the most stressful to me to be honest at the time. Thinking, what if he can never get a driver's license. What if he doesn't get married and have children. What if he never gets a job. What if he lives with me forever. Those are all very scary scenarios. Every parent dreams about having a baby and what that baby is going to be like. And what they're going to grow up to be like and you never ever think my child is going to grow up and never talk. My child's going to grow up and never be able to work because of their disability. You never think that and then it happens and then you have all these brand new fears that you never had before. Because parents are going to have fears about their children regardless.*
>
> *And then you have a child with a disability that's a whole new world of scary. Because there's so many levels of autism you never know if they're going to regress. That's another really scary thing when they're little, is that they'll do something, they'll hit a milestone they've never hit, and then they never do it again.*
>
> -Victoria

One parent used that fear to be a driving force to continue to search for help.

> *I want my children to be able to take care of themselves one day. And live independent lives…I want them to be independent. I want them to have a life. That drove me to keep pushing for something better until I found it.*
>
> -Caroline

Experiencing this concern of an uncertain future brings awareness of a realistic future. Two families expressed that they went through a period of reconciling their fear with realistic expectations of their children. Nancy, and Daniel and Helena, experienced a period of grieving the loss of an expected 'typical' life for their child, and are continuously learning to celebrate and grow with their child as they develop at their own pace.

> *You want, you want your child to be able to do all this other stuff and it's coming to terms with that too. And it's the same with him. It's for him to come to terms with certain things too and our process that we're going through is similar with him. It's accepting it and moving on and seeing what place in the world is for you.*
>
> -Daniel and Helena

Daniel and Helena's son is now a teenager and is looking to his future. This family is finding themselves having progressively more difficult conversations with their child about his abilities and realistic expectations. Both parents and son are learning to adjust expectations together.

> *...we've touched that stage right. That's a whole new— because to know like when you graduate, I'm going to go and work here, I'm going to be a dentist, I'm going to be a doctor, you know, he's asking can I be a pilot, can I be a doctor, or a police officer, and you have to say the truth. No—probably not because if you want to be a pilot you've got to know physics, you've got to know chem. You've got all of this math and when he's struggling with 6 X 9, you know. So then you're sort of setting him up for 'I can be a pilot...' Oh no, I can't be a pilot. And then it's like he's almost 16 and his cousin is driving so 'Am I going to be able to drive?' And we're like, you can't even cross the street. You know what I mean, so, it's, ya, when you really start thinking about deep down into the future, like it gets to be like a big, it swirls. I try not to think too too far in advance cause— But then again, it's a process for us as parents to, I mean when we*

> *bought this place, we already planned it out that if he does decide or he has to stay with us…*
>
> -Helena and Daniel

How Parents Educated Themselves About ASD

Parenting a child with the unique needs of ASD can be challenging for parents and caregivers. As mentioned earlier, studies have found that parents who receive education on techniques for parenting children with special needs not only increase skills, but reduce stress. Also, good communication between healthcare provider and parent improves parental perspective and relieves stress. Parents are provided with materials, names, and brochures upon receiving a diagnosis; however, those were often not the first resources parents turned to.

> *So I got on the Internet and I started googling*
>
> -Janet
>
> *Mostly the Internet and asking, I really only had one person in my life, that acquaintance of mine that had a child with autism. Once we got diagnosed I found some parent groups on Facebook and they were really very helpful. It's strictly for parents so parents can vent about whatever they need to openly without having to worry about service providers being in there hearing feedback on maybe what might be negative or anything like that. But there's always people asking for advice on these portals too. Asking what's the best way to go...home or center. So everyone's got their opinions on what works best*.
>
> -Victoria
>
> *And before we got the diagnosis it was over a year on a waitlist for a diagnosis. So already just basically on the Internet, just looking what could this possibly be. I would*

punch in his symptoms or whatever we were struggling with. I'd punch it in on the Internet what to do and things would pop up and it was typically something on the autism spectrum. So I had already been reading a lot about that. But basically just the Internet.

–Florence

A lot of research. I know Helena did a lot of reading. I'm just not the reader, so I did a lot online. And then it's kind of hard to do it that way, cause it's not like Downs. Basically, the kids are all the same. Autism is all over the board so we didn't know what to expect because we didn't know whether he was going to be high functioning, low functioning, or, because everything was still new to us so that made it a little stressful because we didn't know—is he going to be, you know, interact with the kids.

- Daniel

I did lots of reading and lots of looking at things on YouTube and talking to people, and talking to friends who had children who had problems.

-Caroline

The second most common resource that parents used was friends, friends of friends, or teachers and special educational assistants.

I have one friend who had a friend that had a kid with autism and she connected us. And my mom's friend had a grandson with autism who was attending [facility]. So, for me being a new parent with a kid with autism and not having any idea what it is, I went to the simple easy [facility] because it's an all in one centre.

-Janet

Yes. So that's basically where our information was coming from. From TA's at school and other moms. And on the Internet I would kind of just read about stuff but I *didn't really find out where to get help*.

-Florence

It was through the parent meeting where we found out about the different types of therapy that could be possibly out there. Of course, at that point I still didn't understand what the heck ABA was….

-Lisa

Only one out of the eight families interviewed had any type of guidance and support from a healthcare professional. Nancy had a Child Development Centre visit the day after receiving the diagnosis, which provided her with resources and people to turn to and talk to. However, Nancy, much like others, still had to self-educate about what autism actually was.

And then just kind of educating myself about what this means, and what this does not have to mean. And a lot of your just kind of learning as you go. But it's scary.

-Nancy

I literally didn't know what autism was and I joke that I still don't know it. It's so complex. I still joke that I don't even know what it is. And there aren't even doctors that know about autism.

-Janet

Why does he have autism? So there was that process of what did I do wrong maybe. Or, they still aren't fully understanding the reason why some people get it. But you know there is obviously a genetic link. I think they've figured that out. I think it's environmental but there's so much stuff out there and some of it says this and some of it says that and you're like, well, some say it has nothing to do with that. So there's a lot of

> *contradictions out there. And I think as parents you want to know.*
>
> -Daniel and Helena

Lisa had found a service assembly she liked, and saw positive changes in her child. However she found she had to continue to educate herself as her service provider did not provide any education on autism to her or her family.

> *…and I signed myself up for a course, which was the beginning of December I think it was, and I took a three week course through POPARD [Provincial Outreach Program for Autism and Related Disorders]….The introduction to ABA at POPARD. I took the introduction and then a level one. So, it not only introduced me to what ABA is, and a broader understanding around autism, because they really go into what is autism. It was[n't] just reading it off the Internet. You had someone describing it. Making it, putting it more into logical sense. So I was about to wrap myself around it more that way. Then I also gained lots of tools and understanding of what these girls and ladies were doing in my home when they were in there with B [daughter] and why. So, you know, and it also gave me approaches and things I could start doing with her. On my own time, right? Because of course, screaming doesn't do anything, you can't just ignore the child, you have to find out ways. But when you don't have those tools.*
>
> -Lisa

Parents try to help their child in the best way they know how; however, there appears to be an information gap that exists in the area of parental education on ASD. Unfortunately, this method in self-education of autism spectrum disorder extends to how families discovered resources and service assemblies for their child.

How Parents Sought and Received Information about ASD Services

Research has shown that there is a positive developmental trajectory between age of child with ASD and intervention: the younger the child is in receiving intervention has been shown to significantly improve a child's cognitive abilities over time. As noted earlier, some therapies are better than others. Parents are aware that not all therapies are equal and want what is best not only for their child, but also for their family. Studies have found that parents need support and guidance about empirically supported services and treatment options. Unfortunately, receiving a red folder or white binder full of information wasn't the first resources many families interviewed turned to. The first resource most commonly turned to was, again, the Internet.

> *It wasn't too bad for us, because we could sort through and do research online*.
>
> -Curtis

For six of the eight families interviewed, the majority, if not all of the information they received about services, was from friends, acquaintances, and sometimes co-workers.

> *My next move was to contact friends online, cause I belong to an autism group on Facebook. And I started throwing it out there, does anybody have any really good therapists for their kids? Then you start to get suggestions. And then I started researching their suggestions and calling around.*
>
> -Caroline
>
> *The OT was like…I know this other lady who has a child with autism and it might be really helpful to talk to a parent. And he connected me with this lady*.
>
> -Nancy

> *So, I left [facility] and then I went on the recommendation of the friend that I met, the son with autism, she was working with another organization which ended up crumbling because this lady was the same thing.*
>
> -Janet

> *Based on my friends recommendations. She was using a home based team and that's the way I wanted to go also.*
>
> -Victoria

These families struggled to find a service that would walk with them and explain to them possible ASD services, what they were, and what types of services could most benefit their child and family.

> *Yeah, I mean again, it's not like anybody was coming to us saying: "Hey this service is available, hey this service is available." It's more kind of, you end up hearing it from other parents who heard about this service from their provider, or somebody who worked/does this, you know for MFCD, or some other service, kind of thing.…It's kind of like the grapevine rumour mill to learn about some services, sometimes.*
>
> -Curtis

Two families greatly benefitted from the Child Development Centre in their geographical area. Lisa went to a parent group that was hosted by the Child Development Centre that had a social worker speak. However, all the information she received about services were still from fellow parents who attended the group, not Child Development workers.

> *I got a hold of [Child Development Centre worker], she told me there was this wonderful group that was, it's a parent group for children with ASD, and other mental*

> *health disorders. We're really lucky that there's a parent group and somebody to come and talk about…So I met a social worker, I met some parents, they gave me notes of certain consultants to possibly use. One that came extremely recommended was [consultant]. So of course, I went, read up on her a little bit. I kinda, really sorta, after that meeting, decided ABA was probably going to be the best approach with B [daughter].*
>
> -Lisa

Through happenstance, Nancy had an occupational therapist from the Child Development Centre come for a scheduled visit to attend to her son's speech and sensory issues the day after she received the diagnosis.

> *We actually had an appointment scheduled the day after diagnosis, so they show up, and I have my red folder on the table. And they're like: "OK! You have news!" So, instead of having the meeting they were gonna have, they started telling me about different services and what not. And emphasizing I need to go see the social worker immediately.*
>
> -Nancy

> *We got a red binder or red folder, and it had information on the ACT website, so I started reading through that almost immediately. I had these people from Fraser Valley Child Development Centre giving me a good start, and then, I started poking around, I think I may have gotten papers from the social worker. I got a list of the local consultants with a little comment: I would look into these ones but I'm not telling you why. So I just started poking, going through the list, I didn't really know what I wanted.*
>
> -Nancy

The last resource families tended to use was the ACT website's RASP list. The RASP is the Registry for Autism Service Providers, which could be found easily on the Autism Community Training website. However, as of July 2017 the Ministry of Children and Family Development has taken over management of the RASP list. All of the parents interviewed received their diagnosis well before July 2017. Regardless of the RASP list's location, it can be an overwhelming resource and is often the last resource parents go to when looking for a service.

> *I finally, actually went back to this RASP list and I googled it and thought there's got to be something to this. I did, I googled it, I printed it off, and I went through every single name, called and then met with a few people.*
>
> -Janet

> *When we went to see our social worker, she gave us the RASP—the ACT website and then she said you can find people who can help you through that*.
>
> -David and Helena

Some parents struggled to find services that were a good fit for their child and their family, and one family interviewed continues to struggle. The grief of receiving an ASD diagnosis, coupled with the stress of self-education and finding services has already been described as overwhelming to say the least. These families do not want to face the journey of autism alone. Families reached out to the resources that were made available to them, and to other supports they already had set in place to help guide them through their autism journey.

> *I was calling, I have a life coach, I was calling my life coach like, I'd send her messages, I can probably even show you, messages of desperation saying, like "This is it! —I can't do it anymore" and she'd be like "Call me please!" And you know, my*

> *husband…my husband was ready to like leave.*
>
> -Caroline

What Services and Supports Families Feel They Needed/Wished Existed

Each parent wished for something to be different about their experience between the time of diagnosis of ASD to service assembly. But the common underlying theme was support. Parents did not want to go through this journey feeling alone. Parents did want someone to guide them, support them, and educate them—not other parents or the Internet, but an expert or healthcare professional.

> *That's what I have found. I have found that I've reached out to so many people. I need help with K[daughter]. K is suppressive. K hits, K kicks, K bites. I mean, I've had black eyes, hair pulled out, scratched, cut, kicked. You name it, it's happened. That's what, I can't get anyone to help me with that. Nobody has a clue. They, do you know what I mean, there's no help for that kind of stuff.*
>
> -Janet

Parents want guidance. These families wanted someone to lead them on their autism journey. Receiving a binder or folder full of information did not ease the stress of finding services, nor did it help families find services more quickly. Parents desired an expert within the area of autism to educate them and help them find a service that was best for their child.

> *There's no help, there's no guidance, there's nobody to hold your hand and walk you through it. And when you don't know. I literally didn't know what autism was and at no point at any part in that journey did anyone actually sit down and say, it's a neurological disorder. I mean, you can Google it, it's right there, but what does that*

> *mean. You know what I mean, what does that mean, what is autism? So that was for me the biggest hurdle as I was just so lost in trying to figure it all out that, ya, I think, and I don't know if a package for you when you walk out the door is what I think parents need. I think parents need a little bit of time to decompress. Wrap their minds around it. I probably too quickly jumped into [facility] in a panic. I think is what I probably did. Which I think they count on a lot of people doing.*
>
> -Janet

> *But there should be some kind of 'point to' people. There should be someone to sit down and explain to you how the funding actually works, because you don't even know that. And walk you through it.*
>
> -Janet

> *I felt like there wasn't any care or sensitivity. Here you go, this is what your son has. He's on the autism spectrum. He'll get some help, apply for some funding, apply to here. Call this place and all of it was French to me. Cause I was like oh, okay, could I have one contact person that could walk me through this?...Hold my hand, walk me through some of this. Not just, ya, the pamphlet.*
>
> -Florence

Parents want to be educated. All of the parents interviewed did their own research on autism. Some bought books, others sought out friends and online support group resources, and others relied on Google for their education. These methods of self-education leave room for false information and can cause parents to miss clinically based truths.

> *If there was some process in place leading up to that where we had a little more information on autism, and we can kind of get ahead of that curve a little bit, it might have been a little less overwhelming*.
>
> -Nancy

> *SLP, BI, BA, there's just so many things that you don't know any of what that means coming out of the diagnosis but I just wish that everybody felt that way coming out of it. I wish that they gave that information at the time. That's a whole other appointment on its own. Just giving the parent all the information they need, not just handing them a folder full of information and saying, make an appointment with the Social Worker*.
>
> -Victoria

Parents want to be heard. They know their child intimately, and are aware of the needs of their family as a whole, their voice is important.

> *And that's what I'm talking about, is about listening to me, and my needs. And my children's needs. Because I spend the most time with my children, than anybody else, I know their needs, so if I'm trying to talk about what the needs are to somebody, people should be listening to me. They shouldn't be nodding, then planning their own schedule behind my back.*
>
> -Caroline

Most of all, parents want to be supported.

> *No. There were none [services] and I, no, there were none. It was all word of mouth, talking to people that I kind of met through this autism life. There were none. And it's interesting because you now, people, like other people come to me. I don't even know*

my own stuff. Everyone is different, every kid is different. Trying to explain that to people. At the blog now people think I'm this expert but I'm not.

-Janet

Uh, I would say that, what I would love to see in the future, when parents start noticing things, there has to be more access. More availability to the different mental disabilities that are out there. Not just autism, but ADHD, depression, all these things. There's gotta be something where parents can go to when they start to feel like their doctors aren't listening, so that they can feel that they are getting the best advice. And making the best decisions for their children. Even if it's accessibility online, to start forming those opinions, to bring up proper questions to their doctors…

-Lisa

Finding the right medical professionals would have been helpful. And being able to not cut corners. But get through the system a little better would have helped.

-Curtis

And I was saying, having that red folder, having that one page inside with the checklist—Step one: call MCFD, Step 2 do this—was great but when it's the first page of many inside a folder, I said the only thing I could think of was put a sticker on the front saying: "Before you open this, call this phone number"…Just step one. Because then you have one thing that you are looking at, and when you have whole list and you are still overwhelmed, even starting with number one on the list can be a bit much. Just one little thing that you're looking at. Even if you lose the page. This is where you start. That's the only thing I could think of. Trying to get ahead of information.

-Nancy

Some of these families really struggled mentally and emotionally all the way to a completed service assembly they were happy with. Other families continue to struggle. These families now understand at a deeper level what future families receiving an ASD diagnosis will go through, and are willing to help if they can. Victoria spoke of how she seeks out parents who are recently diagnosed to try and help them.

> *Trying to help them make the best decision and let them know what my experience was and help them through just getting diagnosed to that really scary stage where they don't know what anything means and they don't know what their options are and just letting them know these are what your options are.*
>
> -Victoria

Questions Parents Had and Still Have

Throughout the process of interviewing consultants and ASD resources, parents expressed a lot of concern and questions they had throughout their autism journey from diagnosis to service assembly. Most of these questions went unanswered until either families self-educated themselves, or answered questions through their own experience and experimentation. Most of these questions could have been answered by a health care professional.

> *What is the difference between Reggio and ABA? What is ABA? You leave with this diagnosis as a parent and there is just not enough information to really make decision for your child, because ultimately you are their advocate. How do I know ABA is going to be OK?*
>
> -Lisa

> *I didn't know what a Behaviour Consultant was, a Behaviour Interventionist, a Speech Language Pathologist, an Occupational Therapist, a Feeding Therapist, which K does all of these things now. I had no idea. I literally didn't know what autism was…*
>
> -Janet

> *I tried to think about the concerns that I had about my child. So Ok, these are the behaviours that…these are the concerns that I have, these are the behaviours that I'm noticing, tell me a little bit about how this therapy works. Like what exactly are you doing —you're not plugging him into a machine or anything—so what exactly is the process look like.*
>
> -Nancy

Other questions parents had centred on behaviours of their child with ASD. Families were looking for support and guidance.

> *That as a parent in the beginning that's all you're thinking about: is this going to stop? How is this going to work? I mean, C [partner] was so overwhelmed in the beginning he would have to leave the house because B [daughter] would be, basically, throwing herself into the bedroom door, under that table screaming non-stop.*
>
> -Lisa

As already discussed, many parents were looking for information, but were not sure where to turn to.

> *There is nobody that you can call and say, what do I do? What is my next step? I've got this kid with a disability. I don't know anything about it. What do you mean the*

> *Autism Funding Unit? What do you mean a RASP list? I'm so confused*.
>
> -Janet

Lastly, parents weren't sure what to ask consultants and facilities when they were interviewing services. Nancy did the best she could, and asked the consultant what questions she should be asking.

> *So this is the behaviour, what does your kind of intervention look like, what does the process look like. And then I was asking questions like; I have no idea what I'm talking about – so what kind of questions do parents ask who actually know what they're talking about, and how would you answer that. So, I did my best*.
>
> -Nancy

With this being a family's most common experience, this question was asked: "Was there anything you wished you had known then that you know now to help you better navigate through the process?"

What Parents Would Tell Their Past Self

When parents were asked; "Retrospectively, was there anything you wished you had known then that you know now to help you better navigate through the process," three families answered that question with ideas of services they wished had existed then that still do not exist today. Of the other five families, only four families would give their past self any type of advice or encouragement.

Two families would have given emotional support to their past self, given themselves the words they felt they needed to hear when things were difficult.

> *I think I'd tell her to just keep going with your gut instinct. Because you were right. And not to give up.*
>
> -Lisa

> *It's not like I regret the entire 18 last years of my life, it's been this horrible show I would never want to remember. There have been parts that have happened where I would gladly have avoided them completely and had them not happen. But with any child like this, I mean there's days where they're happy and days where they are not. There are peaks and valleys. Like with any child. It's just a lot more extreme. Because they can go from being super super sweet and all cuddly to…melting down and screaming and slamming doors and ripping paper and…why? They just go completely incoherent sometimes. Maybe that's the one thing I would tell myself in the past: You know what? Sometimes there's just nothing you can do.*
>
> -Curtis

Two other families would have given themselves advice on education and support services. They felt that they had been taken advantage of during their time of desperation and need, post diagnosis, when looking for services.

> *I think, just looking back I think maybe I would not have been so quick to, at such a young age that J [son] was when he got diagnosed, to leave him in a facility where I wasn't sure fully what the treatment entailed…Ya, I would redo the first year of being diagnosed but feeling like we were drowning and thinking we'll take anything. Okay, that's what you say works, we gotta do that full*-time, *okay. I would do that over*.
>
> -Florence

> *I think…the number one thing that comes to mind is that, just because a company appears like it's got its act together. Doesn't mean that it does. I don't know how I could have changed things, because I didn't know anything. I was a newly diagnosed family with needs. Educating myself.…Just because a company appears, they show up with this big binder, and they have all these people sitting there and they all look professional, but they don't know their asshole from their...whatever that saying is*.
>
> -Caroline

One family was divided in whether they would tell their past selves anything. Daniel was glad he didn't know anything. He expressed that the knowledge of knowing how hard having a son on the autism spectrum was going to be, and the knowledge of knowing the years of searching for services and never attaining one, would have made the process a lot harder for him.

> *I think for me, if I would have known, like the results is the big thing. Like if I would've known what we were getting. If we were guaranteed to be able to have M [son] excel in all of his programs I would go back to that but I just—it's so disappointing.*
>
> -Daniel

Daniel's wife, Helena felt slightly different. Retrospectively, Helena couldn't see how changing the choices they made would have made any difference on receiving help for their son. However, she still hopes that if she had been a little more educated, maybe things might have been easier.

> *I think for me it's just you get thrown so much stuff in the beginning and it's very overwhelming and you don't, you believe, when you are together with people that so supposedly have been in the industry and have done this sort of thing for a number of*

> *years, you trust them. And we did that. We trusted them. And then we would trust them for a number of years and then we would start to see a different side of things and I think for me going back, I wish I was a little bit more cautious and somehow researched things a little...I don't know.*
>
> -Helena

Key Assertions

These interviews are powerful narratives of real struggle and true grief. These parents share a common experience and share an awareness to how wanting this autism journey can be. Review of the interviews yielded three key assertions in parental experiences from diagnosis to completion of a service assembly.

Assertion one. Parents who had a *guide* of some type within their autism journey spent less time looking for services and found a service that best fit the needs of their family and child, comparatively faster than parents who did not. This autism guide looked different from family to family. For Nancy, it was the occupational therapist who helped her get started the day after diagnosis. For Victoria, it was a mutual friend whose child received an ASD diagnosis several months earlier. And for Lisa, it was parents she met at a Child Development Centre gathering. This guide alleviated stress and answered questions when they occurred. These three families still experienced stress and emotional anguish, however, did not experience the frustration or disappointment of employing multiple service providers.

Assertion two. All parents and families that participated at some point grieved an autism diagnosis. This grieving process looked different for each family. Though Lisa and Victoria stated they felt relief after receiving the diagnosis, as these two parents told their narrative they expressed moments of fear of the future, and concern of a changing dynamic within their family.

Each participant parent experienced a period of refocusing realistic goals for their child, and a mourning of what the future looks like for their family at variable lengths of time.

Assertion three. Parents want to receive help and to be educated. Many of the parents within their interview expressed not knowing who to turn to, or what steps came next in their process of trying to achieve a service assembly. Education was provided to each parent in the form of a red folder or binder which they received from their assessment clinic; however, at the time—post diagnosis—this information inside was found to be too overwhelming for parents, and difficult to absorb. Most parents still tried to educate themselves through Internet resources; however, these resources are unregulated, not peer reviewed, and can contain much false information unknown to parents.

CHAPTER FIVE: DISCUSSION

This study examined the experiences of families after receiving an Autism Spectrum Disorder diagnosis until achieving a completed service assembly for their child. After examining the themes extracted from the interviews, there was a better-informed understanding of each family's needs. The interviews provided confirmation of the disparity between what literature suggests as being optimal and the actual experiences of these families.

The first observation from the interviews was that not all parents were emotionally ready to receive an autism diagnosis. For the majority of parents interviewed, receiving the news of a diagnosis was not a surprise, but an affirmation. Despite this, actually receiving a diagnosis caused considerable emotional distress. Receiving and accepting an ASD diagnosis altered these families' hopes, desires, and expectations for their child. Five of the families expressed a need for "space" and time to process mentally and emotionally their newly received diagnosis before receiving any more information.

At that moment in time (after receiving the diagnosis), parents found themselves emotionally grief stricken. Autism Spectrum Disorder had suddenly redefined what is normal within these families' homes. These parents were handed an educational folder or binder by a physician. This information is meant to be educational, helpful, and used as a guide to begin the autism journey. However, though the information can be helpful, in the mental state in which parents received this information, parents reported feeling overwhelmed and distressed. This emotional reaction to the folder or binder provided to parents caused families to shy away from it and the information it contained. This reaction motivated parents to seek to educate themselves by means other than the contents of the folder.

Hypothesis One

Prior to commencing the study, it was hypothesized that many parents in the lower mainland of British Columbia are educating themselves using books, media, the Internet, and word-of-mouth resources instead of learning from their healthcare professionals. This study confirmed that hypothesis. All parents sought to educate themselves on Autism Spectrum Disorder primarily through the use of the Internet. One parent, Lisa, took a course through POPARD (Provincial Outreach Program for Autism and Related Disorders) to further educate herself about Autism. However, it was found that the other seven parents did not seek further education beyond the Internet, though a few parents sought education through secondary resources such as books and word-of-mouth. Self-education can lead parents to inaccurate and false information. For example, if a family believes that diet causes autism then they may be prone to look for resources that align with that thinking and look for sources that can “cure” their child. Families are doing the best they can with the information that they find for themselves, not knowing what information is unfounded or clinically based. This was shown through Curtis’s story. This family was self-educated and believed that because their daughter’s ASD was caused by genetic mutation, behavioural therapies would not be of any help to their daughter. This understanding of ASD and behavioural therapies is in direct contrast to findings in clinical studies (Eikeseth, 2009; Reichow & Wolery, 2009; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). Currently, there is no known appointed healthcare provider or autism specialist providing information for these parents, answering questions that they may have, and guiding them through genuine and substantiated information and services.

Hypothesis Two

The second hypothesis made was that parents are not aware of the resources that are available to them after receiving a diagnosis, and are therefore seeking help for their child and assembling services in much the same way they self-educated themselves. This study confirmed this second hypothesis. When families receive a diagnosis they are provided with a list of Board Certified Behaviour Analysts (BCBA) within British Columbia via the Registry of Autism Service Providers (RASP) list. The service provided by a BCBA consultant is financially supported by the Autism Funding Unit (AFU), which allocates a finite amount of money to each family diagnosed with autism every year. The list of BCBAs is helpful to parents; however, other resources such as programs, sports, camps, and other types of therapies, which are also financially supported by the Autism Funding Unit, are not provided for families. If a family does not have a BCBA approved consultant or worker already, a family may not be aware of other resources that are available to them. This study demonstrated that families' primary resources for finding services and BCBA consultants was through word of mouth or internet searches, despite the RASP list being provided to them.

Within the red folder or binder, parents received a web link to the RASP list. This list provides parents with over two hundred names of BCBA accredited consultants, speech therapists, and occupational therapists across British Columbia. This extensive list of names can compound the feeling of being overwhelmed that parents already have when beginning the search for services and therapies for their child. Based on the experiences of the participants in this study, parents are told to look for services and therapies for their child, but are unaware of what productive therapy looks like. This relates to the review in literature, which displayed how education and parent training relieved stress and produced confidence in parents. However, this study revealed that parents feel they are not given proper questions to ask consultants on the RASP list, nor are they made aware of signs they should look for after hiring services. Nancy expressed this when she interviewed BCBA consultants, by asking *them* what she should ask. Families should be educated in what indications to look for in services, feel confident in whether the services are a good fit, and know whether their child is progressing appropriately. If parents receive more education by professionals, as shown by Nancy's story, the time between diagnoses to a completed service assembly should decrease significantly. Empowering parents through education would in turn hold service providers to a higher standard in providing therapies for ASD families.

Additional Themes

Other over-arching themes, observed through the families interviewed, was the strain on family relationships. Parent to parent, parent to child, and sibling to sibling relationships all felt strain after receiving an ASD diagnosis. The divorce rate amongst families with special need children is high, and with a child with ASD, the rate is even higher (Kasari & Sigman 1997; Bromley et al., 2004; Martins, 2007; Dabrowski & Pisula, 2010). Families are reaching out for help. This was displayed through Lisa and Caroline. Lisa sees a psychologist regularly, and Caroline has a life coach whom she talks to when the stress of life builds. Every family interviewed expressed stress or strain on their family relationships. Many of the families interviewed did not have a service in place to help navigate the autism diagnosis as a family. Providing healthy coping mechanisms for families has shown to positively affect relationships and reduce stress (Sofronoff & Farbotko, 2002; Marucs, Kunce, & Schopler, 2005; McConachie & Diggle, 2007; Singer, Ethridge & Aldana, 2007). Many services are available for a child with ASD; however, services for the family to deal with role and family dynamic changes in a healthy way are not as well known.

Lastly, every family expressed they wished there was something more for them. Families wanted a resource to guide, support, and educate them throughout their autism journey. Autism is not stable in its behaviours over time. ASD behaviours change as the child ages, as do all children's behaviours as they grow older. Parents articulated the need for a service to turn to when things got difficult or family strain became too much, even after they've found a completed service assembly. A support system has been shown to be very important and can positively influence family relationships (Benson & Karlof, 2009; Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003); however, these parents have been unable to find a service to provide that needed support.

Limitations

This study examined the experiences of families after receiving an Autism Spectrum Disorder diagnosis until achieving a completed service assembly, and although the current study identified many family needs, it is important to acknowledge the limitations of these findings.

The first limitation pertains to the study's small sample size. The qualitative method of open-ended interviews provided detailed and rich insights into parents' experiences. However, these insights are limited to eight families. Having additional families from differing cities may better illustrate the need of parents. Also, more families from various areas would be able to show if different regions have more or less resources available for families.

A second limitation to the study was the principal investigator's embeddedness within the collection of data. All the participants of the study were familiar with the investigator and were asked personally to participate in the study by the investigator. Despite this personal connection between the participant and the investigator, it is believed that this previously established relationship allowed for genuine expression of experiences and allowed parents to be at ease when talking about stress, grief, family, and personal relationships.

Implications for Future Research

This study examined the time interval between receiving an Autism Spectrum Diagnosis and achieving a completed service assembly. Previous research has studied the relational strain a child with ASD causes on the family (parent to parent, parent to child, and sibling to sibling) and the best types of behavioural therapy to positively change a child's cognitive trajectory. However, there has been little research looking at the impact of receiving an ASD diagnosis, and how parents find and receive help. There has also been a lack of research on educational programs for families looking at the impact and prevalence of educational programs for parents and families after receiving a diagnosis. This subject area is important and more work and study should be done. Families within the study state that they need and want help. These data align with Keenan, Dillenburger, Doherty, Byrne, and Gallagher (2010), who sought to document the experience of receiving an ASD diagnosis for their child. Seventy-seven percent of their participants felt that they were not provided sufficient information from their health-care professional for their child and family regarding information on ASD and services provided. This divide between parents and information was replicated in this study. This gap in knowledge, guidance, and professional help was detrimental to families, directly affecting the length of time it took for families to achieve a completed service assembly. Whether it was lack of relationship between family and physician, or a void in actual services to aid families during this time, families reported that they did not feel adequately cared for.

Future research should focus on the unique relationship of care between parent and physician or health-care professional. Most of the parents within the study did not mention within their narrative that they had asked a health-care professional about any questions they had regarding ASD and next steps. This may reflect the disconnect families feel while going through the process from diagnosis to service assembly. Families need to know that they are cared for. Through future research this could be demonstrated through the provision of supports beyond a large binder. Schat (2016) showed that ethical care provides positive outcomes for families and creates an openness and willingness to listen to recommendations and/or guidance of professionals. However, as displayed by the lack of doctor-parent relationship within the narratives shared, these families do not report receiving the care they want. Barriers need to be broken, families need to be educated, children need to be properly cared for, and perhaps, policy needs to change—especially if there is a positive developmental trajectory between age and intervention as research suggests. More research into these relationships, or lack thereof, might reveal how to best aid these families, hopefully revealing a better lived experience to families who receive an ASD diagnosis

Future research should consider examining levels of stress and distress families feel through the use of standardized testing, as a more appropriate measure to quantify these emotional expressions. Throughout the study parents expressed experiencing high levels of stress and distress. Using Likert Scale type instruments would allow future researchers to have a more tangible and quantifiable expression of these experiences; these instruments could be useful for larger scale studies and allow easier study replication, providing more generalizable results.

A mixed-methods approach of coding interviews for keywords such as: overwhelm(ed/ing), stress, strain, fear and anxiety, may give researchers a clearer idea of primary issues families feel or encounter. This approach to research would provide data on the primary concerns of families and bring focus to particular issues or reported feelings.

Understanding the primary needs of parents would allow researchers to concentrate their efforts and utilize proper resources to create services. These services would allow professionals to properly care for families in the ways they need most.

Another method of value could be to develop and use a detailed *check-list* or *need determination instrument* of parents' needs. This type of instrument could help future researchers gather information and permit a statistical and/or descriptive examination of that information. All of these suggestions could provide a better reflection of the needs of parents, allowing for a larger sample size and more diversity within its population.

An obvious limitation to this study is the sample of convenience used and the size of the sample. A larger sample size with a more diverse population to better reflect the population of families who receive an ASD diagnosis would be beneficial. Using a wider geographical focus, whether expanding to different locations within British Columbia, or other provinces, will provide fascinating and important insights into this phenomenon of overwhelmed and distressed parents post ASD diagnoses. However, despite the study's small size, the results of the study did align with previous studies in terms of parental grief, marital stress, and gaps in professional support.

Though it is believed that the principal investigator's embeddedness within the study was a strength, as it allowed for greater emotional depth and openness from the participants, the use of a dispassionate researcher could also be of value. The use of a dispassionate or neutral researcher to do a similar or replicable study may provide differing results and allow for a more impersonal perspective.

Through the use of quantitative measures of stress and grief and the use of qualitative methods to hear family stories to better understand their needs. Future research could inform important and necessary change, to help parents better navigate their autism journey.

CHAPTER SIX: CONCLUSION

This study examined the perceptions of families during the time interval between receiving an autism spectrum diagnosis and achieving service assembly. Through the use of qualitative methodology, this research gathered the narratives of parents in hopes of understanding the true experiences of families during this time. Throughout the study there were consistent themes and key assertions that emerged in the narratives, revealing some of the emotional effects that having a child with autism had on parents, families, and relationships. The interviews and stories shared by these parents allowed for a deeper understanding, specifically of these families experience of grief and their desire for support and guidance. This study's implications, strengths, and limitations add to developing the literature in ASD research and lead to suggestions for future research.

Parents Experience Grief

Every family interviewed experienced grief at some point in their autism journey. Though expressed differently at varying times, at some point these parents mourned the ASD diagnosis of their child. Parents felt "grief for the loss of the person as known and for the loss of hopes, wishes and aspirations, grief for the disability caused by the illness and the disruption to the family and relationships." (Godress et al., 2005, p. 88). This grief differs from that of losing a loved one, as it is not specific in its cause of pain nor has an exact starting moment. The grief these parents experienced began with a worry from within that *something isn't right* with their child.

Those who have a child with ASD, experience grief along a continuum: it ebbs and flows. This grief doesn't mean that the love these parents have for their child waxes or wanes in any way. Nor does this grief mean they wished they had never received the diagnosis. For some families receiving the autism diagnosis for their child was a relief, an answer, a confirmation of fears. But they still experienced grief as they realized their future plans and dreams for their families had changed. For other families, receiving the diagnosis caused a grief that felt like a heavy burden. These families agonized over an ASD diagnosis as they became aware of the loss of future aspirations for their child, realizing the future they had dreamed was now changed.

This changed future becomes fear as their child ages. Parents are unsure if their child will reach developmental milestones, if their child will regress and lose skills, or if they will ever be independent. Cycles of grief rise and fall as parents learn more about ASD and the implications this diagnosis has for their child, family members, and extended relationships. These families learn to celebrate new skills and small victories, while also experiencing loss and pain as their hopes and dreams for the future are disrupted.

The dynamic phases of grief remain with time as their child ages. Families learn to reconcile expectations with reality and acknowledge the true abilities their child does or does not have. Parents learn to accommodate the strengths and weaknesses of their child, much like Helena and Daniel for their son, they prepare for the potential realities that their child may not ever learn to drive, live on their own, or hold a job. The joy of bringing a child into the world, and the desire parents have to watch them grow, succeed, and thrive is altered upon receiving an ASD diagnosis, and can cause the future to seem ominous and even frightening.

These families at times have a feeling of overpowering grief, feeling inundated by the demands of “regular life” alongside the demands of raising a child on the spectrum. Parents have uncertainty of the future during this post-diagnosis time interval which is a cause of great burden to parents. Not knowing what the future holds, while also feeling relational strain and stress, combined with feelings of grief can cause parents to struggle as they carry on, alone, with no one to guide them

Families Want Better Support and Guidance

Parents within this study expressed a need for guidance throughout their autism journey. Though not explicitly stated by every parent, this was shown through the actions of each family. All parents who participated spoke of asking friends, family, acquaintances, Special Education Assistants, teachers, and internet forums about what to do and who to hire. Every parent was looking for a *guide*.

The parents within the study found that a guide greatly affected their autism journey, by shortening the time from diagnosis to achieved service assembly. Nancy, Victoria, and Lisa’s time interval between diagnoses to service assembly ranged from three weeks to three months. The other families, who did not have the experience of an individual acting as their autism guide, had a time interval ranging from nine months to six years from diagnosis to achieved service assembly. Not to be forgotten are the two remaining families that have not yet achieved a service assembly for their child. The amount of time is discouraging and disheartening, considering the accepted importance of receiving behavioural therapies as soon as possible.

Parents who need to continue with daily life, work, and care for their families, are suddenly being asked to find consultants, educate themselves about ASD, and maintain various relationships. There has been much research on the relational strain, both marital and generally, within families that have a child with ASD. Parents are struggling, grieving, and often feeling overwhelmed, yet they continue to move forward. Families expressed that they do not want to go through this journey alone. They are searching for someone to guide them, whether it be a friend, teacher, or the Internet.

Parents want Information and Education

Parents and families want to be better educated about their child’s needs. As shown within this study, families wanted to learn and find best practices for their child. The way in which parents receive information from health-care professionals was emotionally overwhelming. Parents were not emotionally ready to accept a package of information on ASD within minutes to hours after receiving the autism diagnosis. Parents are being provided with information and resources by healthcare professionals, but found it came in a way that appears lacking in human connection and care.

It is human nature to seek relationship, to find others who have gone through similar experiences, or seek wisdom from those with experience. All parents in this study did this: sought relationships, found others with similar experiences, and asked others what they should do. However, the majority of these relationships did not involve a healthcare professional; they involved the Internet and parent forums.

The primary resource of these families, for self-education or general information on ASD, was Google and Facebook parenting groups. These groups and forums are important to families. Within them parents feel supported. They can ask questions openly and they know for the first time in perhaps a long while that they are not alone. Social media has provided parents with outlets to discuss therapies, ask about consultants, and struggle aloud with experiences and questions they have. Unfortunately, these outlets and media forums are not regulated and can often spread misinformation. This misinformation can itself cause problems and exacerbate worry and grief.

Some of these forums have parents who state that they have “cured” their child of autism often with bizarre interventions. Some contain discouraging messages such as this one found on www.gethealthyagain.com: “Unlike doctors who tell you there’s nothing you can do, this report provides real hope and concrete steps you can take to reverse your child’s autism.” Statements that contain such certainty are appealing to parents who are desperate, grieving, and overwhelmed. However, these claims are unsubstantiated, unstudied, and sometimes feature a truly outrageous philosophy. Yet, parents may be desperate, and many are willing to try anything to help their child.

Common anecdotes found on forums and parent websites claim that autism can be “cured” through diet and vitamins. Others state essential oils increase learning and focus, and more recently parents have shared articles, claimed to be written by scientists, that state collagen in drinking water hinders brain development and causes autism. Their cure is to have children with autism only drink Fiji brand drinking water, which they say does not contain collagen. There are many families within the lower-mainland of British Columbia who have spent thousands of dollars stocking their fridges with Fiji brand drinking water, believing this would help. Other suggested causes of autism on some of these parent forums include childhood vaccinations, Tylenol, pesticides, Lyme disease, and various environmental toxins.

Parents need to be educated with accurate and reliable information. Parents need not only to be educated in what ASD is and current scientific understandings of causes, but also accurate and legitimate methods for treatment of ASD.

If parents are appropriately educated in therapies and intervention styles, they may turn to more appropriate methods of aiding their child’s development. Parents should be educated in questions to ask consultants, indications of what to look for in their child and family, to see if their child is progressing appropriately and if the therapy type is a good fit for them. If parents are more educated in scientifically-based treatment options for their child and have a better understanding of what good therapies are, consultants and facilities that are not providing the best care could be eliminated with time. Educating parents could change the landscape of consultants and facilities, augmenting standards of care and practice.

Families Want a Better Way

This study explored the experiences of families from diagnosis to completed service assembly and found a need for each of these families: human empathy. Parents were not always treated with compassion or care throughout this time interval. There was little time for parents to process their emotions, understand their grief, and mourn their future post-diagnosis. Parents had no opportunity to breathe before receiving an overwhelming package of information from their diagnosing physician and sent home with no follow up, to start the autism journey on their own.

Ethical care practices seemingly did not exist for these families post-diagnosis. There was minimal support given to the parents emotionally and educationally. Parents did not have a human as a point of contact if they were stressed or lost in the next steps, only a folder full of brochures, names, definitions, and websites. Parents were not educated by health care professionals about best practices for their child, therapy (styles and types), counselling (child, family, and marital), and were not verbally given general information about autism. Parents were handed a folder full of arguably important information, but it was up to the parents to decide what to do with that information. There was little, if any support, care, or guidance for parents. The next step for these families was to gather enough strength to reach out on their own.

There may be a better way to reach these families, support them, educate them, and answer any questions they may have as they go along this emotionally stressful journey. If parents received one phone number to call post diagnosis at a time when they felt emotionally ready, the beginning steps of the autism journey might be far less intimidating. If there was a centre that existed for families to turn to when they were ready to begin their autism journey, families may feel less overwhelmed and more supported. This autism informational centre could provide education for parents, be able to answer questions they have, and empower parents with resources, next steps, and support. There is a large information gap between health care professionals and parents of a child with autism spectrum disorder. Something should be done to begin the process of closing that gap.

Helping children and families get the best support they need post diagnosis is important and should be studied further. Research has shown that receiving behavioural intervention therapies as quickly as possible positively affects a child’s cognitive growth and development. Unfortunately, as shown by this study, without support and guidance, parents can take from weeks up to years to find a behavioural therapy that is a good fit for their child and family. To help these children receive best therapies and interventions available to them, first we must start with the families. Caring for parents, educating families, and helping children with ASD, could assist families to achieve a service assembly faster, easier, and with hopefully less grief.

Recommendations

While this is a small qualitative study, this research gave voice to eight British Columbian families and their experiences of receiving an Autism Spectrum Disorder diagnosis. This research allowed for an in-depth analysis of only eight families, which reduces confidence in generalizability and concedes many limiting factors. Limiting factors include the embeddedness of the principal investigator, small geographical location, and the use of only English fluent, non-immigrant families, in addition to the study’s small sample size. The recommendations that follow could be applied to any subsequent replication studies. In addition, one supplemental recommendation is made reflecting the perceived needs and themes extracted from the narratives of these families.

Recommendation of Quantitative Approach. There are several quantitative approaches that could be very beneficial to future research in the area of families experiencing stress, grief, or distress in the time interval between ASD diagnoses to achieved service assembly.

Likert scale. Considering the use of Likert Scale type instruments would allow for more tangible quantifiable expression of experiences and more objective interpretation of results.

Mixed methods. Considering a mixed-methods approach of coding interviews for keywords such as: overwhelm(ed/ing), stress, strain, fear and anxiety, may give researchers a clearer idea of primary issues that families feel or encounter. This approach to research would provide data on families' primary concerns and bring focus to a particular issue or feeling that was reported.

Check list. Considering a detailed *check list* or *needs determination instrument* of parental needs could yield important information. This type of instrument may help future researchers gather information and permit a statistical and/or descriptive examination of that information.

Recommendation of a Support Centre. The idea of a support centre is the final recommendation from this research. There are several groups and agencies already established in British Columbia that seek to provide help and supports to families who have a child with ASD. Several major agencies have a strong online presence and hope to assist families within B.C.: Autism Information Services of British Columbia, AutismBC, Canucks Autism Network (CAN), Provincial Outreach Program for Autism and Related Disorders (POPARD), and Child Development Centres and Autism Community Training (ACT). All families within the study used one or more of these services during their journey to completed service assembly or after achieving a service assembly. In spite of their existence and many resources, families report they still struggled. This raises a logical question: Do these services not offer what these parents want or need?

It is hypothesized that these services may be unaware of the extent of stress and grief parents experience during this time interval. Not one service or website provides all information needed to make informed decisions about autism-specific services available for families and their child. POPARD is a comprehensive resource for learning about what autism is and educating about what practices exist, especially within a school setting. This was shown through Lisa and her narrative. Many parents within the study turned to AutismBC, or the ACT website to look at the RASP list to find a BCBA consultant and be made aware of the many resources available for parents, which some reported that the latter was their “last resort.”

Many of these services provide information on their websites regarding training, resources, and other materials via web-links. It is hoped that these websites would portray the richness in resources and educational practices of services that already exist in British Columbia. However this online presence does not address the key issue directly as revealed by this research: that parents want a *guide* and are in need of human, ethical, care.

This study recommends the establishment of a support centre for families proceeding from initial diagnosis to service implementation that addresses these human needs. Guided by the results of this current study, there is a need for an evidence-based practice that is welcoming, informative, and will mentor parents through the many stages of grief, distress, and fear that come with receiving an ASD diagnosis for their child.

The structure of this centre must be flexible, portable, and above all human. While a single geographical location within B.C. may be helpful, the recommendation is for this centre to be useful to parents from all B.C. regions through the use of satellite campuses. Highly personal care would be of great importance to this centre to empower and educate parents. For this centre to be usable across all of British Columbia, it should contain a well-constructed website, available email, telephone numbers, and video calling capabilities, making information easily available and convenient to parents. As satellite support centres are established, other services may be provided. Parents, especially those with a child with special needs, have difficulty finding child-care. Taking into account the difficulty parents face when trying to seek professional help outside their home, home visits could be arranged and be just another method of offering warm and personal support.

With the guidance and support of provincial government funding and ministerial support, whether it be the ministries of education or health, this centre could be available to parents and families offering them empathetic and effective support. Providing information in the form of lists of resources, contacts, professionals within the area, while also educating parents about therapies, ASD, and child development with a human connection and personal guide, may ease much of the anxiety and overwhelmed feelings parents face. This will allow parents to feel supported and educated, while also providing a safe place for parents to ask any questions they may have. Parents do not want to be alone in this process and a support centre could provide an informed human connection and encouragement.

If such a support centre existed for the parents in this study, it is suggested that the journey from diagnosis to service assembly, or even failure of service assembly, would have been dramatically changed. Parents would have felt better supported and possibly have saved thousands of dollars in therapies that were not a good fit and were later abandoned. Families may have saved money and heartache on “cures” for their child, and perhaps felt a little less overwhelmed as they sifted through the many names provided on the RASP list of B.C.. Perhaps the experiences of these eight families could have been significantly better, with their feelings of fear, stress, and grief mitigated by the existence of such a centre.

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APPENDIX A- Semi-Structured Open-ended Interview Questions

1. Tell me about when you first got your diagnosis.
2. How old was your child?
3. How many years married/with your partner?
4. How did you educate yourself about Autism? What kind of resources did you turn to/not turn to? Was this helpful?
5. How did you find/hear about help?
6. How long did it take for you to get help?
7. How did you hear about consultants?
8. How did you hear about different kinds of therapies?
9. How many consultants did you interview?
10. How many different consultants/services had you hired and then let go until you were satisfied?
11. Was there a resource that you found that was helpful (websites, videos, friends, books etc.)?
12. How was your mental state during this period of time?
13. How was your family state during this time?
14. Was there a strain on your family during this time?
15. Retrospectively, was there anything you wish you had known then, that you know now to help you better navigate the process?

APPENDIX B- Letter/email for Recruiting

Dear (Insert Name)

I am writing to let you know about an opportunity to participate in a research study about services for parents of children with Autism Spectrum Disorder between diagnosis and service assembly. This study is conducted by myself, Kaitlyn Born, as a part of my Masters in Special Education thesis from Trinity Western University. This study wants to examine the experience of parents and families of children who have ASD after diagnosis to service assembly (e.g. early intervention, speech pathology, physiotherapy, respite, occupational therapy, etc.). I want to find out the true experience of families during this time period. The hope is to reveal whether or not these true experiences coincide with what existing literature suggests to be optimal.

If you choose to participate in this study there will be a small time commitment. There will be two interviews set up, approximately 60 minutes per interview. The first interview will be to hear your story from diagnoses to service assembly. This interview will be guided with open ended questions, and the interview will be recorded and later transcribed. At a later time, a second interview will be set up, where it will be asked that you go over the transcription of the interview, and whether or not you agree with the common themes and issues that I extracted. With your participation, you will be promised your complete anonymity, and any information used within the study must be approved by you, the participant.

If this study interests you, and you would like further details, I would love to exchange emails, or set up a phone call. Know that a request for more information does not obligate you to participate in the study.

Thank you so much for your time, and considering this research opportunity. I look forward to hearing from you.

Kaitlyn Born

APPENDIX C- Other Services Required Confidentiality Agreement

Confidentiality Agreement

An Inquiry into Services for Parents of Children with ASD between Diagnosis and Service Assembly

I, ______________________________, the ______________________________ (specific job description, e.g., interpreter/translator) have been h~~ired to~~ ______________________________

I agree to -

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s)*.

2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.

3. return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks.

4. after consulting with the *Researcher(s),* erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive).

5. other (specify).

______________________________ ______________________________ ______________________________

(Print Name) (Signature) (Date)

Researcher(s)

______________________________ ______________________________ ______________________________

(Print Name) (Signature) (Date)

APPENDIX D- First Meeting/Orientation Script

Hello!

Thank you for agreeing to meet with me and participate in this study. Everything you say is strictly confidential and neither you, nor your child will be identified in my study I any way. If for any reason you do not want to answer any question, please just say "pass" and we can move onto the next question with no explanation needed.

The intent of this study is to examine the experience of parents and families of children who have ASD after diagnosis to service assembly (OT, PT, BCBA consultant, or any other kind of therapy or respite). The hope is to reveal the true experiences of families between diagnoses to service assembly and whether or not these true experiences coincide with what existing literature suggests to be optimal.

Throughout the interview I'm going to ask open ended questions as a simple guide to hearing your story. The interviews will be recorded, and later transcribed. Please know that at any time you can ask for the recording device to be turned off at any time, no reason required. Once it is transcribed I would like to meet again to go over details of the interview to make sure I properly depicted you and your story. At any time, with no reasons required, you decide not to participate in this work- interviews will cease. No reasons need be given for making such a decision and there would be no repercussions of any kind. If after the interviews have taken place, at any time you can decide to have the interview removed from the record and destroyed. If you remain in the study your name and identity will be protected under the use of pseudonyms. I hope with this knowledge it gives you the freedom to be as honest and open about the process as you are willing. If you have any questions at any time, please let me know and I will do my best to answer them, and if you need a break at any time we can definitely make time for breaks.
Is there anything I can answer for you now before we get started?
Awesome, let's get started.

.

APPENDIX E- Debriefing Script

Thank you so much for participating in this study. What you said in your interview was vulnerable, honest, and was great insight to how families receive services after an ASD diagnosis.

Today, I'd like you to look over our interview and tell me whether you are agree/disagree, or anything you'd like to expand on. When you are finished I pulled out some themes and issues that I felt were particularly important and I would like you to tell me whether you agree or disagree with these items.

Take your time, be honest. This is your story and I want to make sure I got it right, and that this correctly depicts you and your story.