

Picky Eating Redefined: Exploring the Extreme Food Behaviour and Feeding
Environment Challenges in Children with Autism Spectrum Disorder

by

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CERTIFICATE OF APPROVAL

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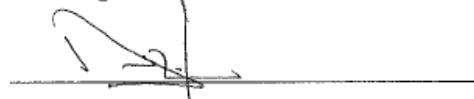
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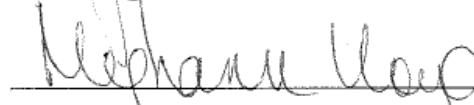
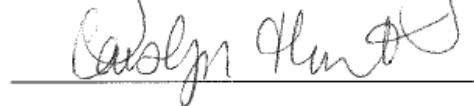
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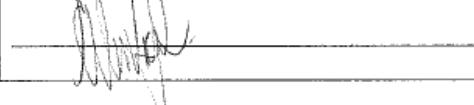
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Abstract

The most recent evidence indicates that 1 out of every 68 children has Autism Spectrum Disorder (ASD) (Center for Disease Control and Prevention, U.S. Department of Health and Human Services, 2014) emphasizing the importance of understanding ASD from multi-disciplinary perspectives. This qualitative, exploratory study focused on parental experiences with food behaviours and feeding environments of preschool-aged children diagnosed with ASD. Semi-structured one-on-one, interviews were conducted with 8 parents. Findings identified challenges to feeding/eating; the perceived influence of these challenges on the health of each child; and factors affecting care/supportive services. Recommendations call for increased knowledge and education related to the food behaviours and feeding environments experienced by families of children with ASD and individuals providing care to children with ASD. Areas for future research include exploring the severity of feeding challenges; specialized education of supportive service providers, dietitians, parents and families; and the use of effective strategies when facilitating feeding; and the effect of ASD on children's health outcomes.

Key words: food behaviours, feeding environments, dietitian, Autism Spectrum Disorder (ASD), qualitative, health, children

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List of Abbreviations Used

ABA	Applied Behavioural Analysis
ASD	Autism Spectrum Disorder
BMI	Body Mass Index
CAM	Complementary and Alternative Medicine
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4 th Edition
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, 5 th Edition
ER	Edible Reinforcement
GFCF	Gluten-Free Casein-Free
IBI	Intensive Behavioural Intervention
ID	Intellectual Disability
IOTF	International Obesity Task Force
SCO	Supportive Community Organization
SI	Supportive Individual
TD	Typical development
UOIT	University of Ontario Institute of Technology
WHO-ICF	World Health Organization-International Classification of Functioning, Disability and Health

1.0 Introduction

This master's thesis was designed and developed to understand the experiences of parents, regarding the food behaviours and feeding environments when having a child with Autism Spectrum Disorder (ASD) Chapter 1 outlines the study intentions, purpose, research questions, and objectives.

Chapter 2 includes an extensive literature review regarding the information available about this topic. Information presented in available literature demonstrates where the gaps were evident in the population of children with ASD.

Chapter 3 discussed the methodologies section of this study. The methodology was developed to provide a detailed outline of all methods and procedures used during the investigation.

Chapter 4 discussed the findings that emerged from the study. This chapter provided an analysis and discussion of the data collected during the investigation.

Chapter 5 includes the conclusion, recommendations, and personal reflection of the study. The findings were summarized in this chapter and utilized to develop and provide recommendations to improve gaps that emerged in the data, while closing with personal reflections on the part of the researcher

Chapter 6 concludes with a bibliography of the study. All literature and sources referred to in this investigation were included in the final chapter. An appendices of all additional information utilized during the study is presented after chapter 6.

1.1Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a childhood neurodevelopmental disorder (Fombonne, 2009). According to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V), ASD consists of persistent deficits in reciprocal social communication and social interaction, as well as restrictive repetitive behaviours, interest, and/or activities (American Psychiatric Association [APA], 2013). Symptoms are often present during early childhood development and can limit or impair areas of everyday functioning (APA, 2013). This disorder is a developmental disability that significantly affects verbal and non-verbal communication and social interactions and has been referred to as with Pervasive Developmental Disorders in the past (PDD) (APA, 2013; Gillberg, 1990).

Diagnostic criterion includes deficits in social-emotional reciprocity, non-verbal communication, and difficulties developing, maintaining, and understanding relationships (APA, 2013). Children with ASD may have stereotyped behaviours, requirements for sameness, restricted patterns, fixated interest, and hyper- or hyporeactivity to sensory inputs when in specific environments (e.g. cold or heat sensitivities) (APA, 2013). The DSM-V established this criterion to clinically classify children with ASD (APA, 2013). However, the DSM-V criteria cannot be solely used to clinically diagnose children with ASD (Gillberg, 1990). A medical doctor or trained professional assessment is also required to diagnosis an individual (Gillberg, 1990). Medical doctors or psychologists clinically classify ASD according to the DSM-V criterion and diagnose individuals according to clinical presentation (Center for Disease Control and Prevention [CDC], 2014).

Symptoms and/or behaviours of ASD exist over a continuum of mild-to-severe (Gulick, & Kitchen, 2007). Historically, ASD included: early infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder; however in the 2013 DSM-V all of these disorders fall under the category of ASD (Kanner, 1943). Characteristics of ASD include communication and social impairments with delayed language/speech development, delayed and/or unusual play routines, along with restrictive, repetitive and/or stereotypical patterns of behaviours, interests and/or activities (Gillberg, 1990; Kogan et al., 2009; Gulick, & Kitchen, 2007). When diagnosing young children, it can be difficult to differentiate between an intellectual disability (ID) from ASD, and both disorders (APA, 2013). Children with ASD are at increased risk for developing an ID. Approximately 3 of every 4 children with ASD demonstrate some form of an ID (Matson & Nebel-Schwalm, 2006).

Rates of diagnosis of ASD have nearly doubled over the past three decades (Matson & Nebel-Schwalm, 2006). The most recent literature states that the prevalence of ASD is approximately 1 out of every 68 children in the United States (Center for Disease Control and Prevention [CDC], U.S. Department of Health and Human Services, 2014). This statistic is utilized universally to represent the most current prevalence rate of ASD. This increase in prevalence may be a result of confounding factors, such as increased population awareness and/or improved screening and identification strategies that have influenced the diagnosis of ASD (APA, 2013; Frombonne, 2009; Kogan et al., 2009). Regardless, it is important to consider that the prevalence rate of ASD increases the need for information about this population. Understanding the complexity of the

disorder is important when exploring the differences in both behaviours and environments of children with ASD, in comparison to those without ASD. Children with ASD may have comorbidities, including an ID, which can influence development. Therefore, it is also important to consider the characteristics of ASD in regards to the characteristics of individuals with an ID. It is essential to acknowledge and understand the differences and similarities between each disorder.

1.1.1 Intellectual Disability (ID)

An Intellectual Disability (ID) is also referred to as an Intellectual Development Disorder (APA, 2013). An ID consists of deficits in intellectual function (e.g. problem-solving or planning) and adaptive function (e.g. limitations in personal independence) (APA, 2013). These deficits are observed during the key developmental periods and may be present in childhood or adolescence (APA, 2013). An ID can result in a variety of intellectual limitations and adaptive behaviours, including conceptual, social, and practical skills (APA 2013). Severity in limitations range from mild-to-profound and are determined using an adaptive function test to evaluate how well an individual meets community standards of personal independence and social responsibility in conceptual, social, and practical domains, in comparison to individuals of a similar background (APA, 2013). Children may also be classified using intelligence function tests, which consist of intelligence quotient (IQ) test scores and clinical development test scores (APA, 2013). An IQ test score between 65-75 is an indication of an ID (APA, 2013). The classification and characteristics of an ID are important when exploring individuals with ASD, as both disorders have similar attributes and can co-exist.

There is a paucity of research available regarding specific characteristics that are used to identify children with ASD. As a result, resources specific to children with and ID are often utilized as a supportive source of information when working with children with ASD. A brief explanation of both disorders was included to increase the knowledge about the population utilized in this study, as well as the supportive population used when reviewing the available literature.

1.2 Parents' Experiences with Feeding Behaviours and Food Environments in Children with ASD

Children with ASD and those with developmental disabilities often display difficulties related to eating and mealtime behaviours (Curtin, Anderson, Must, & Bandini, 2010; Levin & Carr, 2001). This may include problematic behaviours (e.g. tantrums), food refusal, and severe food selectivity (Riordan, Iwata, Wohl, & Finney, 1980). The current study explored parents' experiences with food behaviours and feeding environments when having a child with ASD. Food and feeding behavior development is an important aspect of childhood development, and can potentially impact an individual's long-term health.

Available research has indicated that the incidence of overweight and obesity has increased in children with developmental disabilities, including ASD (Curtin, Bandini, Perrin, Tybor, & Must, 2005; Choi , Park, Ha, & Hwang, 2012; Curtin, Anderson, Must, & Bandini, 2010; Xionig, et al., 2009; Lloyd, Temple, & Foley, 2012). A number of factors have been linked to weight gain in this population, such as: genetics, medication use, decreased physical activity, and unhealthy nutritional habits (Lloyd, et al., 2012). This research explored relationships, connections, and/or outcomes that could result from

food behaviours and feeding environments during early developmental stages. This study explored parents' experiences of the family environment, food selectivity, the use of food as reward, and the use of treatment-centered approaches used to assist children with ASD.

1.3 Major Research Questions

The primary goal of this study was to explore the food behaviours and feeding environments experienced by children with ASD and their parents. Over the past three decades, the diagnosis, awareness, and prevalence of ASD has increased dramatically; however, there is a paucity of research available on parents' experiences with food behaviours and feeding environments with regards to this population (Matson & Nebel-Schwalm, 2006).

1.3.1 Research Questions

Research questions explored the population of children with ASD and gaps evident in the literature. Exploring the food and feeding environments of children, aged 2-5 years, with ASD was the primary objective of this study. Examining the feeding behaviours from the perspective of parents who have a child with ASD was the secondary objective of this research. This research explored:

1. What are the parents' experiences with food selectivity, including variety and choice?
2. What are parental concerns about food and dietary preferences during meal times?
3. What are the food-related challenges parents' experience when having a child with ASD?

4. What are parents' experiences with using edible rewards within the family environment?
5. What are parents' experiences with treatment approaches that incorporate edible reinforcement and/or rewards?

(See Appendix A for a copy of the Major Research Questions)

1.3.2 Purpose

The purpose of this study was to increase the understanding of the experiences with food behaviours and feeding environments of children with ASD. There is a paucity of research available documenting the specific challenges related to children in this population. Children with ASD have altered dietary patterns and individual feeding characteristics that affect growth, weight and nutritional status, in comparison to children with typical development (TD) (Xiong et al., 2007). Lifestyle factors, including nutritional behaviours, associated with children with ASD are overlooked and understudied as possible contributing factors linked to the development of future or current weight issue (Curtin, et al., 2005). A major influential environmental factor that plays a crucial role in dietary behaviours and is predominantly understudied is the roles, influences, values, and experiences perceived by families and parents of children with ASD (Ha, Jacobson Vann, Chio, 2010). This research focused on the perspective of the family environment, specifically, the parents' experiences with food behaviours in their child with ASD. This research was used to facilitate an understanding of the family feeding practice and how parents recognize feeding/eating challenges and the health of their child with ASD. Additionally, this study increased the understanding of behaviour

management approaches, including the use of edibles as reinforcement and reward, among families of children with ASD. Ongoing research will benefit children with ASD and help when addressing the knowledge gaps experienced related to food behaviours and feeding environments in this population. This research focused on providing supportive evidence to the prevalent gaps in the available literature.

This research was used to explore and confirm the importance of an increased understanding of parents' experiences related to food behaviours and feeding environments when having a child with ASD. This research was developed to enlighten, as well as, increase awareness and acknowledgment, regarding emergent trends of underweight, overweight, obesity, and increased weight gain among children with ASD; as well as other feeding issues.

2.0 Literature Review

2.1 Autism Spectrum Disorder (ASD)

The diagnostic criteria for Autism Spectrum Disorder (ASD) includes a range of continuing deficits in social communication and interaction (APA, 2013). Characteristics include a history or current deficits in social-emotional reciprocity, social interaction barriers in non-verbal communication, and developing, maintaining, and varying issues with understanding relationships (APA, 2013). Impairments include two or more of the following in selective restrictive, repetitive patterns of behaviours, interest, and activities (APA, 2013). Symptoms of ASD must be present in early developmental periods; however, severity may vary by context and fluctuate over time, or manifest when demands exceed limits (APA, 2013). The classification of ASD encompasses manifestations of the disorder that vary in severity, level of development, and chronological age (APA, 2013). Additionally, symptoms must cause clinically significant impairment to areas of current functioning and all of the deficits should not be better explained by intellectual disability (ID) (APA, 2013). It is important to understand that although an ID and ASD differ in social communication and behaviour deficits, they can co-exist (APA, 2013).

During the early years of understanding ASD, it was established that classification of individuals required multiple methods for an appropriate diagnosis (Gillberg, 1990). A single rating scale could not clinically diagnose a child with ASD; children were individually assessed, using multiple approaches (Gillberg, 1990). Clinical diagnosis, cognitive and neuropsychological testing, genetic considerations, developmental and medical history were all utilized for diagnosis of ASD (Bailey et al., 1996; Gilberg,

1990). Today the DSM-V criterion has become a standardized method to diagnosis of ASD, that includes additional descriptive characteristics of all neurodevelopmental disorders (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). The influence that the diagnosis of ASD has on parents and their children was considered in this research.

2.1.1 The Diagnosis of ASD

This diagnosis of ASD has a lifelong effect on the child and their parents (Abbott, Bernard, & Forge, 2012). With the disorder of ASD it is important to understand the effect that the diagnosis can have on these parents. According to the available literature, the news of a diagnosis of ASD is experienced differently in all families (Abbott et al., 2012).

In the work of Minden and O'Neill (1999), parents reported noticing that something was not as expected or ‘different’ with the development of their child. In multiple studies, parents often expressed frustrations prior to the diagnosis of ASD (Abbott et al., 2012; Mansell & Morris, 2004). Parents expressed anger towards the length of time it took to receive an official diagnosis, as well as receiving multiple misdiagnoses before professionals classified their child with having ASD (Abbott et al., 2012; Mansell & Morris, 2004). Parents experienced delays with an appropriate diagnosis, and diagnoses that are incorrect or misleading (Howlin & Moore 1997; Minden & O'Neill, 1999). The process of receiving a final diagnosis also caused mixed emotions and feelings in parents.

Receiving a diagnosis can result in significant positive and negative emotions at the time of diagnosis and afterwards (Abbott et al., 2012; Wachtel & Carter, 2008). Some families may not have a positive response to this outcome. Parents can experience shock

and confusion with the diagnosis, as well as being in denial, angry, and feeling hopeless (Abbott et al., 2012; Mansell & Morris, 2004). Parents may be unsure as to why their child behaves in a certain way. Mansell and Morris (2004) state that negative feelings are expressed because parents worry about the future health and support that will be given to their child's. Although negative outcomes have been experienced during diagnosis, studies report that parents who express negativity become more accepting of the disorder with time (Mansel & Morris, 2004).

When receiving the official diagnosis positive outcomes were also experienced. Mindence and O'Neill (1999) report that parents felt relieved with the diagnosis. Parents report that being given a diagnosis is a way of providing and confirming explanations of their child's problems (Howlin & Moore, 1997; Abbott et al., 2012). Parents are then able to educate themselves on the disorder and its characteristics. Additionally, Mansell and Morris (2004) state that this helps parents to explain their child's behaviour to themselves and allows them access to supports available. Although, negative feelings in families are experienced during diagnosis, literature available suggests that more families were relieved when their suspicions were validated (Mansell & Morris, 2004).

This research considered the positive and negative outcomes that may be experienced in families when their child receives a diagnosis of ASD. Parents' responses to the diagnosis of ASD was also considered in this research when attempting to understand the steps parents have taken to improve the behaviours and environments in their children, through care and supportive services.

Positively, through the use of research criterion, DSM-V, has been established to improve the approaches used to diagnose individuals with ASD. Using DSM-V criteria,

the diagnosis of ASD has become standardized and includes additional descriptive characteristics of all neurodevelopmental disorders (Volkmar et al., 2004). Research has resulted in the ability to adapt and improve clinical diagnostic criteria and information surrounding this disorder (Gulick & Kitchen, 2007). The diagnostic criterion has been developed by understanding and acknowledging differences in children with ASD, in comparison to those with typical development (TD).

2.2 Children with Typical Development (TD): Comparative Population

Children with no known developmental disorder during development were referred to as children with typical development (TD); these children follow the predetermined stages of growth and developmental milestones. Although children all have unique development processes, many characteristics develop in a predictable pattern during specific time periods (Popli, Gladwell, Tsuchiya, 2013). A child may have a developmental disorder if they have one or more delays or regressions in developmental milestones (Siperstein & Volkmar, 2004). When attempting to understand the behaviours of children with ASD, children with TD are utilized as a reference population. Previous research with children with TD was used to facilitate and explore differences or similarities of food behaviours and feeding environments in children with ASD. Among the many influences on this population are factors that influence the ability for an individual to develop positive behaviours and environments beneficial to health.

Developing and maintaining a healthy lifestyle is essential to long term health. To prevent the development of chronic disease, including obesity, strategies of healthy eating and active living are necessary during childhood (Sigman-Grant et al., 2011). It is

important for individuals, institutions, and organizations to create social and public health policies or guidelines that benefit health during childhood development; including those related to physical activity and nutrition (Koplan, Liverman, & Kraak, 2005). Physical activity and nutrition are important to maintaining healthy weight throughout life (Koplan et al., 2005). Although physical activity was considered in this research, feeding issues, including dietary factors were the primary focus of the study. Families, particularly parents, were primarily responsible for the development of healthy habits in preschool children, aged 2-5 years (Sigman-Grant et al., 2011). It is crucial for families to develop and create supportive mealtime environments that allow children to gain control over their food intake (Satter, 1999; Sigman-Grant et al., 2011). Supportive feeding environments provide nutritious foods, while maintaining an appropriate physical and social setting that establishes healthy routines. This enhances development and maintains trust between the child and the family (Sigman-Grant, Christiansen, Fernandez, Fletcher, & Johnson, 2008). The experiences of the family and the feeding environment were explored in this research.

2.2.1 Prevalence of obesity and overweight in children

The number of overweight and obese Canadians has increased dramatically over the past decade. Recent evidence suggests that approximately 11.7% of children aged 5 to 17-years are obese, and 19.8% are overweight (Roberts, Shields, deGroh, Aziz, & Gilbert, 2012). Obesity is a risk factor associated with a number of chronic diseases (Minihan, Fitch, & Must, 2007). Increased weight in childhood can lead to adult overweight and obesity, which may lead to additional health consequences, including: diabetes and hypertension (Agras, Hammer, McNicholas, & Kraemer, 2004; James,

Leach, Kalamara, & Shayehgi, 2001).

Previous research has focused on early preventative strategies used to identify early determinants, or “warning signs” of weight issues (Brisbois, Farmer, & McCargar, 2012). To combat the issue of overweight and obesity in children, public and population health agencies are working to create approaches to resolve this problem in its early stages (Froehlich-Grobe, & Lollar, 2011). Studies have stated that interventions and preventative strategies should begin as early as three-years of age, to decrease the burden of persistent weight issues, on individuals later in life (Barlow & Dietz, 1998; James et al., 2001).

Dietary intake has been associated with weight issues in childhood (Agras et al., 2004). In research, difficulties assessing diet and small variations of caloric intake may not have immediate measurable effects on the dietary intake of young children; however they may lead to overweigh problems in later life (Agras et al., 2004). As a result, understanding food behaviours and the feeding environment in children is extremely important, especially in those with ASD (Agras et al., 2004).

There is a paucity of literature available related to nutrition and children with ASD. Research indicates that individuals with disabilities are at increased risk for obesity than the general population (Froehlich-Grobe, & Lollar, 2011). The statues of obesity and overweight in children with disabilities receives little scholarly attention and their weight status of often under-managed and overlooked due to previously existing disorders (e.g ASD, ADHD) (Ha et al., 2010; Curtin et al., 2005; Froehlich-Grobe, & Lollar, 2011). Increased weight issues may not be an existing issue for the children in the current study, however the risk of long-term and accumulative weight issues should be considered. It is

imperative to understand possible outcomes that early food behaviours and feeding environments have on children with ASD. The current examined the possibility of weight related outcomes in children with ASD when exploring food behaviours and feeding environments during childhood.

2.2.2 ‘Best’ practices for feeding children

Feeding patterns (e.g. food refusal, restrictions etc.) are different in children with and without a disability; however, feeding practices and responsibilities of parents and children may be similar. Attitudes about why we eat and why it is important to eat are similar in these populations. Feeding is an opportunity for a parent to offer love, care and attention to a child (Slaughter, 2000). Interaction during meal and snack times affects the physical, emotional and social health of children, as well as facilitating a strong parent-child connection (Slaughter, 2000). Ellyn Satter, a family therapist and feeding specialist, examines how behaviours and concepts, influence eating patterns related to *how* we eat, not *what we eat* (Satter, 2005). The work of Satter has been compared to Maslow’s hierarchy of needs, in that it has been determined that getting “enough food” is a basic creature need; and “enough food” is determine by what each individual perceives as acceptable (Satter 2007). Therefore, emphasizing that accurate nutritional and dietary education and this interaction is a key priority when applied to *how* we are eating (Satter, 2007).

Selection of food is a complex interaction that includes ingestion, as well as regulatory behaviours between parents and children (Satter, 1999). The relationship or bond created between parents and children, in feeding is similar in those children with, or without a disability (Slaughter, 2000). According to Satter, the golden rule of feeding,

requires that parents are responsible for *what, where, and when* feeding takes place and children are responsible for *how much* and *whether* eating will occur (Satter, 1999).

Recommendations provided, include approaches and suggestions to help parents find a healthful balance and reasonable middle ground in nutritional extremes, from not worrying at all, to worrying too much about children's eating habits and health (Slaughter, 2000). Approaches include providing appropriate and/or inappropriate food to reward or punish children.

2.2.2.1 Restricting foods and using foods as a reward. Risks associated with withholding foods was examined in the work and feeding theories of Satter (2005). Food restriction practices, specifically 'treat'/reward foods are negatively associated with feeding habits (Satter, 2005). Research indicates, children who were "forbidden" to eat specific foods are at increased risk to over-consume those foods when given the opportunity (Satter, 2005). Satter determined that even moderate food restriction makes children food-preoccupied and increases risk for overeating (Satter, 2004). Food selection should act in a way that "helps without harming children" (Satter, 2005). Essentially, incorporating "forbidden" or treat foods into the diet helps to moderate food and lower the risk for overeating (Satter, 2005).

Snack foods have also been used inappropriately by caretakers (Satter ,1999). When teaching children appropriate eating habits, snack foods may be inappropriately used as reward or punishment (e.g. removing a snack food when a child does something wrong). Using snack foods as punishment contributes to the development of inappropriate eating behaviours (Satter, 1999). Restricting foods increases the likelihood that one will over eat the specific food once permitted to eat it again (Satter, 1999). To

avoid the development of forbidden foods, planned snack times are essential (Satter, 2005). Parents need to commit to teaching children proper “snack” and eating behaviours and continue these strategies throughout their lifespan (Satter, 2005). Children with disabilities differ in regards to dietary patterns and food choices in their diet. Therefore, there is increased parental responsibility for monitoring and developing appropriate eating habits in children with ASD. The role parents have with dietary outcomes was a factor considered in this study.

2.2.3 Food and feeding behaviours

It is essential to promote dietary diversity and establish healthy eating patterns during childhood, to prevent food selectivity and chronic malnutrition problems. (Sharp, Berry, McElhanon & Jaquess, 2014). Selective and restrictive eating behaviors in preschool-aged children with TD are concerns often expressed by parents (Levin & Carr, 2001). Approximately 45% of preschool aged children with TD have problematic mealtime behaviour (O’Brien, Repp, Williams, Christophersen, 1991). Additional research has determined that approximately 25- 35% of children with TD have feeding problems (Kodak & Piazza, 2008). Children with TD experience some problematic mealtime behaviours; importantly it is reasonable to assume that problematic mealtime behaviours are equally if not more prevalent in children with developmental disabilities.

Approximately one third of children with developmental disabilities represent a particular vulnerable population with clinically significant dietary deficiencies, with even higher estimates amongst children with ASD (Sharp et al., 2014; Shreck et al., 2004). Studies have compared children with TD to children with ASD to determine if problematic feeding behaviours differ (Schreck & Williams, 2006). Results indicate that

children with ASD are idiosyncratically selective with the food items they chose to accept and they have an increased variety of feeding problems (Schreck & Williams, 2006; Sharpe et al., 2013). Children with TD and ASD experience limitations regarding the variety of foods accepted during childhood development, however the degree of these challenges increase in children with ASD (Lukens & Linscheild, 2008). Additionally, children with ASD have repetitive behaviour patterns, which can include insistence on wearing the same clothes and eating the same foods (Leekam et al., 2007). These behaviours have a primary role in ASD diagnosis (Leekam et al., 2007) and are frequently linked to ASD. Some estimates suggest that as many as 46-89% of children with ASD experience some form of a feeding difficulties (Sharp et al., 2014; Ledford and Gast, 2006). Conversely, food selectivity in children with TD during preschool ages is an intermittent and transitory stage, experienced during normal childhood development (Levin & Carr, 2001; O'Brien et al., 1991). Studies have concluded that 2-year-old children with TD, tend to display similar repetitive qualities (Leekam et al., 2007). Longitudinal studies using questionnaires were used on two similar populations of parents to determine the relationship of repetitive behaviours in their children. Results concluded that 2-year-old children with TD had a wide range of repetitive behaviours that have been found in children of all ages with ASD.

Although children with TD may exhibit some problematic eating behaviours, children with ASD have increased feeding behaviour problems, than children with TD (Kozlowski, Matson, Belva, & Rieske, 2012). Due to high prevalence of feeding behaviour challenges in children with ASD, an increased comprehensive understanding of feeding problems is required and concerns of dietary insufficiencies and the use of

dietary manipulation approaches requires further exploration (Lockner, Crowe, Skipper, 2008; Sharp et al., 2014). These differences in specific food and feeding behaviours experienced were explored in children with ASD. This research focused on preschool aged children, as studies suggest this is a time period where children are developing specific skills and characteristics (Knight & Lee, 2009). Milestones related to behaviour and social growth are achieved during this time (Knight & Lee, 2009).

2.2.3.1 Critical Window for Development. The children in this study were in the preschool developmental period of growth and were between the ages of 2 and 5. As reported in the literature, preschool is time period where children begin to personally and socially develop life skills (Knight & Lee, 2009). According to the literature available, there are critical and sensitive time periods during early childhood development where children learn a variety of life skills (Popli et al., 2013). Sensitive phases, critical moments, optimal periods, crucial stages, susceptible periods are all different terms used to refer to a portion of time in which there is a “window for opportunities” in development of certain characteristics (Bateson, 1979). In this study critical or sensitive periods of development were explored to understand the effect this theory can have on food behaviours in children with ASD.

This theory was originally cited by Lorenz (1935) in response the theory of imprinting that occurs in animal during early development (as cited in Bateson, 1979). Lorenz (1965) used this concept to develop the theory that organisms are primed to receive and code certain environment information at a specific time (as cited in Udall, 2007). From this it has been theorized that there are critical areas or “windows” of development to which children learn certain behaviours (Popli et al., 2013). Although

later learning is still possible, it was believed that if these opportunities are missed during the critical time period, it can cause difficulties when attempted them later in life.

Humans are required to feed and eat every day in order to live. In the first year of life infants go through changes in eating behaviours. When first born infants are fed only liquids and as they grow they transition to eating solid foods (Dijk, Hunnius, & vannGeert, 2012). Around 5 to 6-months children are introduced to difference tastes and textures of food and begin to master new motor skills (Dijk et al., 2012). It is around this time that there is a window of opportunity for children to become familiar with solid foods and chewing. According to Illingworth and Lister, (1964) if children are not given solid foods around 6- to 7-months they will have a much more difficult time eating and chewing solid foods when later introduced. Udall (2007) also claims that children need to be introduced to solid foods at the appropriate time and a longer delay of introduction will make it more difficult for children to accept chewable foods. Udall felt that that missing critical sensitive time periods would negatively affect all other aspects of development (Udall, 2007). Dijk et al., (2012) further supports this theory by stating that delayed introduction to solid foods has been linked to difficulties when getting children too self-feed.

When studying children with ASD it was important to consider all aspects of feeding difficulties experienced in the families. Although age is an important factor for critical development, Health Canada states that that not all children develop feeding behaviours at the same time (Health Canada, 2014). Therefore, the child's developmental progress and age are important factors to consider when introducing solid foods. It was important to consider if these families experienced difficulties with the introduction of

solid foods to their children; and if delayed introduction did occur, did it have an effect on the feeding preferences and feeding challenges experienced.

2.3 Autism Spectrum Disorder (ASD) and Eating Behaviours

Children with ASD have behaviours that are different than children with TD, including food behaviours and feeding environments (Xiong et al., 2007). The aim of this review is to establish a profile of the population that was used in this research, as well as recognizing dominant feeding issues experienced by this population.

Children with ASD have restrictive, repetitive and/ or stereotyped behaviours (Leekham et al., 2007). The themes discussed in this review were used to increase understanding of food issues and behaviours related to the feeding environments experienced in this population. As well as exploring how these behaviours and environments may become or are a factor contributing to increased body weight in this population.

Research has determined that children with an ID and/or ASD are vulnerable and at increased risk of being overweight or obese, due to predisposing factors (e.g. medication or comorbidities) (Chen, Kim, Houtrow, & Newacheck, 2009; Choi et al., 2012; McPheeters et al., 2011). A secondary data analysis of a national survey in the United States determined that 30.4% of children with ASD were obese, in comparison to 23.6% of children without ASD (Curtin et al., 2010). Health and risk factors that contribute to weight gain may be associated with behaviour differences in this population. These may include, but are not limited to, increased caloric intake, difficulty with appetite self-regulation resulting in overeating, comorbidities, medication side-effects, and decreased opportunities or abilities to engage in physical activity (Chen et al.,

2009; Curtin et al., 2005). Ongoing research is necessary to determine the extent to which these factors increase the risk of developing health problems in children with ASD. This research explored food behaviours and feeding environments in this population.

2.3.1 Weight considerations: Predisposed risk

It is important to consider factors unrelated to food behaviours and feeding environments when exploring weight challenges in children with ASD. These children have complex behaviours, including persistent deficits in social communication, social interaction, and restrictive repetitive patterns (APA, 2013). Deficits may contribute to issues that are linked to an increased prevalence of overweight and obesity in this population. When comparing different age categories of children with developmental disabilities in South Korea, prepubescent (6 to 9-10-years); early adolescence (9-10 to 14-years); and late adolescence (14 to 18-years), it was determined that the prevalence of obese and overweight children increased with increasing age (Choi et al., 2012).

According to a study in the United States, overweight status during early development increases the risk that children with ASD will remain obese or overweight throughout their lifespan, potentially resulting in additional health complications (Agras et al., 2004).

Additional research by Xiong et al. (2007) had similar findings, which support weight status increasing with age in China. This poses as a significant health concern as the likelihood of obesity or overweight status progressing into adulthood and contributing to the development of chronic disease (Memari & Ziaeef, 2014; Xiong et al., 2007).

Data gathered from available research concludes that obesity is a significant risk factor for children with an ID, as well as for those children with ASD. When exploring the weight status of children, the Body Mass Index (BMI) is used to classify weight, in

relation to height. In this study; BMI was utilized to understand the health status of each child with ASD. Height and weight measurements are used to calculate the BMI; this standardized measure is calculated by taking weight (kilograms) and dividing by the height (centimeters) squared ($BMI = \text{weight}/\text{height}^2$) (Cole, Flegal, Nicholls, & Jackson, 2007; Cole, Bellizzi, Flegal, & Dietz, 2000). The study utilized the most recent measurements of height and weight to calculate the BMI of each participant's child with ASD. When classifying the weight status of children, BMI values change substantially with age (Cole, Freeman, & Preece 1995). Therefore, the International Obesity Task Force (IOTF) developed BMI cut-offs that were sex and age specific to increase the consistency of weight classification in children aged 2-18 years (Cole & Lobstein, 2012). The IOTF established international child BMI cut-offs for thinness, overweight, and obesity using 6 countries (Cole & Lobstein, 2012). This study utilized the BMI cut-off values established by the IOFT to determine the weight status of each participant's child with ASD.

Alternative associations to weight gain were considered when exploring weight issues as a possible outcome of food behaviours and feeding environments in children with ASD; including, impairments and comorbidities (e.g, an ID), treatment approaches through the use of medications, and physical activity limitations. Additionally, underweight as a risk factor were also recognized.

2.3.1.1 Comorbid conditions. Factors that contribute to obesity and overweight differ in children with ASD compared to children with TD (Curtin et al., 2010). It is important to consider the extent to which co-existing conditions may be contributing to weight outcomes. Two or more psychopathologies in one individual are common in

children with ASD (McPheeters et al., 2011). There is a wide range of pre-existing comorbidities linked to the development of weight issues in individuals with ASD (Mermari & Ziae, 2014). Assessing comorbidities in children with ASD is particularly difficult. Children with ASD have difficulties communicating symptoms and symptoms may vary during development. The DSM-IV suggests clinical diagnosis of the most dominant disorder only, and many disorders overlap with ASD (Amr et al., 2012). Amr et al., (2012) concluded that 63% of individuals with ASD had at least one comorbid condition. In the literature, ASD and ID disorders were often examined in similar contexts (Matson & Nebel-Schwalm, 2006). Although they are different disorders, approximately 75% of children with ASD have some form of an ID (Matson & Nebel-Schwalm, 2006). Commonly reported psychiatric comorbidities include anxiety disorders, attention deficit hyperactivity disorders (ADHD), conduct disorders, major depressive disorders, seizure disorders, and bipolar disorders (Amr et al., 2012; McPheeters et al., 2011; Myers & Johnson, 2007; Mermari, Ziae, Mirfazell, & Kordi, 2012). There are also several genetic disorders linked to ASD that are correlated with weight gain. These include fragile X, tuberous sclerosis, neurofibromatosis, Pander-Willi syndrome, and Gilles de la Tourette (Memari, Ziae, Mirfazeli, & Kordi., 2012). Different management and treatment methods have been proposed and trialed in an effort to improve the quality of life for individuals with ASD (McPheeters et al., 2011). To date, there is no global agreement as to which treatment strategy is most effective (McPheeters et al., 2011).

2.3.1.2 Medications. There is no universal approach to managing ASD, however pharmacologic treatments are used to improve the quality of life for individuals.

Frequently used treatments include medications that target a variety of symptoms, including mood disorders, hyperactivity, and problematic behaviours (McPheeters et al., 2011). These medications focus on treating and controlling comorbidities that may affect ASD and include: anti-psychotics, serotonin reuptake inhibitors, and stimulant medications (Aman et al., 2005; McPheeters et al., 2011). Recently there has been an increase in the use of psychotropic medications, particularly antipsychotics, in individuals with ASD (Mirmari & Ziaee, 2014). Stigler, Potenza, Posey, and McDougle (2004) conducted a study to determine the risk of weight gain in individuals with ASD, using some of the frequently prescribed anti-psychotics. Results concluded that multiple drugs were associated with risk of substantial to moderate weight gain (Stigler et al., 2004). Additional pharmacological research has used randomized control trials to evaluate adverse reactions, including weight gain with medications used to manage ASD Aman et al., 2005). Results indicate that two common medications used by children with ASD resulted in significant weight gain, as compared to a placebo drug (Aman et al., 2005; Owen et al., 2009; McPheeters et al., 2011). Studies determined drug efficacy testing overlooked adverse reactions of weight gain, and still classified drugs used on children with ASD as effective when weight gain was a risk (Owen et al., 2009). Obesity and overweight outcomes often become a secondary concern to the disorder that is being treated, however these medication need to be carefully considered and closely monitored to decrease the risk for the development of additional detrimental health outcomes (Stigler et al., 2004).

Ongoing research is required to determine the extent to which comorbid conditions and pharmacologic therapy affect individuals with ASD. Although the focus

of the present study is unrelated to the influence of pharmacologic treatment on weight in individuals with ASD, it is essential that this be acknowledged as a potential contributor to comorbidity in this condition.

2.3.1.3 Physical activity. A healthy diet and regular physical activity are essential to decrease the risk for obesity in preschool children (Sigman-Grant et al., 2011).

Children with disabilities are at greater risk for obesity and overweight due to decreased involvement in physical activities (Hinckson, Dickinson, Water, Sands, Panman, 2013).

Minihan et al., (2007) stated four major family issues that influence the activity levels of children with disabilities. These include mobility limitations that are restrained with family resources, parents/teachers becoming overly protective and discouraging activity participation, social isolation due to disability limitations during physical activity opportunities with other children, and behavioural problems that cause struggles with peer interaction and limit inclusion in physical activity (Minihan et al., 2007).

Conversely, secondary health conditions, including overweight and obesity, can further diminish the independence and level of function of children with disabilities (Lloyd et al., 2012). As stated by Minihan et al., (2007), regular physical activity is required in all children, despite their health care needs, or possibly more because of them.

Children with ASD are also more sedentary due to a preference for activities that do not require active play (Memari, & Zieaa, 2014). According to Memari and Zieaa (2014) there are no clear definitions of sedentary behaviours, and sedentary activities are defined as: sitting, reading, watching television, playing certain video games, and computer use for most of the day with little or no vigorous physical activity. In this population, sedentary activities are also used in therapeutic approaches and interventions

(e.g. video modeling series) (Mermari & Ziae, 2014). If children are not monitored, supported, and included in active play they are at increased risk to be inactive, which increases their risk of weight status issues (Memari, & Ziae, 2014).

Modifiable lifestyle factors, such as poor dietary choices and limited physical activity are contributors to obesity and overweight, increasing risk for health concerns in individuals with disabilities (Froehlich-Globe & Lollar, 2011; Minihan et al., 2007).

Physical activity and a healthy diet are essential components in the prevention of overweight and obesity (Roberts et al., 2012; Sigman-Grant et al., 2011). Dietary habits and physical activity levels are developed in early childhood, and are highly influenced by parental practices and the family environment (Etelson, Brand, Patrick & Shirali, 2003). Children with disabilities need to be provided with the opportunity to participate in activities related to their nutrition and physical health (Minihan et al., 2007). Healthy living strategies are required during early development, to improve the health of children with disabilities, specifically children with ASD (Lloyd et al., 2012; Hinckson et al., 2013). Although, it was recognized that physical activity plays a role in positive health outcomes, the primary focus of this research was the food behaviours and feeding environments experienced in families of children with ASD.

2.3.1.4 Underweight considerations. This research explored the food behaviours and feeding environments in children with ASD. Long-term health conditions and concerns related to body weight were considered as possible outcomes. Research has concluded that children with disabilities are at increased risk of over and underweight status (Minihan et al., 2007). Data gathered from Choi et al., (2012) determined there was coexistence of weight status issues in children with an ID, in that 14.3% of these children

were underweight, while 24.1% were overweight or obese. Children with an ID often deviate farther from the norm with respect to weight (Emerson, 2005; Lloyd et al., 2012). Additional results obtained similar outcomes, and children with ASD were at increased risk over being both over and underweight (Xiong et al., 2007).

Food refusal and restriction can cause challenges associated with inadequate energy intake in children, increasing the risk for underweight concerns (Rogers, Magill-Evans & Rempel, 2011). It is important to acknowledge the prevalence of the risk of over and underweight status in this population. Food behaviours and feeding environments that contribute to weight concerns in this population were be the primary focus of this research; factors including weight gain and weight loss were considered as secondary information for this study.

To conclude, causation weight gain and weight loss or lack of weight gain in children with ASD is multifactorial. Recent research indicates a high prevalence for underweight in the population of children with ASD in comparison to children of TD, however later studies suggest a weight increase in this population (Memari, & Ziaeem, 2014). Memari, and Ziaeem state (2014) that previous studies only recruited individuals with a severe disorders and that individuals with mild forms of ASD were excluded, resulting in mixed outcomes of weight status. To better understand changes in body weight in this population, all levels of the disorder severity were included within the data set. Children with ASD have comorbid conditions that increase the risk of weight gain, utilize medications that have weight related side effects and have decreased physical activity levels. These children also have health factors that increase their risk of an underweight status. This research encompasses an analysis of food issues and family and

feeding environments of children with ASD; this includes the exploration of specific food related treatment approaches used to modify behaviours in children with ASD and possible contributing factors that are associated with increased weight in this population.

2.3.2 Food issues in feeding preferences and patterns in children with ASD

Best feeding practices and responsibilities of parents and children during feeding are similar in all family environments. However, dietary patterns and what children chose to eat may differ between specific populations. Children with ASD have stereotyped, restrictive, and repetitive behaviours; which include repetitive movements, unusual sensory responses, restrictive interests and routines, and rituals that may affect their feeding environment (Leekam et al., 2007). Eating habits of children are often referred to as overly selective (Curtin et al., 2010). Food selectivity refers to rejection of food due to type, texture, and/or presentation (Sharp et al., 2013). Reasons why some children with ASD dislike foods include food texture, colour, temperature, taste, and visual appearance of the food (Rogers et al., 2011; Schreck & Williams, 2006; Martins, Young, & Robson, 2008; Curtin et al., 2010). In these situations children are still following their role in feeding practices by controlling *whether* they chose to eat specific foods (Satter, 2005). However, it is possible that children with ASD and their eating habits, including selectivity, contribute to the development of obesity and overweight in this population (Curtin et al., 2010).

2.3.2.1 Food selectivity: Children with TD and children with ASD. Research indicates 56% of children with ASD display food selectivity, in comparison to 46% of children with TD (Martins et al., 2008). Additional research suggests 25-35% of children with TD exhibit feeding selectivity during development whereas; children with ASD

experience these behaviours more frequently and are unlikely to grow out of them (Kodak & Piazza, 2008). Food selectivity pilot studies indicate that parents of a child with ASD report a higher incidence of eating problems, food cravings, and pica (appetite for non-nutrient substances), in comparison to children with TD (Martins et al., 2008). When conducting research on mothers that have a child with ASD, it was determined that onset of feeding challenges ranged from the time of birth to as late as 12 to 24-months (Rogers et al., 2011). Children with ASD have feeding difficulties, and these patterns of selective eating are distinct from that of picky eating in children with TD (Rogers et al., 2011). Results conclude that there are significant differences in eating behaviours of children with ASD, in comparison to children with TD.

Food selectivity is a transitory milestone experienced in preschool children with TD (Levin & Carr, 2001; O'Brien et al., 1991). Children with ASD have greater difficulty adapting to change, leading to an increase in the frequency of problematic dietary patterns; patterns that often persist over many years (Martins et al., 2008; Levin & Carr, 2001). Children with ASD eat a less varied diet and have an increased need for sameness. They experience inconsistent food jags, have comorbidities that affect food sensitivities, refuse food items due to presentation and they may have specific behavioral challenges or oral motor problems that limit the foods they can eat. These challenges may require specific utensils and result in food aversions related to food textures (Rogers et al., 2011; Schreck & Williams, 2006). Overall, children with ASD exhibit more challenging eating patterns, with varying degrees of severity than children with TD; which warrants further examination.

2.3.2.2 Dietary preferences. Food preferences can influence dietary patterns and the health of children with ASD. Evans et al., (2012) observed and compared food preferences of children with and without ASD. Results indicated that children with ASD prefer energy dense foods, which are often associated with weight gain (Evans et al., 2012). Other studies have determined that feeding selectivity, in children with ASD, results in preferences toward carbohydrates, snacks and processed foods (Sharp et al., 2013; Schreck, Williams, & Smith, 2004). Vegetables and fruit were the most commonly avoided foods by children with ASD (Martins et al., 2008). Additionally, those children with ASD were more likely to consume juice, sweetened beverages and sugary snacks, than those with TD (Evans et al., 2012). According to Health Canada, ‘best practice’ approaches in feeding children with TD recommend limiting the use of sweetened beverages and juices (Health Canada, 2014). Research suggests that the consumption of sweetened beverages is a modifiable factor which contributes to weight gain. Sweetened beverages comprise 10-15% of the total caloric intake in children with TD (Wang, Bleich, & Gortmaker, 2008). The influence of sweetened beverage consumption, on body weight in children with ASD has yet to be determined.

Studies have also shown that children with ASD have an increased preference for sweet foods and reject sour/ bitter foods (Schreck & Williams, 2006). Although a causal relationship has yet to be determined it is hypothesized that children with ASD have become habituated to continuously tasting sweet foods, which may result in decreasing the child’s ability to experience a sweet taste and an increase in cravings for these foods (Schreck & Williams, 2006). Research suggests that children with ASD have increased sensory stimulation to bitter tastes and experience bitter food at a higher intensity

(Schreck & Williams, 2006). Examining the feeding behavior and food environment patterns in children with ASD is required to elucidate food taste preferences and the influence they have, on body weight and overall nutrition in children with ASD.

2.3.2.3 Dietary relationship. It is important to determine if there is a dominant relationship between family members and feeding patterns in children with ASD. The question as to whether dietary patterns in children with ASD influence family food selection or whether the family food selection influences feeding patterns in children with ASD, remains unanswered (Evans et al., 2012). During early development, dietary patterns are highly influenced by parental practices and family environments (Etelson et al., 2003). Eating habits in children with ASD have a relationship to those of family members (Evans et al., 2012). Although the direction this relationship remains undetermined, it is important to consider the relationship and its influence on dietary patterns as a whole. As indicated, multiple variables can influence food preferences in children with ASD (Schreck & Williams, 2006). This research will focus primarily on the feeding relationship between child with ASD and their parents.

Role modeling is influential in the development of social and supportive feeding environments (Sigman-Grant et al., 2011). Ha. Jacobson Vann, and Choi (2010) explored mothers' perceived weight status of their child, and weight status of the mothers. Of the participant in the study 33.7% of mothers were overweight along with 46.6% of children. This data suggests that the weight status of the parent may influence that of their children though similar findings are required to provide a causal relationship.

Pachucki, Jacques, and Christakis (2011) highlight the importance of understanding relationships have a major role on influencing eating behaviours. Role

modeling is also important when considering the relationship these families may have during mealtimes. The study of Pachucki et al., (2011) was developed to understand how social environments influence healthy behaviours, including eating; the study concluded that certain relationships can transfer these behaviours socially. This study observed the influence that family environments had on feeding behaviours of children with ASD. Role modeling behaviours were considered to see if these relationships are socially transmissible in this population (Pachucki et al., 2011). According to Kral and Rauh (2010) parental behaviours have a crucial role in the formation of food preferences and eating behaviours. Parents' model taste preference, food selections, access to certain types of foods and the amount of foods available (Kral & Rauh, 2010). It is suspected that parents have an important role in the development of behaviours because food preference in children can be modified by factors in the home environment (Kral & Rauh, 2010). The extent to which parental modeling occurs was considered in this research, along with the influence sibling relationships can have. There is limited research available on this topic, however Salvy, Vartanian, Coelhi, Jarrin, & Pliner, (2008) considered social eating through sibling influences. Sibling influence is an important aspect of role modeling to consider in families because siblings often eat at similar times and share meals, while interacting with each other. Salvy et al., (2008) determined that children were more likely to eat when co-eaters are family or siblings, and that familiarity of family has an impression on the success of eating in children. Children also ate more food items when their co-eater was a sibling (Salvy et al., 2008). To conclude, available literature suggests that the extent to what individual eat is influenced by whom they are socially connected to (Pachucki et al., 2011). The influence that parental and sibling models have on

children with ASD are unknown. Sibling and parent influences were considered in this research to understand the extent relationships have on feeding behaviours and environments in this population.

Dietary issues may be influenced by family patterns during early childhood development. Children with intellectual and developmental disabilities are more dependent on others for tasks of daily living as compared with children with TD (Ha, Jacobson Vann, & Choi, 2010). As stated in Schreck and Williams (2006), family food preferences control children's food preferences; families of children with ASD, who report having more diet restrictions, have children with equally restrictive diets. Social engagement and social reinforcement play an important role in promoting dietary diversity in children with ASD (Sharp et al., 2013). Limited research is available on children with ASD and parental perceptions, knowledge, and the roles parents and families have on food choices. The parental population was utilized in this study to explore preferences and selectivity issues in preschool aged children with ASD.

2.3.3 Family and the feeding environment

2.3.3.1 Parental knowledge. Families play a significant role in the development of healthy behaviours, such as physical activity and healthy eating, in children (Ha et al., 2010). A parents' ability to recognize overweight or obesity, in their child, is essential to creating and implementing programs to help prevent and solve weight issues (Etelson et al., 2003). If parents do not recognize overweight or obesity they will not accept or seek help to modify unhealthy behaviours. Therefore, a parents' readiness to assist children with dietary and physical activity behaviours is a powerful influence on a child's overall/long term health (Ha et al., 2010).

Weight misconceptions refer to a disconnection between parental perceptions and the weight status of their child (Doolen, Alpert, & Miller, 2009). A meta-synthesis was conducted to determine the extent to which parent misconceptions occur when assessing a child's weight status (Doolen et al., 2009). Results concluded that parents were able to appropriately assess a child with normal weight, yet had difficulty classifying children who were overweight (Doolen et al., 2009). Research conducted to assess parental attitudes towards childhood obesity, knowledge of healthy eating patterns, and perceptions of weight in children weight found that 78 percent of parents stated they would be 'quite' or 'extremely' concerned if their child was overweight (Etelson et al., 2003). However, these same parents consistently underestimated the weight status of their children (Etelson et al., 2003). Additional case study research revealed 62.5% of parents with overweight children, and 75.6% of parents with obese children, expressed no concern about their children being or becoming overweight (Carnell, Edwards, Croker, & Boniface, 2005). Only 6% of parents with overweight or obese children were able to accurately recognize a weight issue in their children (Carnell et al., 2005).

Underestimating weight in children is an error observed in studies conducted in the United Kingdom, Australia, Italy, and the United States, suggesting universal beliefs and values are influencing factors used to assess childhood weight status (Dooleen et al., 2009). These factors include cultural and personal beliefs, a hesitation to label a child as overweight, environmental factors (including socioeconomic status), or simply because parents know longer know what 'normal weight' is (Doolen et al., 2009; Etelson et al., 2003; Ha et al., 2010). Research related to why parents misclassify weight in children and what factors influence parents' perceptions of weight is lacking. Understanding how

parents perceive weight is critical if appropriate nutrition and lifestyle interventions are to be implemented.

Unfortunately there is limited research on parental perceptions of weight in children with ASD. According to an American study by Curtin et al., (2005) the prevalence of obesity is 1.2 times greater in children with an ID as compared to children with TD (Ha et al., 2010). Parental perceptions of weight are essential as the risk of obesity is increased in this vulnerable population. Assessment and management of weight in children, aged 2-5 years, may decrease long term risk of overweight and obesity in individuals with ASD, as well as prevent the development of other nutrition related chronic diseases that can negatively impact health (Curtin et al., 2005; Sigman-Grant et al., 2011). Therefore, increasing awareness in parents and reframing discussion in terms of future preventative strategies may be the most effective means to way to improve parental knowledge on this problem (Carnell et al., 2005). Parental values, actions, and beliefs about feeding behaviours and practices need to have a positive influence on current and future health of children with ASD.

2.3.3.2 Stress. It is important to consider the influence of stress on the feeding environment, in addition to that of the family. Parents and families are primarily responsible for the health habits of preschool aged children (Sigman-Grant et al., 2011). Significant challenges experienced in feeding problems in children with ASD results in increased stress within the family environment (Kodak & Piazza, 2008). Problematic feeding behaviours are common concerns expressed by parents of children with ASD (Kodak & Piazza, 2008). Parents play a major role in the division of feeding responsibility, and when negative, the burden of serious feeding difficulties can result in

parental and family stress (Sharp et al., 2014; Satter, 2005). Approximately 90% of children with ASD have feeding problems, which is a chronic and common stressor experienced in the families (Kodak & Piazza, 2008; Ledford and Gast, 2006). Parents often feel frustrated and depressed when their child exhibits problematic feeding behaviours, which ultimately influences the family environment (Kodak & Piazza, 2008). Additionally, children with ASD may be unable to eat with others, resulting in missed opportunities for social engagement (Sharp et al., 2014). Families with children with ASD, experience more stress with feeding and are more likely to miss out on religious observances that often include food, have fewer opportunities to eat at restaurants or social occasions, and are less involved in social activities that incorporate eating (Sharp et al., 2013).

Mothers of children with ASD have greater emotional responses and behavioural control practices of eating habits of their children, compared to mothers that have a child with TD (Martins et al., 2008). This may affect parents' roles when taking on dietary responsibilities (Martins et al., 2008). Additional studies suggest that there is a strong relationship between a mothers' stress level and the frequency of the child's eating difficulties (Martins et al., 2008). Due to increased selectivity, *what* children with ASD will eat increases the complexity of *what* the parent presents to be eaten, and the manner in which (*where* and *when*) it is presented (Satter, 2005). Other parental stressors may include financial concerns, caretaker time and energy, and pressure associated with careers (Minihan et al., 2007). The health of their child, including the potential for malnutrition and dehydration, difficulties related to learning behaviours and socializing and the risk of death are additional stressors, parents often have to cope with (Minihan et

al., 2007; Kodak & Piazza, 2008). The accumulation of multiple feeding challenges may result in increased family stress; including differences in the management of food behaviours and feeding environments within and between family members.

2.3.3.3 Controlling the food environment. Parents of children with disabilities find it difficult to control and set limits of food choices available to their children. In the work of Minihan et al., 2007), parents expressed feeling guilty about many things their children were unable to do Rogers et al., (2011) concluded that mothers may fear their child will no longer accept a preferred food if they try to alter it in any way (i.e. adding ham to a grilled cheese sandwich may result in the child refusing the meal or food choice). Parents also felt that they needed to “pick their battles with their child” and were reluctant to challenge their child's diet due to concurrent behavioural conflicts or out of concerns related to limiting rewards (Minihan et al., 2007; Memari & Ziaeef, 2014). This may lead parents to feeling that they are de-emphasizing healthy eating habits in their children (Minihan et al., 2007). With a higher incidence of feeding concerns in children with ASD, there is increased need to identify and develop empirically supported treatments to assist families with these problems (Sharp et al., 2013). Feeding concerns and explanations as to why specific feeding habits develop were explored to increase understanding of these concerns from the perspective of the families. Explanations for parents utilizing specific methods of dietary manipulation, as an effort to control the feeding environment were also investigated.

2.3.3.4 Diet manipulation There is no known cure for ASD and the etiology and causes of ASD remain unknown (Elder, 2008; Whiteley et al., 2013). As a result, a variety of techniques have been utilized on children with ASD in an attempt to find the

best treatment for each individual (Marcason, 2009; Whiteley et al., 2013). Parents often resort to complementary and alternative medicine (CAM) therapies, as a means to improve the lives of their child (Marcason, 2009; Whiteley et al., 2013). Research regarding feeding problems in ASD and increased dietary vulnerabilities has resulted in increased interest in dietary manipulations as a potential treatment modality (Sharp et al., 2013). Alternative dietary methods are sought by parents, due to problematic feeding behaviours experienced by children with ASD. These may include the restriction of potential food allergens, the use of probiotics, following a yeast-free , gluten-free casein-free diet (GFCF), and the use of dietary supplements (Marcason, 2009). Among the most common dietary treatment, is the GFCF diet (Marcason, 2009; Sharp et al, 2014; Whiteley et al., 2013).

The GFCF been hypothesized, and has not proven, to enhance ASD behaviours, social behaviours and psychological symptoms (Pennesi & Klein, 2012). This regimen eliminates gluten (found in wheat, rye, and barley) and casein (the main protein in dairy products) from the diet (Elder, 2008; Sharp et al, 2014). It is thought that children with ASD have abnormal intestinal permeability that results in the absorption of larger peptides and the incomplete break down of proteins, specifically gluten and casein (Elder, 2008; Maracason, 2013). It is hypothesized that the peptides act as opioids and cross the blood-brain barrier, which results in behavioural issues in children with ASD (Elder, 2008). This is referred to as the “Opioid Theory” (Elder, 2008). Other research on children with ASD suggests that additional gastrointestinal problems or food sensitivities are improved with the GFCF diet (Elder, 2008). Conversely, alternative research suggests an increased potential of a parent placebo effect that is directly related to the

effectiveness of the GFCF diet (Elder, 2008; Christison & Ivany, 2006). Also, it is important to consider this that the removal of gluten- and casein-containing foods, results in the removal of grain and snack foods that are often the preferred food items of children with ASD (Sharp et al., 2013; Sharp et al., 2014). This may lead to weight loss, nutrient deficiencies, and potential bone loss (Sharp et al., 2014; Marcason 2009). The potential influence of the GFCF diet on the overall physical health and welling-being of children with ASD remains unknown.

Although some literature claims positive dietary interventions result in children with ASD, it has not been proven and there is high controversy regarding the effectiveness of this approach. Interventions, using other dietary manipulations, lack evidence-based research to support them (Marcason, 2009). These trials often omit placebo trials, include few participants, are short in duration, have problems associated with outcome measures and the ability to monitor dietary adherence (Whiteley et al., 2013). Success of these interventions may be a result of confounding outcomes that are influenced by other factors, or the use of other CAM approaches that result in positive outcomes (Pennesi & Klein, 2012; Whiteley et al., 2013). The adoption of diets, specifically GFCF, into best feeding practices is cautioned as there is currently no universal consensus related to efficacy in children with ASD (Whiteley et al., 2013). Benefits from dietary manipulations are not an empirically supported or recommended treatment technique (Elder, 2008). Approaches regarding feeding behaviours and food environments were considered as a possible strategy that may or may not be utilized by parents of children with ASD in this study.

Parental stress, as a result of feeding behaviours, can have an impression on the outcome of feeding environments. Due to increased feeding difficulties, specific methods of dietary manipulation are used differently on this population, in comparison to those with TD. Conversely, alternate methods of control to treat challenging behaviours and feeding difficulties in children with ASD, have not been clinically approved. Additional considerations of this study include the exploration of services provided to children with ASD.

2.4 Supportive Care and Services

The family feeding environment has an important role in the health of children with ASD. When exploring the food behaviours and feeding environments in parents of children with ASD, it was speculated that health professional roles, including a dietitian and nutritionist, may be commented on. To increase understanding of each profession, the role and responsibilities of Registered Dietitians and Nutritionists were discussed.

The title Registered Dietitian refers to an individual that has obtained a Bachelor's Degree with specialization in food and nutrition, has achieved practical training through an internship, and has passed the Canadian Dietetic Registration Examination (Dietitians of Canada, 2013; College of Dietitians of Ontario, 2013a). A Registered Dietitian's competence to practice is protected through provincial legislation (Dietitians of Canada, 2013). In Ontario, the letters 'RD' mean that an individual is registered with the College of Dietitians in Ontario and is permitted to deliver safe, ethical, and dietetics services (College of Dietitians of Ontario, 2013a). Typically, Registered Dietitians work in hospitals and health care institutions focusing on clinical care of patients and management of food services (Dietitians of Canada, 2013).

The title Nutritionist refers to an individual that provides a different level of care to individuals, and should not be confused with a Registered Dietitian. In Ontario, the title Nutritionist is neither protected nor regulated by provincial law (College of Dietitians of Ontario, 2013b). The training and knowledge of a Nutritionist is different in comparison to that of a Registered Dietitian. To conclude, Ontario Nutritionists can legally provide nutritional information; however, a Registered Dietitian is the only regulated nutrition profession that provides individualized approaches to better one's health (College of Dietitians of Ontario, 2013b).

Variation in the participants' prior knowledge of and prior exposure to the professions of dietitian and nutritionist was taken into consideration. As such, it was foreseen that the participants in the study would demonstrate a varied understanding of each health profession and the services they provide.

2.4.1 Health Care provider knowledge

It is important to acknowledge that gaps may be prevalent in the training of all individuals that provide care to children with ASD, particularly those that are involved with the food behaviour and feeding environment challenges. Limited information was available regarding the knowledge of all professionals providing care to children with ASD. A comparison of the professional training of the service providers was outside of the scope of the study. This literature review focused on the professional training and knowledge of school nurses and dietitians in children with ASD, because they may have experienced difficulties with feeding challenges in this population.

With a dramatic increase in the prevalence of ASD there is a greater need to for awareness and education approaches to better serve this population (CDC, U.S.

Department of Health and Human Services, 2014; Strunk, 2009). Knowledge gaps should be identified so that professional development opportunities can be provided to these health care professionals. Strunk (2009) conducted a study to understand school nurses' knowledge of ASD. The report states that school nurses are knowledgeable on the symptomology and medication use of ASD (Strunk, 2009). However, knowledge gaps were noticed in their communication skills, behavioural therapies, and safety awareness (Strunk, 2009). Although school nurses are not the primary participants of this study, they are involved in the care of children with ASD and may have similar experiences with feeding challenges when in the school environment. Strunk (2009) and Nachshen et al., (2008) also emphasized the need for increased education for school nurses and other health care professionals in the hopes that all health care professionals become better educated about the population with ASD; this will enable health care professional to provide more effective and appropriate care this population.

Additionally, a needs assessment was conducted on children with ASD in 2012 (Professional Development & Conferencing Services [PCDS], Faculty of Medicine, Memorial University, 2012). Due to the context of the current study, the assessment of Registered Dietitians was explored. Their results concluded that dietitians have moderate to good knowledge of food sensitivities and selectivity, yet have poor to moderate knowledge of several characteristics associated with ASD (PCDS, Faculty of Medicine, Memorial University, 2012). This needs assessment concludes that Registered Dietitians require more training to increase their knowledge of the population. When asking dietitians about topics about which they feel they need further training, respondents reported a high need for training regarding dietary complaints and solutions, and

evidence-based treatment approaches (PCDS, Faculty of Medicine, Memorial University, 2012).

To conclude, gaps in training are apparent among some health care professionals that provide care and support to children with ASD (PCDS, Faculty of Medicine, Memorial University, 2012; Strunk, 2009; Nachshen et al., 2008). Due to the multiple outcomes and individualized nature of feeding challenges, knowledge and further training is required in multiple supportive services to assist in addressing these challenges (Rogers et al., 2011). In the current study, knowledge gaps were examined among health care professionals to identify areas that require further professional development with the goal of improving the level of services provided by health care professionals in this field. Additionally, this study explored the established treatment approaches used by health care professionals, service providers, and families to assist children with ASD, specifically the use of operant conditioning through Applied Behavioural Analysis (ABA).

2.5 Applied Behavioural Analysis (ABA)

2.5.1 Operant conditioning: Reinforcement review

Operant conditioning is a principle created by behaviorist, Burrhus Frederic Skinner (Gulick & Kitchen, 2007). This theory was developed using previous behaviourist's knowledge, stating that conditioning models can accurately define human behaviours (Gulick & Kitchen, 2007). Skinner adapted the theory and created a framework that explained external influences on behaviours and the idea of choice (not always overt) and selection (Gulick & Kitchen, 2007). As a result, operant conditioning

principles provided answers to why individuals do things in certain circumstances (Gulick & Kitchen, 2007). This theory provided scientific evidence to support the creation of behaviour-changing interventions that are applied to develop skill instruction, lower negative behaviours, and inflict motivational variables (Gulick & Kitchen, 2007). Once behaviour occurs, a conditioning process (one of three things) is applied to influence whether or not the behaviour will occur again:

- A consequence will occur that *decreases* the chance a behaviour will occur again;
- A consequence will occur that *increases* the chance a behaviour will occur again;
- or
- No consequence will occur

In this theory, consequence can be considered positive or negative. The type of consequence that is administered, punishment or reinforcement, will determine the future of the behaviour (Gulick & Kitchen, 2007). *Punishment*, positive and negative, lowers the odds that a certain behaviour will occur again. This includes, positive punishment, *adding something*, adverse, after the behaviour occurs, to decreases the frequency in the future (Gulick & Kitchen, 2007). Negative punishment, is the process in which something desirable is *taken away*, to reduce occurrences (Gulick & Kitchen, 2007). Conversely, to increase the likelihood of certain behaviours, *reinforcements* are used. Positive reinforcement involves *adding* or *magnifying* a stimulus with a goal of repeated behaviour (Gulick & Kitchen, 2007). Negative reinforcement, *removes* or *reduces* a stimulus to increase the probability the behaviour will occur in the future (Gulick & Kitchen, 2007).

Essentially behaviour change occurs due to a cause-and-effect relationship. Five key principals can be used to establish effectiveness of reinforcement (Gulick & Kitchen, 2007):

- Immediacy: reinforcement delivered right after a target behaviour
- Contingency: reinforcement is only given to the specific target outcome
- Magnitude: reinforcement is provided in an appropriate amount
- Variability: to lower the risk of satiation, varied reinforces should be used
- Deprivation: reinforcement must be controlled to maintain its ‘importance’ to the child

Understanding the effectiveness in the use of reinforcement is necessary to achieve the desired outcome. When working with children with ASD, the literature supports the use of positive reinforcements to help control behaviours (Gulick & Kitchen, 2007). There are five general forms of positive reinforcement including: sensory, activity, social, tangible and edible (Cooper, Heron, & Heward, 2007, pp. 270-275). *Edible reinforcements* (ER) includes preferred foods, snacks, or candies that are used as immediate “rewards”, to increase the likelihood a behaviour will occur again (Cooper et al., 2007, pp. 270-275). *Tangible reinforcement* involves stimuli that are “physical” (can be touched) and may also include food. Preferred foods item are used as reinforcement for conditioning children with ASD (Cooper et al., 2007, pp. 270-275; Gulick & Kitchen, 2007).

Operant conditioning is a behavioural model developed to increase understanding of behaviours. Although, there are many components of this model, conditioning and ER

were included in this study to understand if the use of reinforcements had an influence on the behaviours of the children in this study.

2.5.2 ABA approaches in children with ASD

The work of Skinner and the use of experimental analysis, began the foundation of the scientific field of behavioural analysis (Gulick & Kitchen, 2007) which lead to the development of experimental analysis of behavior (EAB), scientific methods to modify behaviours to understand predictable areas of study, and Applied Behavioural Analysis (ABA) (Gulick & Kitchen, 2007).

There are many approaches used to teach children with ASD, and parents. Although, many methods are controversial and surrounded by hype, a select few have proven to be effective through data collection and statistical significance of peer-reviewed research (Gulick, & Kitchen, 2007). Research has consistently supported ABA as an effective method to teach skills to all types of learners and reduce problematic behaviours (Gulick & Kitchen, 2007). The ABA approach is a practical and theoretical framework used to teach academic content to children and adults with ASD. It is a ‘natural’ social science approach that uses scientific applications to improve human conditions to change or modify behaviours (Gulick & Kitchen, 2007). The goal of this technique is to minimize core features and any associated deficits, maximize all forms of functional independence and quality of life, and alleviate any family distress (Myers & Johnson, 2007). The ABA approach has become accepted as the ‘*gold standard*’ for interventions and education of life skills, for children with ASD as well as other disabilities (Gulick & Kitchen, 2007). The ‘official’ definition of ABA was, derived by Baer, Wolf, and Risley (1968, p.20), and synthesized by Cooper et al., (1987, p.14):

Applied Behavioural Analysis is the science in which procedures derived from the principles of behaviour are systematically applied to improve socially significant behaviour to a meaningful degree and to demonstrate empirically the procedures employed were responsible for that improvement.

Operant conditioning and the use of ABA has become a tool used when reducing behaviours, while providing opportunities to enhance human conditions (Gulick & Kitchen, 2007). Operant methods, used in ABA, involve the use of reinforcement, extinction, and punishment, to condition and change behaviours (Gulick & Kitchen, 2007; Matson, Hattier, & Belva, 2012).

The ABA approach has become an effective tool for teaching adaptive living skills in children with ASD (Matson et al., 2012). Adaptive living skills include: work skills, self-help and self-care, independent living, hygiene, and feeding (Matson et al., 2012). Children with ASD develop differently than those with TD and those with other developmental disorders (Kroeger, & Sorenson, 2010). The use of ABA in this specific population was considered.

Parents, school employees, and supportive programs are all involved in the development of skills and learning behaviours in children with ASD; ABA has been utilized to improve these behaviours. Independence through self-help and self-care is difficult for individuals with ASD (Matson et al., 2012). LeBlanc and Coates (2003) used ABA to teach perspective-taking skills (understanding that another person's perspective is different from reality, changing their responsive behaviour in the future) to children with ASD through the use of video modeling and ER's. The use of video technology allowed children to correctly observe tasks, and the modeling explained the strategies used in the video (LeBlanc & Coates, 2003). Preceding the video, children were asked,

perspective-talking questions and provided with an ER if correct; if incorrect, the video was repeated (LeBlanc & Coates, 2003). In this study ABA approaches of ER were used to teach children with ASD conversational and self-care skills, however the extent to how much ER was used and any effects it had on the children was not included and/or evaluated.

It is important to remember that adaptive behaviour deficits range in this ‘spectrum’ disorder, therefore systemized training is essential for both children and caregivers (Matson et al., 2012). Children with ASD have difficulties applying skills in certain environments and with specific people, therefore training parents on approaches to assist with these difficulties is essential (Kroeger & Sorenson, 2010). An intervention study conducted by Kroeger and Sorenson (2010) evaluated an intensive training protocol used to teach parents appropriate ABA techniques to toilet train their child, with ASD. In this study, a stimulus was presented to children as a positive reinforce when the child conducted the “toilet training task” properly (Kroeger & Sorenson, 2010). The child was provided with an immediate stimulus of an ER (a Popsicle or candy-coated chocolates) and an activity reinforcement (a planned escape to a preferred activity) (Kroeger & Sorenson, 2010). Results concluded that teaching parents techniques of ABA to toilet train their child was successful and maintained overtime (Kroeger, & Sorenson, 2010). These methods are used to assist parents with teaching children hygienic and independent living skills (Matson et al., 2012). However, limited information was available on the use of ABA methods on children with ASD and the potential effect ER may have on their health.

In parent training models, ER is encouraged when experiencing behavioral difficulties (Kroeger & Sorenson, 2010). Children with severe selectivity, undergo behavioural interventions aimed at expanding dietary variety (Sharp et al., 2013). Food rewards have been used to increase the food selectivity of children with ASD; “reward” foods are effective when combined with non-preferred food items, to increase acceptance towards other foods (Kodak & Piazza, 2008). Desired foods are used to encourage children to eat foods that are less well liked. Additionally, foods are used by parents (as well as others, e.g. teachers) as a strategy for behavioural control (Minihan et al., 2007). Common strategies include therapists, coaches, and parents using energy-dense, low nutrient “junk” or snack foods as a reward for preferred behaviours (Mermari & Ziaeef, 2014; Minihan et al., 2007). Within this research it was important to distinguish between reinforcements (immediate rewards in reaction to a behaviour) and rewards, to which both can be used to enhance behaviours.

It has been suggested that the practice of reinforcement and reward, results in a positive desirability from receiving these foods, leading to the development of poor eating habits (Minihan et al., 2007). Explanations for weight concerns in children with ASD include, but are not limited to, nutritional problems, specifically using food as a reward or reinforcement (Lloyd et al., 2012).

Through the use of coaching techniques incorporating ABA, children with ASD are able to develop important life skills. Although the method is effective, additional research was required to understand the effects and demands of these techniques, including the use of edible foods as reinforcements and rewards, have on children with ASD and their parents.

2.6 World Health Organization: International Classification of Functioning, Disability and Health (WHO-ICF)

2.6.1 Model Overview

To increase understanding of those characteristics that may influence food intake in children with ASD, the World Health Organization (WHO) classification of functioning, disability, and health (ICF) will be utilized. The WHO created a framework of International Classification of Functioning, Disability and Health (ICF) to understand health and disability from a functional perspective (World Health Organization [WHO], 2001). The framework describes what “health” and “disability” are, at the individual and population level (WHO, 2001). The ICF model of health and disability was established to help all individuals, understand that disability is a wider concept of health and that those individuals affected by a disability are provided with the opportunity to live a full life, in their communities (WHO, 2002). The ICF model acknowledges that all human beings experience a decline in health over the lifespan, often resulting in some degree of disability (WHO, 2001). The ICF model provides a mechanism to document the social and physical environments that influences individual functioning level, creating a shift away from the causes of disability to that of its impact (WHO, 2001; WHO 2002). The ICF model has been used to assess functional status and goal setting and in treatment planning, monitoring, and outcome measurements (WHO, 2001). Additionally, the ICF model has been utilized in social policy and impact, intervention, and application research (WHO, 2001). This framework identifies disability as a universal human experience.

2.6.2 Autism Spectrum disorder (ASD) and the ICF

The WHO-ICF framework was utilized to increase understanding food behaviours and feeding environments in children with ASD. Specific stereotyped behaviours, including deficits in social communication and social interaction, restrictive patterns, requirements for sameness, and selectivity, may influence food behaviour and feeding environments in the individual and families of children with ASD (APA, 2013; Frombonne, 2009). Figure 1 presents the WHO-ICF model that was utilized, to explore the feeding behaviours of children with ASD and the influence that multiple factors can have on ones level of function.

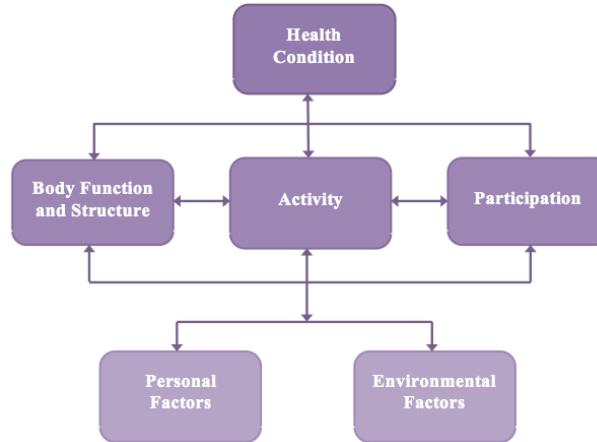


Figure 1: WHO-ICF framework for the classification of health conditions and functioning



The WHO-ICF framework is a theoretical framework that has been used because the diagnosis of ASD alone cannot predict or provide sufficient information for health

planning and management purposes, while identifying an individual's level of function and disability (WHO, 2002). A diagnosis is not adequate to fully understand the behaviours associated with ASD and what families experience. The framework was utilized to increase the understanding of children with ASD and their food behaviours and feeding environments.

The disorder ASD is classified as a "spectrum", with varying degrees of severity. Although levels from mild to severe ASD were included in this research, purposeful sampling was utilized to select children with specific characteristics. Parents with documented food/feeding issues and behaviours in their child, with ASD, that were used to explore and understand this disability from a functional level of health.

Body Function and Structure

Bodily function refers to the physiological functions of the body (WHO, 2002). Bodily structures refer to anatomical parts of the body (e.g, organs, limbs) (WHO, 2002). Bodily functions and structures were considered as possible contributors to food behaviours and feeding environments. Research has demonstrated that children with ASD are at increased risk of developing weight issue (Curtin et al., 2005; Choi et al., 2012; Curtin et al., 2010; Xiong, et al., 2009). Existing weight issues and/or other predisposing factors (comorbid conditions e.g, ID) or impairments (ex: physical limitations) were considered as possible risk factors for, underweight, obesity, and overweight as a result of food behaviours and feeding environments. Information regarding bodily function,

structure, descriptive details, and classification of “degree of physical impairments” are beyond the scope of this study.

Activity

The “Activity” category of the model includes the execution of a task or activity and effect what an individual is able to do (WHO, 2002). Activities an individual can or cannot perform, may be the result of bodily functions and structures and/or alternative restrictions, including social or environment (e.g. unavailable equipment that is needed for a child to participate in group physical activities). As well, activity can be related to the food behaviours and feeding environment process in which the family functions. This may be observed through bodily structures and functions that limit food activity, which affect the families’ dietary behaviours, for example, texture aversions. Children and youth with ASD can have colour and texture aversion or preferences that can severely influence dietary choices (Hinckson et al., 2013). What an individual “can do” and an activity limitation that may influence the food behaviours and feeding environments was included as secondary information, however it was not a primary inclusion factor of this study.

Participation

The participation section of this framework refers to an individual’s engagement in life. Restrictions in participation include difficulties becoming engaged in activities

and what the individual “actually does,” (WHO, 2001). Participation may be influenced by the child’s usual activity level and how they perform daily life tasks. Participation in feeding behaviours and family eating environments was included in this model framework.

As previously discussed, children with ASD have specific characteristics that may result in difficulties with feeding experiences. Feeding selectivity and food restriction behaviours are common (Sharp et al., 2013). Food rejection can result from a specific type, texture, and/or presentation of food. This may lead to severe dietary limitations (e.g. eating only McDonald’s French fries, eating only foods of a certain colour). Schreck and Williams (2006) concluded that children with ASD, have challenges related to both food restriction and refusal. When evaluating food restriction and refusal severity, Schreck & Williams (2006) stated that parents claimed their child with ASD accepted fewer than half of the identified foods used in their study evaluation, in comparison to those without ASD. Additionally, Martins et al., (2008) determined that children with ASD were twice as likely to be *currently* experiencing feeding difficulties and those who did, experienced these challenges, three times more often than those children without ASD. This suggests that feeding behaviours from food selectivity and restriction influence the child’s dietary choices, which may then influence the family environment.

Recent studies have provided evidence suggesting that children with ASD are at increased risk of overweight and obesity (Cutrin et al., 2005; Froehlich-Grobe, & Lollar, 2011). One study has concluded that children with ASD have food selection patterns that result in increased intakes of juices and sweetened non-dairy beverages and snack foods, and fewer servings of vegetables, in comparison to children with TD (Evans et al. 2012).

Although children with TD experience food section during development, evidence suggests that dietary choices contribute to this problem, however, due to limited research in this population the long term impression of these choices remains unknown (Froehlich-Globe & Lollar, 2011; Minihan et al., 2007).

Environmental Factors

Contextual factors, including personal and environmental factors were explored in relation to a potential relationship to health condition outcomes and the effect these factors may have on disability and function. Contextual factors have an important role in a health condition. The WHO-ICF framework acknowledges influence that the social and physical environment can have on an individual with a disability (WHO, 2002).

The family environment and parental concerns become challenging when children exhibit restrictive food behaviours, which may result in negative health outcomes. Food related challenges were explored to increase understanding of relationships that may emerge from the participant of the family environment. Parental knowledge, involvement and their ability to understand or adapt to problematic food behaviours has been associated with negative health outcomes in children. The ability to participate may be influenced by contextual factors and choices or techniques used to assist children with ASD.

This research investigated the feeding environments experienced in families with a child with ASD. This feeding environment is effected by participant involvement,

which includes, but is not limited to, food selectivity, dietary patterns and relationships', and parental knowledge of how to adapt and/or make changes to the feeding situation (Sharp et al., 2013; Etelson et al., 2003; WHO, 2002). Additionally, stress levels of the parent may influence the relationships with the child and/or the family environment (Kodak & Piazza, 2008). This may influence the control levels acquired by the family, which may then effect diet and possibly dietary manipulation methods used to decrease health condition symptoms experienced in ASD. Finally, involvement in treatment therapies aimed at improving life tasks and specific food behaviour participation choices of the parent and the child with ASD was explored to understand potential health outcomes.

Enrolment in socially prescribed treatment therapies might contribute to one's health condition. ABA and intensive behavioural intervention (IBI) are treatment approaches utilized to assist families in developing daily living tasks for children with ASD (Gulick & Kitchen, 2007). This treatment includes the use of reinforcements, including ER, to help control and adapt behaviours in children with ASD. It is undetermined the contribution to which these strategies have on this population, as well as the accumulation of these factors. More specifically, how treatment strategies may affect and increase the food intake of children with ASD.

Furthermore, participation in food behaviour and feeding environments is highly influenced at the individual level. As stated in the best practices of feeding, children and parents are responsible for how they chose to participate in feeding. According to family therapist and food specialist, Ellyn Satter, parents are responsible for *what, where, and when* feeding takes place; and children are responsible for *how much* and *whether* eating

will occur from what parents offer (Satter, 1999). This feeding practice relies on both parents and children for dietary participation; therefore, healthy or unhealthy patterns are affected by the child (who eats specific foods) and the caregiver (who provides the food).

This research will assist in identifying and understanding environmental barriers and facilitators, experienced in the family environment, related to food (WHO, 2002).

Personal Factors

The second contextual factor of the model includes the characteristics of the individual. Personal factors influence how individuals experience disability and the influence it has on their level of functioning. Parents of children with ASD were the primary source of information of the study. The children were between 2 and 5 years of age, at the time of the investigation. It can be assumed, that each child will present with different family structures, different beliefs and treatment approaches, all of which influence the child's current health condition. Parents of children with ASD, who have previously expressed or experienced difficulties with food behaviours and feeding environments (e.g., food selectivity problems) were the focus in this study.

Study participants (i.e. parents of children with ASD) will facilitate increased understanding of how food behaviours and feeding environments can be influenced through the individual, institutional, and social level of a child with ASD (WHO, 2002). Due to the young age of the children in this research, it may be too early to assess or identify specific weight related concerns. However, potential "red flags" or pre-existing

risks, feeding preferences and patterns and/or major feeding environment concerns were explored, to understand if precursors for a health outcome (including underweight, obesity or overweight) exist, in this population.

The WHO-ICF framework provides an ideal set of variables to explore the influence of function and disability in an individual. It is anticipated that this research will increase the understanding of early behaviour and environmental precursors that potentially affect the health and weight of children with ASD. Figure 2 represents the WHO-ICF framework adapted to fit the study intentions.

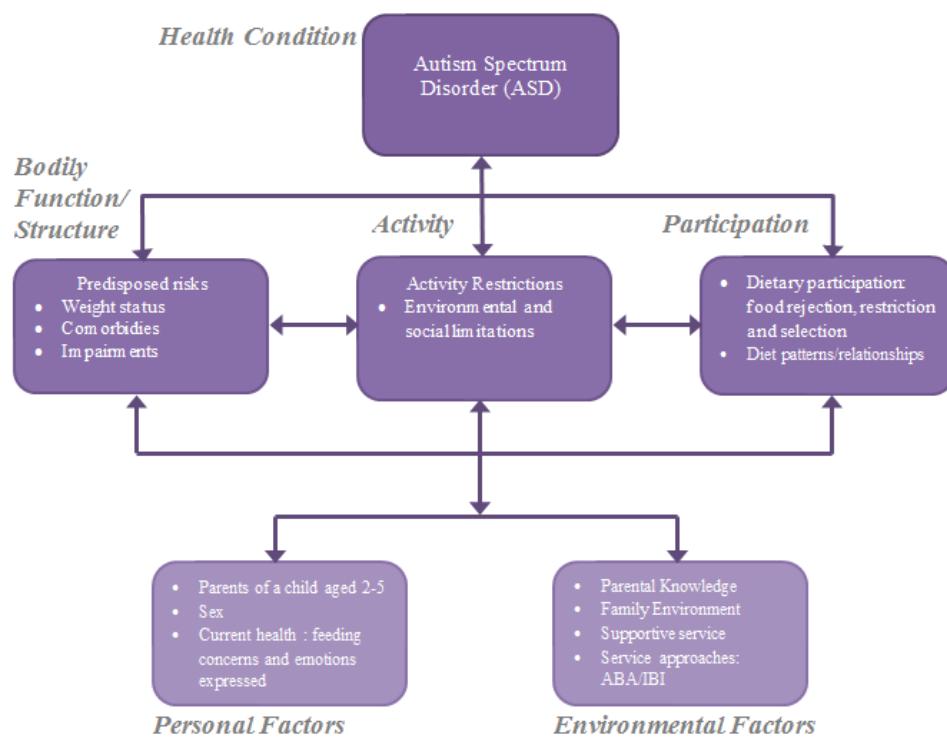


Figure 2: Adapted WHO-ICF framework

2.7 Significance: Addressing gaps in the literature

There are multiple gaps in the available literature, related to children with ASD and food behaviours and feeding environments. Consideration of predisposing factors, including comorbidities, physical activity and medications were considered when exploring weight status, in this population. Family members influence children with ASD and parents are responsible for teaching children healthy behaviours, specifically eating behaviours (Ha et al., 2010). As a result, parental attitudes regarding healthy eating behaviours, influence children during important developmental stages. This could potentially increase the risk for children to adopt unhealthy eating behaviours. Agras et al (2004) concluded that children of overweight parents are at increased risk of becoming overweight. However, similar research with children that have ASD is lacking. Children with ASD have different dietary patterns and behaviours that affect their growth, nutritional status, and family environment, in comparison to children without ASD (Xiong et al., 2007). Additionally, the effect of family support on children with developmental disorders was particularly important as these children are dependent on parents or caregivers to assist them with multiple daily functions (Matson et al., 2012; Ha et al., 2010). Tools used to assist children with ASD, provide supportive strategies for parents and families to develop behaviours in their child, through ABA (Kroeger & Sorenson, 2010; Gulick & Kitchen, 2007). This tool provides a variety of methods to assist children with ASD, including the use of positive reinforcements (Gulick & Kitchen, 2007). The use of immediate rewards, incorporating ER, may increase the likelihood positive behaviour will reoccur (Gulick & Kitchen, 2007). Limited exploratory

research has been conducted, related to the use this ABA strategy by parents. All of the issues identified influence the health and population of children with ASD.

Unanswered questions remain, regarding food behaviours and feeding environment experiences in this population, in addition to increased food intake that may influence weight in children with ASD. Although children in this study may not have an identified weight issue, this research attempted to understand and identify factors that may later predispose them to weight concerns. Predisposing factors, the roles families play in this population, and any adverse relationships that result from the use of intervention strategies to assist children with ASD were explored in this research.

3.0 Methodology

This study explored parents' experiences with food behaviours and feeding environments when having a child with Autism Spectrum Disorder (ASD). In-depth, semi-structured, one-on-one interviews were conducted with parents to explore and gain insights regarding the pertinent issues surrounding this topic (See Appendix B for a copy of the Interview Guide). The qualitative research design, including sampling and data collection strategies, are explained in this chapter, together with an overview of the data analysis processes. The chapter will conclude with a discussion of the study strengths and limitations, biases, timeline and feasibility, and budgetary considerations.

3.1 Ethical Considerations

This study was developed and approved according to the guidelines set forth by the Research Ethics Board (REB) at the University of Ontario Institute of Technology (UOIT), REB #13-050 (See Appendix C for the Ethics Approval Letter). Written permission in the form of a Letter of Support was granted from the Supportive Community Organization (SCO) to conduct the research (See Appendix D). For the purpose of this study, the organization will remain anonymous and a pseudonym of SCO was used. This facility was utilized for participant recruitment. The paediatric doctor, whom was referred to as the supportive individual (SI) in this study, at the SCO used their knowledge of families and their characteristics to select participants for the study, additionally, the researcher had no access to chart information or medical records. To ensure participants met study criterion, the SI was provided with Study Inclusion and Exclusion Criterion to select eligible and appropriate participants (See Appendix E).

Verification of participant characteristics was conducted to ensure that the eligibility criterion was met. Before the study began, parents were asked to sign an informed consent form (See Appendix F). The consent form was used to ensure all study participants understood the intentions of the study, additionally participants were asked for permission to allow the SI at the SCO to release height and weight measurements for each child with ASD to the researcher. Height and weight measurements were used to calculate the body mass index (BMI) of each child with ASD in this study, to classify to classify each child's weight status (Cole et al., 2007). BMI is a standardized measure calculated using weight (kilograms) and dividing it by the height (centimeters) squared ($BMI = \text{weight}/\text{height}^2$) (Cole et al., 2007). The BMI of each child was classified using the International Obesity Task Force (IOTF) cut-offs in order to access child overweight, obesity, and thinness (Cole & Lobstein, 2012). The IOTF cut-offs incorporate the age, weight, and height of children when classifying their BMI (Cole et al., 2007). The IOTF cut-off points were used to calculate the BMI for each child. This approach was recommended by the research supervisory committee. When reviewing the literature the IOTF approach was commonly used. Additionally, it is highly likely that other approaches to calculating the BMI in children would yield similar results to the IOTF cut-off points used in this study.

During the consent form signing, participants had the opportunity to verbally and physically indicate “yes” if they wanted to receive a copy of the transcribed interview. Post study, transcribed interviews were sent to participants that requested them. Participants were then able to review the transcribed interview and provide refinements and feedback, or edit their words in the transcript. This opportunity allowed participants

to agree, change, verify, and, validate all of the information that was stated during the time of the interview. Participants' responses and corrections to transcripts were incorporated into the study data (Mays & Pope, 2000). This method is credible through respondent validation and decreased the risk of error in the data set (Mays & Pope, 2000). Requested transcripts were emailed or mailed to participants with a self-addressed envelope, along with a transcription release form (See Appendix G: mailed and Appendix H: not mailed for the Transcript Release Forms). Participants were asked to sign the transcript release form and return to the researcher with the edited transcript. Due to study time constraints, respondents who requested a transcript were asked to return the transcript within two weeks of receiving the document. Reminders, via email or mail, were sent out two weeks after the mailed date, to ensure participants returned transcripts, to allow for data analysis. In the current study one participant requested to review the transcribed interview and did not make any changes.

To confirm the safety and confidentiality of participants, the transcriber/investigator, members of the supervisory committee, and a co-investigator/colleague that assisted with the analysis of the study signed two statements of confidentiality. A UOIT statement confidentiality agreement and the SCO pledge of confidentiality were signed to ensure that participant safety and confidentiality was achieved during this research process(See Appendix I). Off-site interviews took place in the homes of the participants. During off-site interviews, a member of supervisory committee accompanied the researcher. Additionally, a co-investigator/colleague used a thematic analysis approach to code one of the transcripts during the analysis process of the study. This was used to determine inter-rater reliability of the data. Prior to thematic

analysis and off-site interviews, the colleague and supervisory committee member signed both statements of confidentiality.

3.2 Qualitative Research

The use of qualitative research approaches have greatly increased in the field of health science. This approach has been used to strengthen study descriptions and interpretations of events and life situations (Sofaer, 1999; Thorne, 2000). Qualitative studies include principles, values and assumptions about truth and reality. This research utilized a qualitative approach to build a more complete understanding of reality and interpretation about how people think and feel (Thorne, 2000). This research explored the food behaviours and feeding environments in children with ASD, through the experiences of their parents.

Qualitative research uses naturalistic inquiry to provide subjective meaning to data and how it is observed. When in a health-related field, qualitative research is required to understand complex situations and interactions of people who have different roles and experiences in each setting (Soafer, 1999). There are a number of methods that fit into the “umbrella term” of qualitative research, and each qualitative approach varies depending on the study intentions (Bowling & Ebrahim, 2005).

3.2.1 An overview

The intent of this study was to understand food behaviours and feeding environments in families that have a child with ASD, therefore qualitative research was the superlative approach for this study. There was a paucity of data available on this topic and the findings were used to assist with strengthening the current evidence-base. This

research attempted to understand the experiences of parents in their social environments, while providing a holistic perception of individuals in their natural setting (Polgar & Thomas, 2008). The research design included one-on-one, in-depth, semi-structured interviews with parents of children with ASD, to gain insight on their experiences with food behaviours and feeding environments. This exploratory study required personal and in-depth interaction between the participants and the researcher, in order to gather variable data regarding the lived experiences of each parent (Polgar & Thomas, 2008)..

To establish rigor and quality it was important that this study was a consistent, appropriate, and well-developed design (Soafer, 1999). Qualitative research concepts were used to verify that effective methods were included when developing the research design, data collection, and data analysis approach (Krauss, 2005).

3.2.2 Rigor and quality in research

Qualitative research includes a wide range of methodologies and analytic procedures. Qualitative research cannot be judged on pre-determined settings of quality and rigor, therefor every qualitative study must be judged on its own terms (Bowling & Ebrahim, 2005). It was important that the researcher, in the research setting, established key concepts of rigor and quality during the study (Kefting, 1991). *Reliability, validity, and objectivity* are terms that are not always easily established and/or understood in qualitative research; therefore, assessments have been developed and were utilized in this study to ensure quality in the research findings (Guba, 1981; Krefting, 1991; Bowling & Ebrahim, 2005). The researcher established trustworthiness in this study to support the rigor and quality of the findings (Bowling & Ebrahim, 2005).

3.2.3 Establishing rigor and quality

Verification of data was required to ensure the themes identified during data collection reflected the experiences of the participants (Polgar & Thomas, 2008). A naturalistic paradigm was used to evaluate this research (Lincoln & Guba, 1985). This approach broke down the complexity of the real world and provided a general perspective to the physical, sociocultural, and psychological environments about the individual under study (Lincoln & Guba, 1985). Trustworthiness was evaluated in this study to ensure rigor and quality (Krefting, 1991). According to Guba and Lincoln (1981) there are four aspects used to evaluate study trustworthiness in both qualitative and quantitate research (Guba, 1981).

3.2.3.1 Truth-value (credibility). *Truth-value* is used to determine the confidence of truth in the data findings (Lincoln & Guba, 1985). This determines how well one is able to manage threats on internal validity and explore human experiences as they are lived and perceived by the participants (Guba, 1981; Krefting, 1991). In qualitative research, this is achieved through credibility.

In this study, the researcher obtained credibility by using persistent observation of individuals to identify qualities and characteristics when exploring parents' lived experiences with food behaviours and feeding environments in children with ASD. Peer debriefing with committee members allowed the researcher to test study insights and findings with other professionals and topic experts (Guba, 1981). Research scholars and topic experts, as well as participants, had the opportunity to confirm the correct interpretation of the data. Member checking was also used to test the interpretation of the data findings. The participants that request a copy of the transcribed interview had the

opportunity to validate meanings, ideas, and intentions of statements made during the interviews (Guba, 1981). This was a respondent validation approach that was used to ensure interview findings were credible to the participants (Guba, 1981; Mays & Pope, 2000).

Lastly, triangulation was used to “cross-check” themes and emergent trends in the data to establish credibility (Guba, 1981; Krefting, 1991). A colleague, not involved in the study, was provided with a transcribed interview and the same initial schema developed by the researcher, which included a list of common or repetitive themes that emerged during data collection. The colleague coded one transcript to determine the inter-rater reliability of the study. A coding comparison was run on the coded transcript of the colleague and the primary investigator. The average inter-rater reliability score was 96.6%. Therefore, the colleague and investigator produced similar scores. This method of triangulation increased the study reliability and established data rigor and quality.

3.2.3.2 Applicability (transferability). *Applicability* and how findings are applied to other contexts, is referred to as transferability in qualitative research (Guba, 1981). It is achieved when the researcher presents descriptive data that allows for comparison to similar populations or situations (Krefting, 1991). A thick description of the data collected was required to ensure transferability to other populations (Guba, 1981). Additionally, a detailed description of the data collection approach was necessary to establish the fittingness that the data had to other subjects (Guba, 1981). In this study, purposeful sampling was used to explore specific populations that were important and relevant to the study characteristics. This sampling method did not intend to represent a general population; therefore descriptive details of the selected population will only be

used when applying results to a similar population (Guba, 1981). A clear and organized study was developed to ensure applicability in the findings.

3.2.3.3 Consistency (dependability). *Consistency* suggests that study results are stable and meaningful to the study intentions (Guba, 1981). However, qualitative research tends to emphasize uniqueness in study results and consistency is not always achieved. Variability is often accepted in identical or similar subjects; therefore, dependability was used to evaluate this qualitative research design (Guba, 1981). Dependability implies that the findings were reliable and had “track-able variability,” a variance that can be explained (Guba 1981).

In qualitative research, dependability accessed consistency through auditing of the researcher. The researcher presented a clearly written and descriptive study to allow an external auditor to examine the data collection and analysis process (Guba, 1981). In this study, a colleague coded one of the interview transcripts to ensure dependability was achieved in the study findings. In this study, the colleague and the researcher generated similar results, therefore dependability was achieved (Inter-rater reliability score: 96.6%). Additionally, the expertise of internal committee members was used to ensure study reliability.

To achieve dependability, audibility is also required. The theoretical framework was an alternative verification strategy to audibility that was used in this study. The World Health Organization International Classification of Functioning, Disability, and Health (WHO-ICF) was used to provide structural content to the study. The WHO-ICF model was used to provide a transparent framework to assist with understanding children

with ASD and their food behaviours and feeding environments (Bowling & Ebrahim, 2005).

3.2.3.4 Neutrality (confirmability). *Neutrality* suggests that findings presented in the data represent the informants and are not of other biases (Krefting, 1991; Guba 1981). Neutrality is difficult to establish in qualitative research, because researchers often use themselves as a study instrument during data collection (Guba, 1981). Therefore, neutrality is evaluated with confirmability.

In this study, triangulation methods were used to achieve confirmability, dependability, and credibility in the study findings. This approach constantly tested the rigor and quality of the study outcomes (Guba, 1981). Triangulation was achieved through external auditing with a colleague coding a transcript; supportive evidence that was collected in the literature review, and interview strategies that “cross-examine” the data collected.

Reflexivity was used to consider, appreciate, and confirm the role the researcher had during the study. Although, it was intended for the researcher to be neutral and uninvolved, that is not always plausible in qualitative research. Reflexivity allows the researcher to discuss potential experiences that could have influenced the researcher or the research characteristics (Bowling & Ebrahim, 2005; Mays & Pope, 2000; Guba, 1981). Detailed field notes were used to achieve reflexivity in this study. During the data collection process the researcher kept a journal to reflect and record thoughts, introspects, and feelings during data collection (Guba, 1981; Wolfinger, 2002). The researcher was able to use their notes to reveal and reflect on the roles, characteristics, and observations that influenced the study.

3.3 Site Selection

A SCO (Supportive Community Organization) was used for the selection of participants. This site is a community organization that provides tertiary care and supportive services to children with ASD and parents. This facility offers a wide variety of tools to families of children with special needs, including Applied Behavioural Analysis (ABA)-based services to children with ASD. On-site research was collected in a private office setting at UOIT during the hours of operation. The utilization of this site was determined by the availability of the participants and the facility. Alternatively, due to time constraints, availability, and preferences of each family, some interviews took place off-site. In this situation, off-site interviews were conducted at the homes of the participants in a comfortable, relaxed setting that allowed for undisturbed conversation. A member of the supervisory committee accompanied the researcher during off-site interviews; the committee member did not ask questions, and was only present to provide support to the researcher. A member of the research team was not required for on-site interviews. Additionally, an honorarium (\$20 gift card) was provided to participants to thank them for their contribution to the study.

3.4 Data collection

Appropriate collection methods were necessary to ensure that data was pertinent to the topic of study. The researcher was able to establish a trusting relationship with the participants during each investigation; while establishing an appropriate level of distance between themselves and the participants. This approach was used to perceive and record events with limited personal bias or distortion and understand the personal meaning of their experiences (Polgar & Thomas, 2008). Therefore, the presentation of the researcher

and their ability to establish trust during the primary investigation was determined through the richness of the data collected.

3.4.1 Primary Investigation

In-depth interviews of parents that have a child with ASD were the primary method of data collection utilized in this study. This study explored food behaviours and feeding environments that were experienced by the parents of children with ASD. Purposeful sampling was used to select participants that were eligible and appropriate for the study (Coyne, 1997).

3.4.1.1 Purposeful Sampling. Purposeful sampling suggests that the researcher knows who they were sampling in their study; therefore the logic, purpose and power of data collection incorporated both selective and purposeful sampling strategies (Coyne, 1997). In this study, SI at the SCO selected participants. The SI had expert knowledge of families and their characteristics, which allowed the SI to make appropriate decisions about which participants fit within the study characteristics. Study characteristics included families that have previously expressed (at least once) the following to the SI:

- Food issues in their child with ASD
- Feeding preferences in their child with ASD
- Feeding patterns in their child with ASD
- Issues with the family and feeding environment
- Increased risk of developing a weight problem
- Existing weight issues in their child with ASD

Specific study characteristics that were excluded were:

- Children with severe feeding deficits, resulting in the utilization of medical assistance for the child to meet the dietary needs (e.g, GI tube)
- Children with severe oral-motor deficiencies that impact food behaviours

Inclusion and exclusion criteria were used to study specific characteristics of interest (See appendix E). In qualitative research it is arguable that all research is purposeful, because every study involves a specific group of individuals (Coyne, 1997). Never-the-less, samplings was used in this study to select participants that have had previous experiences with food behaviours and feeding environments when having a child with ASD, and therefore those selected were able to contribute powerful information to the study.

3.4.1.2 *Semi-structured interview.* This study consisted of one-on-one, semi-structured interviews to gather information about participants. This research discussed the families' experiences with food-related behaviours, when having a child with ASD. Open-ended questions, accompanied by probes, were used to gain more insight as the interview permitted. A semi-structured interview allowed for an open-ended framework that gave participants the opportunity to express and reflect on statements made (Bowling & Ebrahim, 2005). Additionally, prior to official data collection a pilot interview was conducted. The pilot interview was used to strengthen the data collection approach and ensure that the interview format and questions are accepted and understood by the participants.

3.4.1.3 Participants: Eligibility Criteria. Parents were selected using purposeful sampling and the study eligibility criteria. The participants (parents) must have expressed one, or more, of the specific characteristics that were previously discussed (See Appendix E). During the research process, one parent of each family was interviewed. One parent, from each family, was requested to participate; if both parents are available they had the opportunity to select which one would participate. Parents that were interviewed had a child aged 2-5 years (at the time of the interview) and were diagnosed with ASD according to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V) and/or the DSM-V guidelines. This research included, families of children with ASD that were registered or on a wait lists to receive services at the SCO. Once, the SI selected participants that meet the eligibility criteria the SI contacted them, via telephone, to notify them about the study. The SI was provided with a verbal transcript to assist them during the recruitment process (See Appendix J for the Telephone Recruitment Script). Parents who wished to participate verbally volunteered themselves for the study and allowed the SI to release their contact information to the researcher. Once in contact with the researcher, interview times were arranged. A Researcher Telephone Script was used to assist with recruitment of selected participant (See Appendix K). Interviews were approximately forty-five to sixty minutes in length. Following the interview, participants were given a thank-you letter (See Appendix L), a list of contacts (See Appendix M), and an honorarium in the form of a gift card (\$20 gift card). During each interview, participants may have expressed concerns that require assistance that the researcher did not have access too; therefore, a list of contacts was given to direct familes to other services and tools that are available to them. The list of contacts was included in the thank-

you letter given to each participant, following the interviews. An honorarium was also given to the participants to thank parents for their contribution to the study. It was estimated that this study would consist of 6-8 participants. The point at which saturation occurred during data collection affected the number of participants utilized in this study.

3.4.1.4 Saturation. The number of interview participants was determined using data saturation. This was achieved when the researcher was confident that the themes and ideas of each interview had become repetitive and that inclusion of new participants would not lead to new trends (Polgar & Thomas, 2008). Although, there was variability in each participant's experiences, saturation was achieved because common themes emerged in the data set. Once saturation was achieved, the researcher was able to conclude the data collection process. It was estimated that 6-8 participants would be included in this study, however to ensure saturation 8 participants were interviewed.

3.4.2 Field Notes

Field notes were used as a secondary source of data in this study. Detailed notes of what the researcher observed and felt during data collection were recorded after each interview (Polgar & Thomas, 2008). Field notes were significant to this study because they provided the researcher with a method of cross-examination (Guba, 1981). After each interview the researcher made field notes to reflect on their data collection observations. Reflections in field notes assisted with the organization of thoughts during data analysis and supported emergent trends in the findings (Wolfinger, 2002). Additionally, comments about the flow of the conversation and organization of each interview were helpful when the researcher was preparing for subsequent interviews.

3.5 Data Analysis

Meanings generated from the findings were dependent on the researcher and the data analysis process and approach (Krauss, 2005). Thematic data analysis is a complicated process in qualitative research; therefore to ensure success the researcher had to be active and demanding during all phases of the study process to ensure that data was understood, read, and interpreted correctly (Thorne, 2000). Specific strategies of analysis were used to interpret the data and transform raw information into a coherent description (Thorne, 2000).

3.5.1 Interpretation of Information gathered: Thematic analysis and Coding

During each interview, a digital audio recorder (Olympus WS-802) was used to capture statements made. Once the data was collected from each interview, audiotapes were transcribed by the primary investigator/researcher. Transcription was used to allow for in-depth data analysis of that data and to ensure that all statements made by the participant were captured.

Transcribed interviews were reviewed several times to capture repetitive and dominant themes in the data. Specific strategies were used during data analysis to ensure that the interpretation and transformation of the raw data was presented in a coherent description (Thorne, 2000). This research utilized thematic analysis to explore families' experiences with food behaviours and feeding environments when having a child with ASD. Constant comparative thematic analysis captured common themes and statements with similar meanings (Thorne, 2000). Filed notes of common themes were made post-interviews and during the initial read-through of the interviews. The researcher compiled repetitive words into a coding scheme that assisted with analysis.

Nvivo version 10.0 was the qualitative software used to encrypt the transcripts, and assist with the analysis and coding of the data collected. The researcher participated in an “Nvivo training session” that took place at UOIT as part of a course requirement. The first training session was conducted on Thursday July 25th, 2013 to introduce the researcher to the software. During the information sessions the researcher was trained on how to import files, understand software navigation, and coding of text. Additionally, the researcher completed a mock data analysis assignment to increase their knowledge about the software.

3.6 Study strengths and limitations

This study explored the experiences of parents that have a child with ASD. In-depth interviews were used to provide insights of the food behaviour and feeding environments experienced in this population. The researcher analyzed the data gathered to increase the evidence-base available and to enlighten individuals on the behaviours and environments that are experienced by parents. Study strengths and limitations were discussed to determine positive qualities of the study, and acknowledge areas that may require further investigation.

Children with ASD have different characteristics, alternative disorders, and/or disabilities in comparison to children with TD, therefore, this study was not generalizable. However, qualitative research does not claim statistical generalizability, nor is it a goal of the research intention (Bowling & Ebrahim, 2005).

Due to limited information available on children with ASD and their parents, selective and purposeful sampling was used to understand the characteristics of this population. Therefore, families selected were in the database of those that were involved

with the SCO. The inclusion of participants and the selection process was one limitation of this study. However, all the families that were registered and receiving services, or on a waitlist were included in the selection process.

There was a possibility of variability in data sets with participant selection. Characteristics and severity varies in children with ASD because it is a spectrum disorder; therefore children had different food behaviours and feeding environment, resulting in variability in the study results. Inclusion and exclusion criterion was included for participant selection, to ensure that those involved had previously expressed some degree of feeding challenge with their child. However, to ensure that enough participants were included in the study, criterion was not overly restrictive.

With a detailed review of the literature, background information was established on the population. This information helped to provide the researcher with potential insight to answers and concerns that could be brought up during data collection. To decrease this risk, the researcher designed the study to ensure that there was flexibility in the analysis process. Acknowledging that alternative subsets of data may prevail was an important strength of the exploratory nature of this research.

In qualitative research there is a possibility that saturation will not be achieved. Due the data set, saturation is questioned because of the huge variance in the population's characteristics. In this study, variability was considered during the analysis process and saturation was achieved because repetition of common themes emerged in the data set.

A major strength of this research was the close collaboration with the organization that specializes in caring for children with ASD. The SI at the SCO has many years of experience working with children with ASD and was included in the participant selection

process. This connection was important when recruiting and gathering participants that were eligible for the study. Additionally, the SI was given the opportunity to provide their expertise and suggestions regarding the development and process of this research.

Additionally, supervisory committee members had experiences that assisted with the current study. Dr. Meghann Lloyd has affiliations with the SCO, has expertise and knowledge regarding this population, and has additional experienced with health and wellness, motor behaviour and developmental disabilities. Dr. Carolyn Hunt was able to provide her advice and expertise throughout the research process. Lastly, the committee supervisor, Dr. Ellen Vogel, is a Registered Dietitian, and has a reseach background in food security and nutrition. Dr. Lloyd and Dr. Vogel have expertise in qualitative research methods and were able to contibute valuable input, direction, and insight throughout the research process.

Another strength of the study was the use of the theoretical framework. The WHO-ICF was a helpful tool used in this study, because the diagnosis of ASD alone cannot predict or provide enough information to assist with health planning and management purposes (WHO, 2002). The framework was utliszed when developing the study design and during the discussion of the study findings. The framework assisted the researcher to understand and organize the characteristics that influenced the food behaviours and feeding environments in children with ASD.

3.6.1 Bias

In this study, the researcher had experience working with children with disabilities. In the past, the researcher has volunteered with services that provide supportive assistance to children with disabilities and has had the opportunity to tutor and

work with children with physical and learning disabilities. Having experience with children with disabilities could have influenced bias ideas and expectations of possible interview responses. Additionally, through an extensive literature review and access to studies, the researcher increased her knowledge regarding the population; which could result in information and opinion bias. Lastly, the researcher had the opportunity to improve her understanding of the processes that the families and facility members go through during a job shadowing opportunity at the SCO. Although, experiences were extremely beneficial, it was important that the researcher was aware of their bias, to ensure there was no interference with the study.

Other study biases include participant selection bias. This study used purposeful sampling to selected participant that were eligible and appropriate for the study design. The SI was given an outline of eligibility criterion. The SI then selected participants that fit within the parameters of the criterion, and those eligible were contacted by the researcher. There was possibility of selection bias from the SI, the individual that was responsible for choosing participants that were appropriate for the study. To limit the risk of selection bias the SI was provided with an outline of eligibility criteria. Additionally, purposeful sampling was utilized to selected participants that previously expressed feeding issues with their child with ASD. Therefore, there was additional risk of selection bias because this study was not a representative sample of all children with ASD.

3.7 Timeline and Feasibility

The proposal defense took place on October 10th, 2013. The defense was conducted to inform all committee members about the study intentions. Upon approval from committee members, permission was sought from the Research Ethics Board (REB) at UOIT. Official REB approval was received on November 18th, 2013 (REB# 13-050) (See Appendix C for the Ethics Approval Letter). Participant selection was used to recruit parents for the study and data collection took place from November 2013 to mid-February 2014. During data collection, transcription and member checking was performed on completed interviews. Once data collection was completed and all interviews were transcribed, data analysis began. Data analysis and thesis revisions were conducted from February to the end of April 2014. Final thesis preparation began in May to June 2014. The Thesis was submitted to the external examiner in June and the oral examination was scheduled for July 10th, 2014. A timeline of the data collection and analysis process was included in Figure 3.

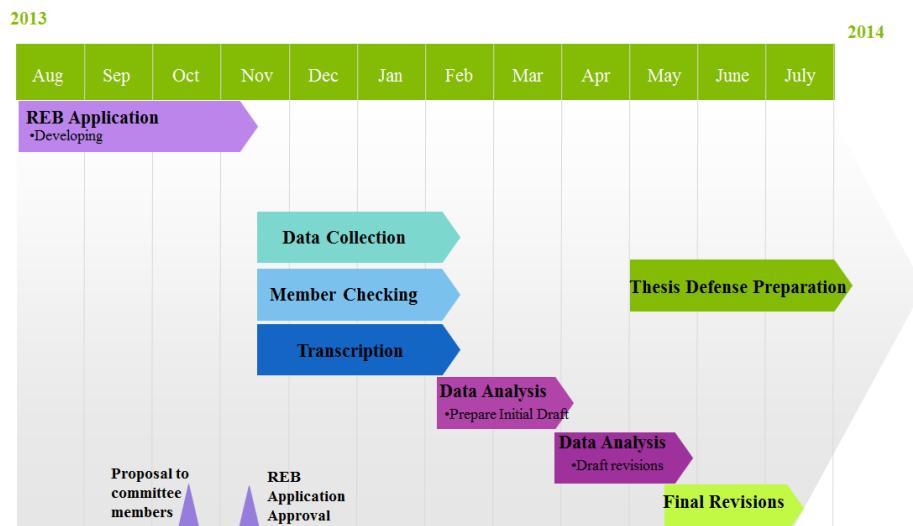


Figure 3: Anticipatory timeline for completion of thesis by July 2014

3.8 Budget

A budget was developed to estimate the overall expenses of this research. An honorarium in the form of a \$20 gift card was provided to parents to thank them for their participation in the study (maximum 8 participants for a total of \$160). For the analysis process, Nvivo version 10.0 software (\$120) was purchased to assist with examination of the data findings. Study findings will be presented during conferences and/or poster presentations, \$1200 is estimated for the dissemination of the study information. Additionally, miscellaneous expenses were included to cover the cost of printing and or addition supplies (e.g. food models) that were utilized in this study (estimated \$500). All expenses and costs were covered by the research account of the supervisor, Dr. Ellen Vogel.

Overview: World Health Organization (WHO) International Classification of Functioning and Disability (ICF)

The WHO-ICF framework was used in this research to document and explore the social and physical environments associated with “health” and “disability” at two levels: children, aged 2-5 years, with Autism Spectrum Disorder (ASD); and ASD at the population-level (WHO, 2001; WHO 2002). This study focused on the participation of the child with ASD and the personal and environmental factors that influence his or her health condition – that is, the level of functioning, disability and health. Contextual factors were examined by understanding parents’ experiences of childrens’ food behaviours and, more generally, the feeding environments of children with ASD. Figure 4 outlines the categories that were examined through the research, using the WHO-ICF framework.

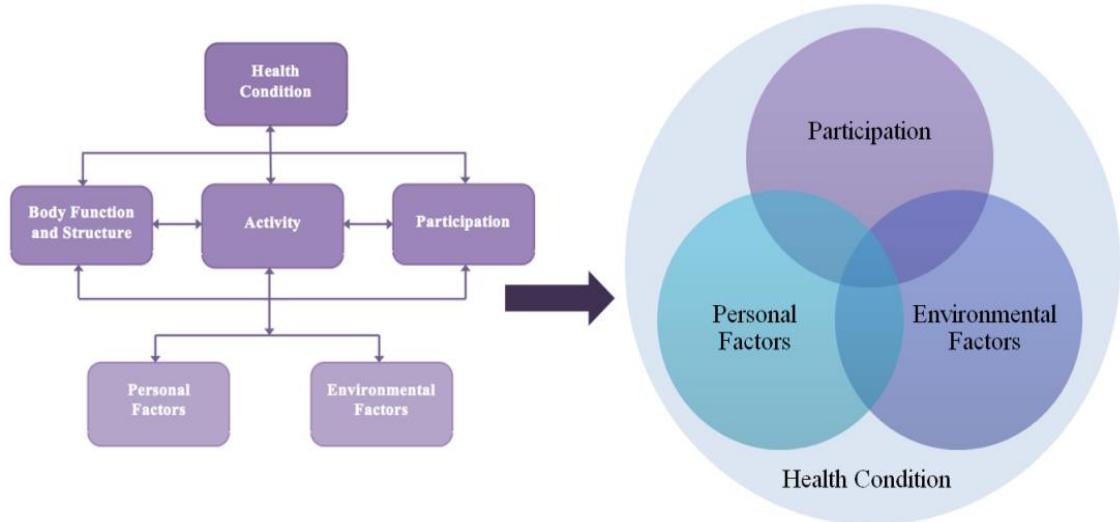


Figure 4: WHO-ICF categories discussed in this study

4.0 Findings and Discussion

This chapter discusses the findings that emerged from the data collected. The World Health Organization-International Classification of Functioning, Disability and Health (WHO- ICF) framework was used to categorize the three major constructs of participation, personal and environmental factors, to understand disability in children with ASD from a functional perspective (Figure 5) (WHO, 2001). The three major themes that emerged from this study include: Feeding challenges (broadly defined); Health of children with ASD; and Care and supportive services. Each major theme was further divided into subthemes that were utilized to organize and discuss the findings of this study.

Figure 5 represents a schematic of the findings to be explicated in this chapter. When reporting the findings, pseudonyms were used to describe participants, their child with ASD, and the supportive community organization (SCO) (Table 1). All quotes were verbatim, with unnecessary repetition removed to increase readability. In order to retain the meanings of the quotes and uphold their integrity, edits to verbatim quotes were minor.

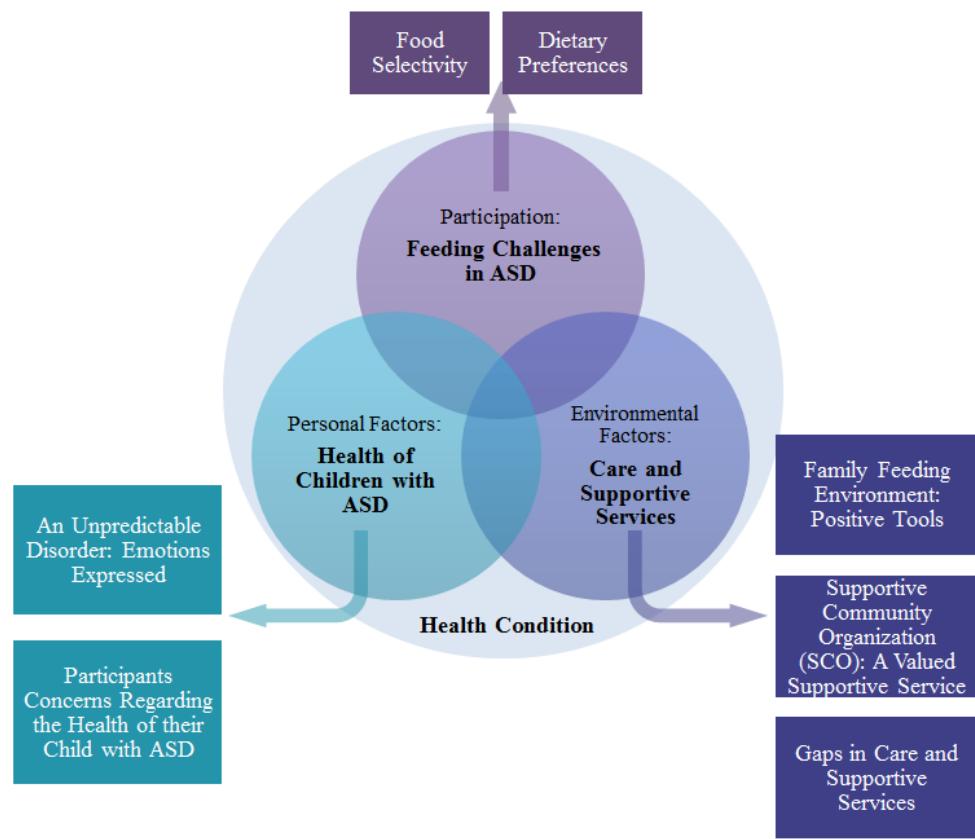


Figure 5: Schematic of the Findings

Note: The major themes of: Feeding challenges, Health of children with ASD, and Care and Supportive Services contain multiple sub-themes that were utilized to discuss and organize the study findings.

Table 1:
Participant Pseudonyms

Participant pseudonym	Child pseudonym	Background
Kayla	Tom	Parent /mother
Sasha	Kale	Parent/mother
Julie	Dave	Parent/mother
Claire	Elyse	Parent/mother
Liz	Maddox	Parent/mother
Bonnie	Bill	Parent/mother
Pam	Paul	Parent/mother
Fiona	Fred	Parent/mother

Note: A pseudonym of Supportive Community Organization (SCO) was used to represent the primary organization involved in this study. A pseudonym of Supportive Individual (SI) was used to represent the key health professional associated with the SCO.

4.1 Introduction to Themes and Sub-themes in this chapter

As previously stated, the WHO-ICF framework was utilized to understand the health condition of ASD. During analyses, themes and subthemes were used to explore each factor. The three main themes of this study include the feeding challenges of children with ASD, the concerns expressed by participants regarding the health of their children with ASD, and the care and supportive services provided to each child and their parents. A subtheme includes food selectivity and dietary preferences that are influenced by the participation of the child with ASD. A second subtheme pertains to personal factors that affect the unpredictability of the disorder and the concerns of participants regarding the health of their child with ASD. A third subtheme relates to the influence of environmental factors on ASD, including the SCO, gaps in care and supportive services,

and the family feeding environment. All themes and sub-themes were utilized to further explore the behaviours and environments experienced in children with ASD.

Importantly, it is necessary to acknowledge that the participants selected for the study had previously expressed concerns with feeding challenges in their child with ASD. The disorder is a ‘spectrum’ that results in a wide range of adaptive behaviour deficits (Matson et al., 2012); which includes feeding and eating difficulties. The children in this study were selected to represent the sub-population of children with ASD that experienced feeding-related challenges.

4.2 Feeding Challenges: A ‘REAL’ Food Fight

Participation refers to ones involvement in life situations and/or involvement in what an individual actually does (WHO 2001). Children with ASD have specific characteristics that influence their food behaviours and shape the feeding environment in the home. In this study, the dietary “participation” of each child with ASD, from the perspective of each parent, was explored to understand the feeding challenges experienced by parents in the home.

In the literature it is estimated that problematic mealtime behaviours were present in all children (Levin & Carr, 2001); and, that children with ASD have higher, yet unknown, feeding problems (Sharp et al., 2013; Shreck et al., 2004). There is a paucity of research in the literature describing the extent to which feeding and food behaviour challenges exist in children with ASD. During the interviews conducted in this study, parents of children with ASD were asked to answer questions about the food behaviours of their children and the feeding environment in the home. The findings suggest that food issues and feeding preferences of children with ASD may be a more significant problem

than what has been portrayed in the literature.

4.2.1 Food selectivity

In this study, purposeful sampling was used to select participants with ASD that had previously expressed feeding challenges. The majority of parents in the study stated that their child with ASD had a variety of restrictions to their diet, necessitating specially modified feeding environments. The dietary restrictions had a major influence on the lives of the children and their parents. Many parents expressed difficulties when trying to achieve a “normal feeding environment” in children with ASD. For example, Fiona, Liz, and Kayla felt that their children’s’ feeding challenges made it very difficult for the family to eat dinner at the same time. Although there are many challenges when raising a child with ASD, Lockner et al., (2008) suggested that more strategies are required to prevent food from becoming an issue that could disrupt family mealtimes. Parents in this study experienced severe feeding difficulties that go “above and beyond” what is referred to in the literature as picky eating. When attempting to understand food behaviours in pre-school children with ASD, food selectivity was considered and the findings are discussed below.

The majority of parents stated that their child with ASD had multiple issues with food selectivity (7). When providing specific information about their child’s diet, parents expressed significant concerns regarding food sensitivities. Food sensitivity includes specific food rejection or restriction due to type, texture, presentation, colour and/or taste (Sharp et al., 2013). When speaking about texture sensitivities, over half of the parents reported that it was an issue. Table 2 displays the variety of texture sensitivities experienced in the majority (5) of the children in the study.

Table 2:

Texture sensitivities reported in this study by parents that have a child with ASD.

Participant Number	Name (Pseudonym)	Type of Texture Sensitivity
2	Kale	Will not eat soft foods
5	Maddox	Will not eat mushy or mixed foods (Shepherd's pie is the only exception)
6	Bill	Will not eat foods that requires a lot of chewing
7	Paul	Will not eat any hard foods
8	Fred	Will not eat any food that is solid

The minority of parents (i.e., those who did not report texture sensitivities in their child with ASD) felt that their child had more general food aversions that they were unable to categorize during the interview. Importantly, all parents reported that their children had a wide variety of feeding challenges and a greater number of food selectivity issues, in comparison to children with typical development (TD). However, the data emerging from this study lacks consistency because no two children with ASD had similar feeding behaviours.

Lockner et al., (2008) suggest parents were more likely to report that their child with ASD was a picky eater, and that the children were resistant to try new foods, in comparison to children with TD. During the interviews, parents were asked if they thought there child was a “picky eater.” The majority of parents answered the question without hesitation, and their responses were overwhelmingly affirmative. For example, Claire responded with a laugh that was quickly followed by the statement: “Yes, that’s putting it mildly.” Liz, Pam, Fiona, and Sasha also described their children with ASD as “very” picky eaters. In this study, findings suggested that the children with ASD had

significant issues with food selectivity, and that feeding challenges were much more extreme than what was typically described in the literature as picky eating.

Furthermore, all of the study participants had multiple children. Participants often compared their children with TD to their child with ASD. For example, Fiona stated:

Um, my oldest is picky, too, but he, he knows he's gotta eat what's on his plate. Whereas, Fred [child with ASD] won't eat it. My middle child, he eats anything you give him... I mean with him [Fred] I have to make a second meal, almost every time.

A second parent, Claire, contrasted the feeding behaviours of her daughter Elyse (child with ASD), to her sister with TD. Claire described Elyse as “really picky,” as some days Claire makes five to six different meals when trying to get Elyse to eat. Claire (mother) also has a sister that has children with TD and she stated that discussing “picky eating” issues and feeding challenges with her sister would not be helpful. Claire felt that the feeding challenges experienced by Elyse (child with ASD), were not comparable to the challenges of children with TD.

Feeding behaviours in children with ASD were a significant problem in the study population, suggesting that the feeding-related challenges go “above and beyond” the picky eating issues experienced by parents that have children with TD (Rogers et al., 2011). One parent, Kayla, described her understanding of feeding challenges in children with TD and she went on to explain why her son with ASD did not demonstrate ‘typical’ food selectivity;

They [health professionals/people] don't take you seriously; they think when you say not eating, it's picky eater... And no...my kid doesn't eat, like he won't even

eat, he won't even try holding a French fry, he won't even be in the same area as French fries. Like the food court is bad news for us.

The findings suggest that parents' experiences with picky eating in children with ASD are different than food selectivity issues experienced by parents that have children with TD. Rogers et al., (2011) reported that children with ASD accepted a smaller variety of food items, had increased need for sameness, and experienced inconsistent food jags (foods are accepted and suddenly no longer accepted), in comparison to children without ASD. During interviews, food selectivity was reported as a serious feeding challenge that was commonly experienced in these families. Kozlowski et al., (2012) acknowledged that children with ASD presented increased feeding problems, in comparison to children with TD; and emphasized that these difficulties need to be assessed and incorporated into supportive care and service approaches. In this study, food selectivity was further explored to understand the degree to which possible dietary preferences are experienced by this population.

4.2.2 Dietary preferences

During the interviews, parents were asked to discuss the overall diet of their children with ASD. Table 3 represents a summary of the dietary preferences of each child at the time of the interview. The dietary preferences were documented as stated by the participant.

Table 3:

Participants' responses regarding the over-arching dietary preferences of their child with ASD.

Participant Number	Name	Age (years)	Sex	Overall Dietary Preferences
1	Tom	3	Male	Only eats baby food with a baby spoon of pureed banana
2	Kale	5	Male	Eats only salty and crunchy foods
3	Dave	2	Male	Has improved in things he will eat. He no longer has a limited diet
4	Elyse	5	Female	General food aversion, phases of dietary preferences
5	Maddox	5	Male	Gluten-free-casein-free (GFCF) Eats hard-to-medium textures
6	Bill	3	Male	Eats soft, solid foods or creamy textures.
7	Paul	2	Male	Only has 3 foods in his diet Soft, creamy textures
8	Fred	3	Male	Soft and dry foods Pureed baby foods

It is recognized that children with TD experience eating difficulties throughout development; however children with ASD are more likely to experience increased challenges (Martins et al., 2008). One study suggests that children with ASD have dietary preferences for sweet foods and sugary snacks (Evans et al. 2012); and that children with ASD consume few vegetables (Martins et al., 2008). Findings from this study did not provide enough data to support or refute the theory of increased dietary preference to sweet foods; however, the majority of parents expressed concerns related to the vegetable intake of their children. For example, Pam, Bonnie, Liz, and Sasha reported that their children would not eat vegetables; and the only strategy to get them to eat vegetables was by hiding them in their food and/or juice. Other mothers, like Claire, felt that vegetables

were important to include in her child's diet and she planned on hiding 'nutrients' in her daughter's food. This strategy of "hiding" or disguising vegetables in well-accepted foods was a common practice among all parents in this study, but it was not always successful for these families. Julie was the only mother interviewed whose son with ASD ate vegetables, and she felt that it was important for him to continue to eat them. The theory that children with ASD are habituated to sweet foods was not supported in this study (Evans et al. 2012); however, parents did report struggles when introducing vegetables and trying to get their child with ASD to accept these foods.

Food preferences had a major influence on the dietary intake of children with ASD. The magnitude and variety of feeding issues made it difficult to determine the dietary preferences or refusal patterns that were consistent in the study population. The feeding challenges of the children in this study were multifaceted, which made it difficult to intervene and assess each feeding challenge, in combination with other feeding challenges (Ledford & Gast, 2006; Rogers et al., 2011). In this study, patterns of food selectivity and dietary preferences were apparent in children with ASD; yet it was unknown if children of this population shared specific food selectivity patterns and preferences. Importantly, the degrees of these challenges were substantially more significant than what the literature has stated as an increased level of selectivity in the population (Martins et al., 2008). More research is necessary to determine if the feeding issues that emerged from this study are more pervasive in a representative sample.

Experiences of parents were explored when attempting to understand these severe feeding challenges. In previous research, parents often stated that their child with ASD accepted a very limited variety of foods and they felt their child was not a "healthy

eater”, in comparison to children with TD (Lockner et al., 2008). This study explored the emotions and concerns expressed by the parents regarding their child with ASD and their health.

4.3 An Unpredictable Disorder: Emotions Expressed

Personal factors associated with each child, with ASD, influenced how parents perceived the influences that food behaviour and the feeding environment had on the health of their children. Unique family structures in this study influenced the child’s level of functioning (WHO, 2002). This research explored the feelings and emotions of parents regarding the health of their child with ASD.

Unpredictability in disorder outcomes is one of many challenges associated with feeding behaviours in children with ASD. Autism is a spectrum disorder; therefore, it is accompanied by a wide range of severities in the behaviours of each individual. Multiple aspects of these children’s lives are unpredictable, leaving parents unsure of what to expect regarding the health of their children. Emotions were expressed by parents about the onset of ASD and related feeding challenges; and their feelings of frustration and lack of control were explored.

4.3.1 Feelings of parents: Onset of ASD and feeding challenges

Throughout the interview process, participants expressed feelings and experiences associated with the initial onset of their child’s disorder. It was important to note that the ages of the children in this sample could have been a contributing factor to the feelings expressed by each participant. During the interviews, the majority of participants perceived that their children had TD, prior to a ‘triggered’ onset of ASD; whereas the

minority of participants in this study reported observing consistent abnormal developmental milestones. The majority of participants (6) who noticed a regression regarding feeding behaviours in their child with ASD during early development also stated that they did not understand why or how the onset occurred. In one interview, Kayla elaborated:

....We actually noticed a big change in his eating pattern at that point. Um, for instance before the 9-month mark hit he was trying all different types of foods, all different colours of foods, all different textures of foods. He had no problems manipulating the foods with his hands, had no problem with it around his mouth and then once the 9-month mark hit it was like something happened and a switch... it was such a different experience for us because he stopped eating; he started withdrawing from the sight of food. He started having really bad... panic attacks when he smelt food, colours of food, he just totally changed.

Children with TD can experience limitations in food variety (Lukens & Linscheild, 2008); however, the descriptors obtained from participants in the study went well beyond ‘normal’ range. The underlying regressions of behaviours, including eating, that are linked to the development of ASD are unknown (Davidovitch et al., 2000). Unpredictable regression of feeding behaviours is a dominant concern expressed in over half of the parents in the study population (7). Parents were often confused about the serious food-related challenges associated with the disorder, as expressed by Bonnie:

...He regressed a bit in what he would eat and I'm not really sure why....Up until he was maybe 18-months or so, he [child with ASD] would eat strawberries, watermelon, he would eat some fruit. He was trying different textures and then, slowly, bit-by-bit, he wouldn't try it. Over time and...his diet has become progressively more limited. And now things that he used to eat, like, strawberries

and watermelon, he would look like he's being poisoned if I put one in his mouth. So I don't understand that [laugh]. That I don't really get, I just don't understand.

The unpredictable onset of feeding/eating problems in children ASD left parents in this study feeling uncertain about the health outcomes of their child. For example, Fiona noticed a change in her son shortly after 18-months. At approximately 19-to-20 months, Fred started to go "downhill" and his eating habits started to change. Fiona reported that he stopped eating solid foods as he became older; she was unsure if that had to do with him learning more about foods, tastes, and textures. Uncertainty as to why feeding regression occurred was a common concern expressed by study participants and would be a critical area of further study.

In the literature, the acknowledgement of regression increased feelings of guilt in mothers of children with ASD (Davidovitch et al., 2000). In the study findings, Kayla described feeling as if her family had missed a "window of opportunity" during her son's growth and development. She stated they missed the opportunity to introduce solid foods to Tom (child with ASD); which made it extremely difficult to get her son to eat and chew solid foods, as he grew older. Kayla stated that if she had received professional guidance earlier, at the time that feeding challenges were first noticed, she may have been able to help Tom when he experienced this sudden regression. The feeling of guilt was described by Kayla because she felt inaction during her son's development contributed to his current feeding challenges. She suggested that she did not act quickly enough when Tom's feeding problem surfaced.

The concerns of feeding and eating regression associated with ASD explained some of the emotions that parents experienced regarding the unpredictable nature of

the disorder, as well as the feelings families expressed about the potential health outcomes of their child. According to Rogers et al., (2011) parental concerns regarding ASD and feeding challenges are valid. The children in this study did not respond to typical feeding approaches, therefore, the concerns expressed by the parents need to be recognized, acknowledged, and further investigated. The parents in this study expressed a range of emotions regarding the difficulties when feeding, including the feelings of frustration.

4.3.2 Failures and frustrations with feeding

When discussing feeding challenges, parents were often frustrated with their inability to predict and improve these issues. These parents were feeling frustrated because they have tried many strategies and were unsuccessful with getting their child to eat. During interviews, participants were asked about strategies and tools used to assist with feeding challenges, the majority of parents stated they “have tried everything.” In reply to this question, Liz stated: “We have tried so many things!”

Parents expressed feelings of extreme frustration because they attempted to resolve feeding issues, often using multiple strategies. When asked about trying specific diets, Kayla reported trying multiple diets to improve her son’s eating, yet she failed every time. When asking Liz if there were strategies available that may help to change or improve her son’s feeding behaviours, she responded with; “I don’t think so. We’ve tried so much”. Constant failures in these families result in significant feelings of frustration, as supported by Claire;

...Cause you’re desperate and you just, at the end of the day, or the end of that moment, you just want your kid to eat something that’s healthier. And after you

sat there and made all these different meals, or you've made what they've asked, and they're just refusing it and you're just so frustrated. That's just what it comes down to, just frustrated. You just want them to eat something...

Claire felt that her daughter does not eat enough foods and she (the mother) also expressed desperation when attempting to feed Elyse. Multiple and unpredictable feeding challenges can pose significant problems for parents that have children with ASD (Kodak & Piazza, 2008).

Parents also discussed frustrations when extended family members introduced feeding strategies to their child with ASD. Children with ASD have stereotyped behaviours, requirements for sameness, restricted patterns, fixated interest, and hyper- or hypo-reactivity to sensory inputs in specific environments (APA, 2013). Therefore, there can be negative outcomes when other family members try to feed the child with ASD using approaches that are different than those used by the parents. The findings from this study suggest that these feeding issues require further explanation to understand if these feeding/eating challenges are a behavioural issue, rather than a feeding issue. In this study, Kayla expressed frustrations with her parents and, more specifically, how her mother thinks that simply putting food in front of her son, Tom, will get him to eat it;

Whereas, there's such a big disconnect between me and my husband, and my parents and [my husband's] parents....The grandparents of the child seem to just not get it. They don't get what we're trying to do; they don't understand that children with autism can have a really hard time with food. That they can be sensitive to both smells and sight. Even the way the food is presented, that's a big challenge. My mom will, will make mashed potatoes and she will just load it up with butter and all the goodness and stuff like that, and just plop it in front of Tom and expect him to enjoy it and like it.

It is extremely difficult when families have a child with feeding sensitivities and extended family members and/or caregivers do not understand the severity or nuances of the condition. During the interviews, parents expressed frustration when suggestions from others to improve feeding outcomes were not successful.

Failures and frustrations were also experienced when families sought professional help for feeding challenges. Liz had gone to see an occupational therapist to try to get her son to sit at the table and eat, and none of the approaches offered were successful for her son. Fiona reported that she has consulted many supportive service providers and has tried their recommendations, in hopes of increasing texture sensitivities in her son, Fred. In one circumstance a service provider suggested slowly adding more texture, referred to as “chunks”, to Fred’s pureed food to see if with modifying the texture, the child with ASD would become more comfortable with different foods.

I’ve tried that, as soon as they get to that spoon that has that [food he does not like], he will spit it out, and he will gag on it. I’ve even tried it the other day, it was really funny. The kids were having pasta with sauce and he was having pasta without sauce. So he has his pasta with butter he will only eat it with butter, I threw a few in there that had sauce, he saw it with his eyes, looked at it and said un-un. He just took them [foods he does not like] out with his hand and threw them on the floor. I’ve tried, I find they have the thought process to see that it’s there and they will take it out and they do not want to try it.

Fiona reported attempting to hide nutrients in her son’s (Fred) diet; however that feeding strategy, as recommended by a health professional, was unsuccessful. The findings from this study further support the need to understand whether the challenges experienced by the families in this study are a feeding/eating or a behavioural issue. Although they were

not always successful, over half of the parents in this study reported attempting to hide nutritious foods into their child's diet. Hiding "nutrient-dense food" was a common strategy used by the parents in this study to get their child to eat certain foods, yet many were unsuccessful. Parents reported that their children were very sensitive and noticed when their foods were changed or modified; which increased the feeding challenges experienced in children with ASD. According to Rogers et al., (2011) when feeding challenges were constantly experienced with children with ASD, mothers often resort to finding other ways to improve their child's nutritional intake. For example, mothers have reported "loading nutrients" into the foods that their child will eat (Rogers et al., 2011). In this study, Bonnie also used this strategy as best as she could to increase her son's nutritional intake:

I guess my big strategy is hiding or disguising things that are healthy in the few textures [of food] that he will eat. For example the juice, I'm able to put vegetables in there. Um when I bake I'll hide some vegetable in muffins or whatever, bake donuts. So ya, my main strategy... oh and in [his] cereal I put avocado in it and I put some omega three supplements. So, basically my strategy is hiding nutrition, in the very limited texture that he will eat.

"Hiding food" was a reported strategy used by the majority (7) of these participants; however, frustrations were expressed when discussing the failures experienced. Sasha would love for her son to increase his intake of vegetables; "Like it's the hugest thing. If I could just get him to eat some spinach once in a while [laugh] or something." Children with ASD often have characteristics that require a "need for sameness" in daily routines (Rogers et al., 2011). Study findings demonstrated that parents reported trying to keep foods consistent while attempting to hide foods in their child's diet. Sasha tried,

unsuccessfully, to “hide” (camouflage) nutritious foods, such as pureed carrot, into her son’s grilled cheese sandwich; he still noticed it and would not eat it. Other parents, including Liz, reported being unsuccessful when hiding nutritious foods in Maddox’s diet, particularly fruits and vegetables;

We do put bananas in his pancakes, so it’s just stuff like that. I have tried to make spaghetti sauce and put veggies in it but he won’t touch it. It’s like he knows there in there, right [laugh]. The pancakes maybe because we’ve always done it that way so he doesn’t know any different. But it’s like he can smell it and knows that there are veggies in it.

Fiona also expressed frustrations when trying different foods with her child.

...That’s an issue, but I’ve tried giving him raisin toast, nope he looks at it, and he, before he even tries to put it [in his mouth], he looks at it and sees something different. Either he’ll pick it out or he will just throw it away...I [child with ASD] don’t want it. I [Fiona] can’t be bothered.

Multiple attempts resulting in constant failures made it difficult for some parents to keep trying to introduce new or different foods to their child. The majority of parents have tried hiding nutritious foods; however failed attempts make it difficult to continue to attempt. Some participants reported, “sticking to what works” when getting their child to eat and resorted to this strategy largely to avoid the onset of other types of feeding problems. Pam reported that using the strategy of “sticking to what works” is the best way get her son to eat;

He’s too finicky... so that’s why a lot of times we just let him stick to his routine, cause I tried off the routine, I’ve tried stuff. Like I put spaghetti on the tray and he will just whip it or just looks at it, or plays with it.... It’s frustrating.

Martins et al., (2008) suggest that mothers of children with ASD had greater emotional responses to persistent feeding problems than mothers of children with TD; and mother of children with ASD have attempted more behavioural control practices to improve their child's eating habits. With the degree of feeding challenges experienced in this study, it is understandable that frustration was a common emotion expressed by parents. Participants' inability to predict when challenges will arise in their children and what they can do to improve their child's diet was a constant struggle for these families. It is important to remember that not all children with ASD have feeding/eating challenges; this study utilized purposeful sampling to select a portion of children with ASD that had these issues. Throughout this study, the inability to predict outcomes through a perceived lack of control over feeding was expressed by parents of children with ASD that had feeding/eating issues; and the influence of these feelings, when having a child with ASD, requires further exploration.

4.3.3 No control/Lack of control

During the interviews, parents expressed feelings of having little control over their children's feeding behaviours, including frustration related to what they can get their child to eat. Kayla expressed how in the early stages of raising a child with ASD, she took feeding and eating for granted;

It's, so broad...I didn't know that children with autism when we first started this journey could have this type of sensitivity to food. I had no idea; I kind of took it for granted that children just eat, when they are hungry they eat and they put something in their mouth and they chew.

As stated, the degree of these feeding challenges and the number of attempts these families have made, increase the feeling of having limited control over these issues.

Many parents were left extremely confused and stated that they could not understand the unpredictable aspects of this disorder, as elaborated by Sasha;

I still don't know what causes him to not want something so much more than not wanting something else. Like sometimes if he really doesn't want it, he'll look at it and gag. But sometimes if I offer it to him and he doesn't want it he'll still hold it in his hand and play with it, and then just throw it in the garbage. So sometimes, he's experimental with it, but sometimes [he's] just like NO.

In this study, unpredictability in the disorder decreased parental feelings of control. For example, Julie's son went through a period of time where he stopped eating all solid foods (i.e. he adhered to a liquid diet), and then one day, unexplainably, he started eating again. Julie strongly felt that she had no control over getting her son to eat. She explained that "he was the one; he decided to start eating... it all started with the peanut butter sandwich. He just scarfed it down as if he'd never seen food." In this study, all parents had other children with TD, yet they only reported serious feeding experiences with their child with ASD. The unpredictability of this disorder has left parents feeling that they lack and/or have limited control over feeding their children with ASD.

4.3.3.1 Dietary manipulation. The literature suggests that reoccurring feeding problems result in increased attempts by parents to control diet through dietary manipulation in children with ASD (Sharp et al., 2013). Kayla and the majority of other parents were not successful when attempting to control their child's diet.

Um, we've tried him on the gluten free, we've tried him on the casein free, we've tried him with no sugars, we've tried him with no additives, no preservatives, we've tried lactose, we've tried soy, we've tried rice milk, we've tried uh you know just basic, like we tried exotic, organic foods. Currently, no he's not, because he's not receptive to anything.

Sharpe et al., (2013) state that over the years there has been a growing interest in Complementary and Alternative Medicine (CAM) therapies, specifically dietary manipulations. There is no cure for ASD; therefore parents often resort to CAM therapies to improve their child's feeding behaviours (Marcason, 2009; Whiteley et al., 2013). In this study, participant Kaya has gone to extreme measures to control her son's diet with the goal of expanding his dietary intake. She discussed the use of hunger inducement, an approach that limits food intake in a child with ASD, with the hopes of circumventing more serious feeding challenges;

...I also go and see, a Doctor....a lot of people don't like him because he's aggressive like that, but his thing is hunger inducement. We've tried that, we've tried hunger inducement with Tom. He went a whole week without eating, he would have formula at nine thirty at night and that was the only thing that he ate. And he dehydrated himself five-times outa that week and so were back into [the emergency room], back-and-forth, back-and-forth. And so then we decided to take him off the hunger inducement and just feed him, [the] Doctor says that sometimes the hunger inducement works and you just snap out of it. They're so hungry and they're so ravenous for food that they'll overcome all of their sensory obstacles... and it works for some children, and doesn't work for all of them.

The literature suggests that dietary manipulation is used as a strategy by parents and that there is very little empirical evidence to support that this approach is efficient

when used on children with ASD (Elder, 2008; Whiteley et al., 2013). When speaking to participants about dietary manipulation, specifically the use of the gluten-free-casein-free-diet (GFCF), the majority of study participants reported trialing this diet. Bonnie stated that she used the GFCF diet for three weeks, and then abandoned it. Sasha reported that she used the GFCF diet and noticed that her son's intake had decreased: "Like his quantity was like going way down, because he wasn't eating it, so we switched him off." Claire also used the GFCF diet; however she has always had a hard time controlling her daughter's diet and could not keep her on the diet;

Ya. I meant.... It's hard sometimes she, because she so picky sometimes we just cave like if she, if she sees something that I'm eating and she really wants it. But she won't have the other 15 choices I've made for her lunch or something, [mom says] fine just eat it.

During the interviews, only one parent reported using the GFCF over an extended period of time with her child. Maddox was on the GFCF diet and his mother believed that the diet has helped him with feeding and health issues. However, there is a paucity of literature available to supports this theory (Marcason, 2009). This research, although limited, supports the findings reported in the literature that dietary manipulation (e.g., GFCF diet) is not a successful intervention to be used on children with ASD.

4.3.3.2 Best practices of Feeding Children. According to Ellyn Satter, a family therapist, Registered Dietitian and feeding specialist of children with TD, parents are responsible for *what, where, and when* feeding takes place and children are responsible for *how much and whether* eating will occur from what parents offer (Satter, 1999). In this study, many parents were following recommended child feeding practices, however, in contrast to Satter's recommendations, without exception, participants felt they had no

control over *what*, *where* and *when* feeding took place. For example, Bonnie experienced challenges when introducing new foods to her son;

Like 99%, there's lots of thing's...vegetable, fruit he won't eat. If I try to put them on his mouth he will immediately spit them out and look like he was being poisoned. Even things like pizza, bread; he won't put those in this mouth at all.

Bonnie reported that she was almost always unsuccessful when offering food to her son, influencing her feeding responsibility and *what* is provided to her child. Other parents expressed concerns related to the lack of control when feeding their children with ASD.

Liz reported that her son used to love drinking almond milk and suddenly stopped liking it; expressing her lack of control with her son's feeding behaviours. Claire described her daughter as having a "general food aversion" and noted that the child had phases of liking foods;

She, one day she'll, she goes through phases of things. So she might love pizzas and she'll eat them and then just one day she's done, she won't touch them again. And it's really frustrating to feed her because sometimes we'll have to go through, three, four, five different meals. And we'll ask her.... What do you want? And she's like peanut butter sandwich.... Okay I'll make it for you. I make it and she's says "these are gross." ... So it's really hard to find something that she'll eat.

The perceived lack of control made it difficult for families of children with ASD in this study to be responsible for *what*, *where* and *when* feeding occurred. Parents had little control over their responsibilities in what Satter (1999) calls the "*Golden rule of feeding*". In this study, Bonnie and Julie reported being "happy for [their child] to eat anything", or being "lucky enough [to get them] to eat." Study participants recognized and understood that they could not control what foods their child consumed, and were

happy that their children were ‘just eating.’ This was important to consider because recommended feeding practices may not apply to children with ASD, in comparison to those without ASD. As well, the severity of ASD often influenced the effectiveness of these feeding practices. This aspect of severity of ASD was further explored in the findings of this study.

4.4 Participants Concerns Regarding their Child with ASD

Parents in this study discussed their experiences with food behaviours and, more generally, the feeding environment in the home. The majority of parents expressed many emotions, often conflicting, including concerns about the current and future health status of their child with ASD. When asking participants about their children, feeding behaviours associated with health risks, including overweight, obesity and underweight, were considered. Particularly, the child’s height in proportion to their weight.

Partly, as a result of the challenging food-related behaviours and stressful feeding environments, parents had serious concerns regarding the immediate and longer-term health outcomes of their children and how the severity of ASD was understood and acknowledged by others.

4.4.1 Health of their children

During interviews, parents were asked about the current and future health of their children. Questions explored alternative health practices and risk factors, including comorbid conditions. Additionally, parents were asked whether their child was taking prescription medications. These questions did not yield sufficient responses from the parents in this study to draw a conclusion. As discussed in the literature, medical

treatments are often used to improve mood disorders, hyperactivity, and problematic behaviours (McPheeers et al., 2011). The majority of children in this study did not have a comorbid condition that affected their health. Additionally, the majority of children in this study were not taking medications for symptoms of ASD. Comorbid conditions and medications were not a major concern of these participants, however parents expressed worries related to the current and future weight status of their children.

4.4.1.1 Current weight status. When asking parents if their child was at a healthy weight for their age, parents appeared unsure about how to answer the question. Many had conflicting perceptions of their child's weight vis-à-vis their health. For example, most parents were not concerned about the current weight of their children. Interestingly, the majority of parents (6) acknowledged that their children were "quite skinny" and underweight for their height. Liz said; "Um, I wouldn't say he's unhealthy but he probably... could use a little bit more chunk." Claire further elaborated, "She's skinny, I would say she's skinny, but I'm skinny and her father's skinny as well. So she's pretty much guaranteed to be on the skinny side."

Parents often referred to doctor's opinions and their children's placement on growth charts when asked about the health of their child. Refer to Table 4 for the most recent measured record of each child's height, weight (from their medical file), body mass index (BMI) and weight classification, according to the International Obesity Task Force (IOTF). Liz said; "He's at the 15 percentile for his weight and his height, but at least it's equal so they [doctors] don't have any concerns for him." Bonnie responded; "At his visit he was at the 50th percentile for both his height and weight pretty much, so... he's average [laugh], he's not below average." Sasha and Pam both reported that at

their last check-up their doctors told them their children were in the normal range for growth. To conclude, parents were able to acknowledge that their children may be underweight, yet the child was at an appropriate weight, in regards to their height.

Table 4

Body Mass Index (BMI) Calculations of each child with ASD in this study.

Child pseudonym	Age (Years, Months)	Height (cm)	Weight (Kilograms)	Body Mass Index (BMI)	BMI Classification
Tom	3, 10	87.5	12.5	16.3	Normal Range
Kale	5, 4	115	22.6	17.1	Normal Range
Dave	2, 3	89	13.2	16.7	Normal Range
Elyse	4, 7	96	14	13.2	Normal Range
Maddox	5, 4	103	15.6	15.6	Normal Range
Bill	---	---	---	---	---
Paul	1, 12	81	17.2	17.2	Normal Range
Fred	---	---	---	---	---

Note: Age used was calculated using the Date of Evaluation and the child's Date of Birth. BMI Values were interpreted using the IOTF cut-offs for thinness, overweight, and obesity in children

When discussing the current weight status of the children in this study, the majority of parents did not express concerns. A minority (2) of parents, who have sought assistance from health professionals, feared that their children were underweight and expressed serious health concerns regarding their child's weight. For example, Fiona thought her son was underweight for his current age; "...for his height, I mean, if you take off his clothes, he's a toothpick...he doesn't have an ounce of fat on him." Another

mother who experienced serious feeding challenges with her son, including very limited dietary preferences, expressed concerns with his physical development:

Like...when you look at Tom's structure, without, his clothes on. You can see his ribs, his bones, his joints; you can see all of that. I think I'm a little bit concerned too about ...how that's affecting his, his physical structure. Because he sometimes grabs his knees and just rubs them. I don't whether that's a tick or if that something that's...

When asking parents about the current weight status of their children, the majority of parents acknowledged that their children were underweight and expressed little concerns regarding the relationship of underweight status to negative health outcomes. However, the height and weight presented in table 4 demonstrates that the children of this study were at a normal weight, in regards to their age and height. Parental perceptions are important to consider when exploring the weight status of children with ASD, and future research should explore this. Doolen et al., (2009) suggest that misconceptions occur when parents are determining their child's weight status. Misconception is a term used when referring to a "disconnect" in parental perceptions. When attempting to understand the health and weight status of children, there is the possibility of misconceptions in parental perceptions (Doolen et al., 2009). Therefore, when exploring the current weight status of children with ASD with feeding/eating challenges, future research is required to understand the extent to which misconceptions are experienced in parental perceptions.

According to the literature, children with ASD are at increased risk of overweight and obesity, in regards to height and weight (Curtin et al., 2010). However, in this study, the majority of the parents expressed greater concerns related to underweight issues in their children, in comparison to overweight issues, likely due to their current situation

where they are experiencing food and feeding environment difficulties. Importantly, the population of children with ASD selected for this study had previously existing feeding issues that may contribute to parents' concerns regarding their weight status. Therefore, the perceived health status of children with ASD in this study was inconsistent with what was predicted in the literature, due to the sample population selected. Additionally, many parents in this study reported serious feeding challenges in their children and perceived their child fit into the category of normal weight or underweight. According to the BMI calculations and categorization using the IOTF cut-points, all of the available participants were in the normal range for weight, in relation to age and height. Future research is required to understand if the feeding challenges experienced in these children are a nutritional issue. It is acknowledged that an in-depth assessment completed by a Registered Dietitian should be included to ensure each child's diet is nutritionally adequate. If children are in the 'normal' range for their weight they may be attaining adequate energy and nutrient intake; therefore, in follow-up to the nutritional assessment, the approach taken to assisting the families of children with ASD may not require a Registered Dietitian. Possibly a behavioural expert would be better qualified to develop strategies to assist parents during mealtimes, or, parents would require assistance from both (i.e. behavioural expert and Registered Dietitian). Discussions regarding the differences in the outcomes of this study were further explored in the conclusions, recommendations and personal reflections chapter.

4.4.1.2 Future health status. Participant perceptions regarding future health concerns in their child with ASD were also explored. Parents were asked about future weight concerns of their children with ASD. The continuation of feeding challenges

posed concern to parents over the long-term. Parents suspected that their child would develop a weight issue if their child's poor eating habits were to continue, or get worse over time. Longitudinal research is required to further explore the concerns expressed by these participants.

The literature suggests that there is a high risk of overweight and obesity issues in children with ASD (Curtin et al., 2010). The risk of this problem will increases over ones lifespan, if obesity or overweight status are present during childhood (Agras et al., 2004). Although, parents in the study expressed little concern for current health problems, few parents (2) expressed concerns regarding future overweight status in their children. Liz and Pam were the exception -- both felt that their sons could become overweight because other family members were overweight; importantly, they were not overly concerned with this becoming a problem. In this research, findings were incongruent with the literature suggesting increased weight status in this population. More parents expressed greater concerns for the development of underweight status in the children of this study, as indicated by Claire:

Elyse tends to be on the skinny side so when she has these phases where she doesn't eat I kind of want to encourage her to because she doesn't have a lot of weight to lose.... So if she's going so long without eating enough ...I worry about her.

Due to the unpredictability of this disorder, parents experience challenges anticipating the nature and/or timing of future feeding challenges with their children. Furthermore, the physical health consequences of extreme food limitations were unpredictable. Bonnie expressed concerns regarding the limitations in her son's diet and questioned whether

current and/or future food challenges could result in short-term and long-term health problems. She felt that the limitations in her son's diet and actual food intake could cause significant problems: "It's very, very limited, [laugh], what he eats so if he doesn't add some new foods to his meal plan... yes there could be issues there." This further supports the need for supportive services to be offered quickly to assist these families with feeding issues, in order to prevent these problems from progressing or getting worse as children with ASD develop (Popli et al., 2013). Fiona expressed her concerns regarding the risk of underweight developing over a lifespan. She felt this may have a major effect of the health of her child once he reaches another growth period;

...I've been to the [SCO] or [other supportive services] or my doctors asked in the past. I said it's the same thing; he's just a very picky eater....This is what he will only eat in his diet, anything else he does not want...and as he gets older... you're growing your body needs more nutrients. I mean what's in that baby food jar for a 8 to 10-month-old baby, I don't think it is [his current food intake] going to be, sufficient for him when he's 3, 4, 5-years old. He's like a toothpick so as he grows older and goes through another growth spurt he's gonna look like he's, severely underweight...As he gets older and becomes more active, he's gonna need a higher calorie intake but if he's not taking it [food].

The unpredictability of this disorder leaves families unsure of when the next feeding challenge will arise, that could result in negative health outcomes in their children. Food limitations and the risk of underweight issues were a major concern of parents, particularly when children in this study go through growth spurts during development. Lastly, these feeding challenges become very worrisome when families fear life-threatening outcomes, as stated by Kayla;

He's [child with ASD] just so tiny, like he's just really tiny. And I'm afraid if he keeps going the way that he's going; he's just going to be so malnourished that his brain is not going to develop. His body is not going to develop. It's going to be much harder for him, to just exist in society, he's not healthy when you look at him....I'm afraid that in a couple of months, or a couple of years. If he keeps going the rate that he's going, he could be considered "failure-to-thrive".... For us that's what we're trying to avoid.

The behaviours of the children in this study have had a major influence on the concerns expressed by parents about the health of their children. Weight issues, over long-term become a growing health concern in this population (Curtin et al., 2005). Food limitations from food rejection and refusal increase parental concerns when asked to consider the short and long-term health outcomes of their children, including weight. Similar to children with an intellectual disability (ID), children with ASD have a greater risk of deviation from a normal weight status (Emerson, 2005; Lloyd et al., 2012). When attempting to understand the feeding challenges and health outcomes in this study, parents reported that severity of ASD is another important aspect to explore.

4.4.2 Severity of ASD and feeding challenges

Eating behaviours of each individual differ during growth in childhood, and the severity of ASD. This study was developed to represent the sub-population of children with ASD that experienced feeding difficulties. The variety of feeding difficulties experienced in this study need to be acknowledged. Children with ASD have a unique developmental process, as compared to those with typical development (TD); and comparing certain behaviours would be inappropriate (Xiong et al., 2007). Research states that children with TD experienced problematic mealtime behaviours during

development (Levin & Carr, 2001). Importantly, the findings from this study concluded that the parents of this study have different opinions regarding the struggles of children with TD, in comparison to those with ASD. Claire clearly stated how feeding behaviours and food environment are not easily translatable to those with TD.

...So ya, it would be nice to see what other people are doing and people I can talk to, my sister, she's got three kids. But they're three typical kids so what she suggests may not work and even, I mean it's hard, and I don't want to just say. It's hard to figure out what is ASD and what are 5-year old behaviours.

Children with ASD experience an increased number of feeding problems than children with TD (Kozlowski et al., 2012). It is important for parents and/or health professionals to acknowledge that feeding difficulties are experienced differently in children with ASD. Additionally, attempts to improve these feeding strategies were approached differently by the participants of this study. Liz explains that she used specific food strategies with her children, for example, food rewards, yet she would not use the same approach with her son that has ASD, Maddox

I have three different children so I don't use that [food rewards] with Maddox. I use that with my older son so I do agree with that statement I just don't agree with it with Maddox. Because he has autism and he doesn't understand everything as a regular child, [I will] say it that way.

This was important to consider because in this study parents explained how methods used to modify food-related food behaviours in children with TD were not as effective when used with children with ASD.

There is no universal approach to managing the challenges experienced by children with ASD (McPheeters et al., 2011); this research supports the need for

individualistic approaches to improve the feeding behaviours in children of this population. When asking participants for suggestions on areas that researchers should consider when attempting to understand the feeding behaviours and food environments of children with ASD, multiple parents echoed Sasha's concerns: "The level of autism I'd say, because I feel like it varies. Like from children who are mild to severe". Therefore, it is important to acknowledge that severity resulted in different behaviours and feeding environments in children with ASD. When discussing her experiences when feeding a child with ASD, Julie described how children with ASD are all different and some are "more finicky" to flavours and tastes.

The characteristics of children with ASD are different from children with TD (Xiong et al., 2007). When asked about their child with ASD, half of the parents in this study stated that researchers need to understand that their characteristics are different. More specifically, a variety of unpredictable behaviours were present in children with ASD. For example, Kayla's son reacted differently when introduced to new foods using a specific approach, in comparison to another child with ASD;

Not all children with autism interact with food the same way and not all children with autism, enjoy the food the same way. Ya, like I've seen some children who enjoy playing in food. They won't eat it but they play in it and its cool, it's really cool to watch; but my son, not ever, not even a little bit. Not even enjoying it, like when we put his hands in the pudding to play around with it, to hopefully get him use to that sensation. He's just terrified, he's terrified.

Characteristics of each individual with ASD are unpredictable, and severity levels in each child are all different (Rogers et al., 2011). Therefore, it is important to understand the health of children with ASD and the level of severity of the disorder in each individual.

Additionally, future research is necessary to understand the characteristic of ASD from a larger, representative sample.

4.5 Family Feeding Environment: Positive Tools

Environmental factors were explored to understand how these relationships influenced disability and function in children that have ASD (WHO, 2002). This section was shaped by both participant involvement and personal factors. This study explored environmental factors through the use of food behaviour and feeding environment strategies when providing care and supportive services to children with ASD.

There were multiple food behaviour and feeding environment challenges experienced in the study population, and parents identified strategies that have helped to create a positive environment during mealtimes. For example, screen time and family role models were two tools used to increase positive food behaviours in children with ASD.

4.5.1 Screen time

Families need to create supportive mealtime environments that allow their children to gain control over their food intake (Sigman-Grant et al., 2011). Feeding was identified as a major challenge experienced in the participants in this study. Interview questions were developed to explore whether screen time assisted with feeding during mealtimes. Screen time included the use of electronic devices during meals, for example: the use of a television, iPad and computer. Findings suggest that participants have employed screen time to assist with creating a positive mealtime environment for their child with ASD. Sasha, one of the participants, discussed how she uses screen time to assist with the preparation and clean-up of meals. This technique was part of a “feeding”

routine that has become a familiar part of Kale's life. Sasha described screen time as "their main motivation to get him to eat."

Yup, so while I'm getting dinner ready he'll be. We have the computer set up on the kitchen table, so he'll play his computer game and I'll make dinner... and then once it's ready I'll close the computer and I offer him his dinner. By now he knows the routine, so close the computer. He eats his dinner, once he's eaten like $\frac{3}{4}$ of it, at least, I'll let him open the computer and he can finish eating it... if he's struggling with it. But most of the time he'll finish it all and then he gets his computer back.

This feeding technique assisted with encouraging Kale to eat during meals. Over half of the parents discussed using screen time during meals and the positive influence it had on reducing feeding challenges. There is a paucity of literature available regarding screen time and the positive outcomes this tool can have on families of children with ASD.

During mealtimes, parents of children with TD are advised to limit the use of screen time to decrease distractions, and to create opportunities for modeling of positive food behaviours (Health Canada, 2014; Satter, 2000). However, in this study screen time was identified as a tool that assisted with feeding challenges, created a less stressful feeding environment and was used as a distraction when feeding children with ASD.

4.5.1.1 Decreasing environment stress. The majority of parents identified that screen time created a less stressful mealtime environment; however, few (3) participants felt that screen time was not useful. Liz did not think that screen time was helpful when feeding her son, yet a successful feeding strategy involved her son (with ASD) sitting and eating on the couch in the living room with the TV; "The TV's on all the time because he loves [TV] and I can't turn it off with him freaking." Liz's response suggested that she

did not make the connection between “sitting on the couch” and “watching TV.” Liz was unable to recognize this strategy as a successful tool that helped to decrease environmental stress during meals and stop her son from “having a behaviour” when trying to get him to eat. Although, some parents underestimated the benefits of screen time, the results from the study suggested that over half of the parents used this strategy as a positive tool when feeding. Participant, Bonnie, was able to identify a significant improvement in the environmental stress level when she introduced screen time to her son during meals;

I think that once we starting letting him watch those music videos, when he’s eating. That seemed to improve meal times and just make it more peaceful and less pressure on him and on us, cause he was relaxed and enjoying himself and if he puts a couple things in his mouth that was good. So that was one strategy cause before we just tried...let’s all sit down and have a nice family conversation but ya that’s not really helping him and he just wants to get up and go cause he’s very active otherwise, so.

During the interviews, multiple parents discussed using screen time to improve the feeding environment. When exploring the literature for positive outcomes and the use of screen time during feeding, results were extremely limited. The literature available often focused on the negative outcomes of screen time use during meals. Importantly, in this study parents reported using this strategy to develop and maintain a positive relationship with their child and other family members, in an attempt to establish healthy mealtime routines.

4.5.1.2 *Creating a distracted feed.* Parents also discussed using screen time to create a “distracted feed.” Multiple parents elaborated on using screen time, such as

computers, television and iPads to encourage their child to eat. Kim, resorted to using screen time with her son; “Um, sort of the distracted feed where you have the iPad and feed him the cereal [laugh].” Claire is another participant who used this approach to “sneak” food into her daughter, without her “having to fight for every bite.” Claire, and other parents, also used screen time to assist with snack times:

...If she, let's say she comes home from school and she hasn't eaten a lot of food in her lunch. She can have a snack while she's watching TV. Or sometimes she'll eat her dinner out there, cause I think they kind of zone out, kids' zone out so they just keep eating.

This approach was used as a way to “basically keeping him occupied,” stated Fiona, when elaborating on the use of this technique. The positive feeding strategy has assisted parents when trying to keep their child busy and occupied during feeding; in an attempt to decrease the constant “food fight” experienced in the participants in the study. The literature available often recommends that families, with children with TD, do not use this approach when feeding or eating (Coon, Goldberg, Rogers, & Tucker, 2001). Yet in this study, screen time was a successful tool used by parents to get child with ASD to eating during meals. Parents and families have a significant role to play when developing healthy behaviours in their children (Ha et al., 2010). This research supports the importance of future research when investigating successful strategies for families. In addition to screen time, role modeling was another successful tool used in this study to improve feeding challenges.

4.5.2 Role models

Role modeling can have a major influence on the development of social and supportive feeding environments (Sigman-Grant et al., 2011). Multiple factors can influence the feeding outcomes of children with ASD, however in this study, dietary relationships, developed through familiar role models, were beneficial in creating positive mealtime environments. These model behaviours increased when families were able to eat together and develop appropriate mealtime manners, and when specific role models helped to teach eating behaviours to children with ASD.

During the interviews, some participants were not aware of the influence that their family eating practices had on their child with ASD. When asked about their experiences with role models, the minority of parents were skeptical and did not think it was an approach that would be successful with their child with ASD. Claire is one participant who felt that role models would not work with her daughter (with ASD); “I’ve tried but it doesn’t always work, because she’s pretty headstrong I guess.” However, during the interviews some skeptical participants provided great examples where role models assisted in creating a supportive mealtime environment. For example, Bonnie described, yet was unaware of the impression her sons’ father had on modeling specific feeding outcomes.

We will put it out in front of him, and he will not eat it [laugh]. That’s pretty much it. Every now and again he might see something, like just recently he started to eat rice crispy squares, which is a different texture for him. Only because his dad eats them all the time he just started eating [the rice crispy squares]....He took it off his [fathers] plate and started eating it.

This research explored the use of specific role models and their ability to positively influence mealtime manners in children with ASD. Findings concluded that familiar role models have a positive influence on the children in this study.

4.5.2.1 Specific role models. There were two specific types of models that were used to increase mealtime success. Parental models have a role in improving food preferences and eating behaviours in children because they influence many factors in the home environment (Kral & Rauh, 2010). During this research, role models had a positive influence on at least half of the families. Participants interviewed were the primary caregivers of the children in this study, and were responsible for providing food and feeding their child. Sasha discussed using her son's father as a role model when getting him (her son) to eat certain foods:

A lot of times if he's not eating or if he's being resistant to eating we'll say that it's his daddy's favourite food and as soon as you say its daddy's favourite food, he'll be like that's daddy's favourite and then he'll take a bite [laugh]. Doesn't work for everything, but sometimes it works.

Other examples included Fiona's son, Fred, watching his father prepare and make soup for his siblings. Fred then proceeded to ask his father to try the soup. Although, Fred did not end up liking the soup, the models around him may have influenced his desire to try the new food item. The use of models was not always successful in the families in this study; however parental models have been able to change their child's opinions and influence their decision to try different foods. The statements previously presented provided examples of positive dietary relationship that have been established, through role models, in these families.

The second specific role model explored in this study was the use of sibling models. Parents focused on siblings as role models, in an attempt to develop positive eating and feeding behaviours in children with ASD. Kayla explained how she often used her son's sibling as a role model, because the two children often ate foods at the same time;

Well my husband is away lots of the time so it's usually just me and Tom and [his baby sister]. And, with Tom I can't really eat myself and feed him and then feed [his baby sister] as well. So it's usually the two of them that are eating, which is kind of good because he's got that model, because she'll try anything.

Sibling role models help to create social interaction during mealtimes (Salvy et al., 2008). In this study, these methods were not always successful in getting the child with ASD to eat and like every new food they tried. Importantly, sibling role-modeling did influence experimentation with different foods. Sasha explains how she used Kale's little brother to influence Kale's eating behaviours:

Kale has a little brother who's a year-and-a-half-old, and he eats everything. So I've been using that as like...oh look what [your little brother] is eating. And then I'll make them both, and Kale a smaller portion cause I know he's probably going to waste it. But he'll kind of just like feed [his little brother] and play with it [the new food] a little on his own. Sometimes he'll taste it, sometimes he'll put it to his mouth, but most of the time he won't eat it either.

Social engagement and social reinforcement can influence dietary diversity in children with ASD (Sharp et al., 2013). Dietary relationships are important when trying to help children with ASD develop positive feeding behaviours. Models in this study were also used to influence feeding outcomes in children during meal. When children are

surrounded by a familiar co-eater, they are influenced to eat or to try more foods (Salvy et al., 2008). Therefore, in this study sibling role models established and influenced positive family mealtime environments.

4.5.2.2 Role models to develop mealtime manners. Healthy eating habits in preschool aged children are primarily influenced by parental practices and family environments (Etelson et al., 2003; Sigman-Grant et al., 2011); which help to establish trust and influence healthy eating routines (Sigman-Grant et al., 2008). Sibling and father/parent role models were used to develop positive mealtime manners, and in multiple cases the parents reported using family members to develop healthy mealtime manners. This trusting relationship in families has enhanced and established healthy feeding routines in the children in this study. Julie provides this example to demonstrate how meals are eaten in their family:

So ya, he's seated when he's eating. Like no running around eating... no body is allowed to run around and eat cause we don't want to teach him or the older ones can't teach the younger ones that...if they're running all over I can't see them if they're going to choke. I can supervise them better.

Dave was able to follow the examples led by his siblings and mother during meals. Eating as a family is another way to establish supportive mealtime environments (Sigman-Grant et al., 2008). Multiple parents in this study supported the idea of eating as a family to increase positive mealtime behaviours. However, difficulties associated with the behaviours and requirements of their children with ASD made it difficult for their family to achieve this positive mealtime strategy. Bonnie elaborated on this statement;

Basically, so we have a 1-year-old as well. So they will sit at the table together and I tend to play kids songs on YouTube. So they will watch a little music video of kids' nursery rhymes and they will sit together and they will have their plates of entirely different food, cause they don't really eat anything the same. And at supper time it will usually be all of us sitting down, the four of us... It probably would be better if we all sat down together more for meals, but I just find because everybody in the family eats something different, the baby, Bill, my husband, and I. It's a little chaotic... [when] making food. And so probably if it were more consistent and calm that might help him, I'm not sure what things would help him try new foods. Even when he's exposed to new food he has no interest in trying it, so..

Bonnie understood the importance of using sibling models and eating as a family, yet the circumstances of her family environment do not always make it possible for the family to eat at the same time. Sasha also expressed concerns with wanting her family to eat together. She felt that eating as a family was not always possible and acknowledged that it was "a really big thing." She felt that if Kale saw their family eating different foods during meals, he might increase his willingness and/or interest in trying new foods.

Chaotic feeding environments experienced during mealtime have influenced the families' dietary relationships and their ability to eat all together. Evans et al., (2012) suggest that there is a strong relationship between the eating patterns and the dietary preferences of families and the child with ASD. In this study, the majority of participants (7) wanted to see improvements in this feeding environment and hoped that they would be able to eat as a family in the future. One parent was able to achieve a consistently positive family eating environment and the majority of participants reported that eating together as a family was often a rare occurrence, as elaborated by Fiona;

Last night it was a quick dinner, we decided to make a breakfast dinner, there was pancakes, we make hash browns, we made scrambles eggs, we has toast. He ate pancakes that I made. So he was sitting down eating, by himself on a chair and I was able to eat dinner by myself too. So it is once every 2 weeks that that will happen, where he [Fred] will eat himself.

Sigman-grant et al., (2011) stated that it is important for families of children with TD to develop supportive feeding practices. This research reinforced the idea of creating positive environments in children with ASD. Evans et al., (2012) suspect that dietary patterns have an effect on the relationship of families and their child with ASD. This research provided sufficient evidence that social environments in this population influenced behaviours, such as eating. Although the influences of these beneficial feeding practices were underestimated and may go unnoticed, this research highlighted the positive experiences in these families. Findings from this study, and future research, will help to enlighten parents about the positive impression role models can have on dietary relationships and the family environment. In this research, the family feeding environment was further explored to determine successful approaches used to assist with feeding challenges, and the services offered to children with ASD and their parents.

4.6 Supportive Community Organization (SCO): A Valued Supportive Service

This research partnered with the SCO for the recruitment of participants. This facility offers a wide variety of services to families of children with special needs; including children with ASD (Supportive Community Organization [SCO], 2013) Participant's experiences and involvement with this facility was explored to understand

the effectiveness of the services offered to the families. During interviews, participants portrayed the SCO as a respected service that has assisted their families.

During each interview, participant portrayed the SCO as a valued service that provided a wide range of services to children with ASD. These services include, and were not limited to Applied Behavioural Analysis (ABA) support, dietitians, medical professionals, and occupational and speech therapists. This facility provided a place for these families to seek support from individuals who understood the dynamics of the disorder and recognized the influence that ASD had on families.

All families reported that they were receiving or waiting to receive services and/or awaiting their next block of services from the SCO. During the interviews, parents provided specific examples where individuals at the SCO were able to help with feeding behaviours. For example, Julie and a health professional at the SCO were able to get her son off of his bottle.

At about, a year-and-a-half. Cause I think his speech therapist at [the SCO] recommended that. She said instead of the bottle to Sippy-cup, try bottle straight to the cup with the straw and then... Ya, he likes it like that.

When addressing food behaviour and feeding environment challenges, parents reported discussing their problems with professionals at the SCO. According to Sigman-Grant et al., (2011) supportive feeding environments are successful when they enhance development, establish routines, and maintain trust. Liz reported how the SCO staff helped to get her son to use a fork and other utensils when eating meals. Parents also sought suggestions from the SCO staff on how to improve certain behaviours. Claire stated that she would like her daughter to improve her focus level when eating. She noted

that a sensory chair (an individualized device used to complete a targeted task, while providing sensory stimulation) was recommended to her and was hoping that this approach would improve her daughter's eating habits. Parents also noticed improvements in other behaviours, because of the services that were provided by professionals at the SCO. Fiona described how a combined approach with the SCO and private care has helped to improve her child's speech; "So he's improved greatly, I think it's between the combination of going for speech therapy, he's in private IBI [Intensive Behavioural Intervention], and being in a preschool setting one day a week for social skills and interaction with other kids." The organization [SCO] was a valuable resource to parents and has assisted families with many challenges, including feeding, when having a child with ASD.

Multiple strategies, treatments, and methods have been used to improve the quality of life in individuals with ASD (McPheeters et al., 2011). The SCO offers a wide variety of tools and services that have improved the challenges experienced in these families. Success stories are important to consider when addressing problems experienced in this population. Additionally, successes help to educate the SCO about effective services and recognize where assistance in supportive services are required.

4.6.1 Supportive Individual (SI): A Lifeline for the families involved with this study

The SCO employs health professionals who provide support and care to families of children with ASD. When talking about the SCO, families were very particular about specific individuals that have had an important role in their child's life. Among these professionals was a specific supportive individual (SI). These families have great respect

for the SI and rely on her for her diagnosis, care opinions, and a complete understanding of each parents' challenges. In many ways this SI was a much-valued lifeline to the families if this study.

When discussing the diagnosis of their child, parents reported that the SI was involved. To some families, receiving an official diagnosis was a way of providing an explanation for their child's behaviours (Mansell & Morris, 2004). Prior to diagnosis, parents reported noticing behaviours of their child with ASD that were unexpected and/or were different from the development of their other children, with TD (Abbot, Bernard, & Forge, 2012; Mansell & Morris, 2004). Multiple parents in this study knew, before a diagnosis, that their child was experiencing some sort of developmental difficulty. Julie reported that since birth she knew something was different in her son, Dave; "...like I knew he was different from his siblings." Fiona also noticed that something was "wrong" with her son;

I noticed it earlier, my regular family doctor did not notice it, and didn't agree with me. And I can tell you and 100 women would tell you the same thing, no one knows their child better than a mother does. They see that child, in and out, every day for average of 16 hours a day and I know some say it's not appropriate to compare one child to another. I wasn't doing that but seeing how my other two boys, I have three boys all together. The two boys were already making, just babbling sounds, as early as 7 to 8-months. And by 12-months they all had [two boys with TD], at least 20 to 25-words. Like your common [word], they would ask for milk, they would ask for cereal, they would say mom or dad, just juice, every day normal words.

When observing her two sons' with TD, Fiona knew that her son Fred was having developmental difficulties. She reported that he did not learn his first word until he was

21-months old. Receiving an official diagnosis can provide relief to parents, and a diagnosis can help to validate and confirm explanations of their child's behaviours (Howlin & Moore, 1997; Abbot, Bernard, & Forge, 2012). Once a diagnosis was official, parents can move forward and seek assistance for their child with ASD (Mansell & Morris, 2004). Parents are then able to understand the dynamics of the disorder and what they could do to help their child (Mansell & Morris, 2004). In the study findings, the SI has been able to provide parents with an official diagnosis of ASD. The SI's assistance with the diagnosis of the child has helped to provide answers to families and guide them to supportive services available.

The SI is greatly respected by the parents of this study. Many looked up to her for assistance with difficulties in behaviours experienced, as explained by Claire when experiencing sleeping problems with her daughter;

She's got sleep issues....They're awful. So she gets melatonin at night, cause if she doesn't take she takes like 2-3 hours to fall asleep...And it doesn't matter if she gets up at 6 in the morning, it's ridiculous. So we finally caved in, [the SI] said you know try it. We finally did, it's awesome. [laugh]

The SI has been able to assist with solving issues experienced by the children of this study. Additionally, the SI was a valuable resource to these families because participants described that she knew and understood the complexity of ASD. Kayla experienced a high degree of severe feeding difficulties with her son, Tom; she expressed how there was a limited number of people who understood the extent of Tom's feeding challenges;

They don't understand, and a lot of people. Even parents who have high functioning kids don't understand the struggles of somebody like [child with ASD] Tom, who doesn't eat. He doesn't eat any type of solid food; he doesn't eat

any other purees except his cereal and the little smidge of banana that I give him. Like when you try and talk to people they have no idea what you're talking about, even Doctors. [There are] only two people who understand when I say "Tom's not eating, we need to do something, he's really not eating"

As explained by Kaya, it is extremely important for individuals, who care for these children, to understand the dynamics and characteristics of ASD. The SCO and health professionals, importantly the SI, were valuable and supportive life-lines to these families. The SCO is a facility that provides positive, supportive, and successful services to participants and their families. However, there is need for improvements in all supportive services that offer care to children with ASD. Throughout each interview, notable gaps in supportive services and care were identified as significant issues.

4.7 Gaps in Care and Supportive Services

The SCO is a facility that offers a wide variety of supportive services to families of children with disabilities, including ASD. These families also seek assistance from other public and private supportive services. When asking participants about their experiences with all of the services they have received, there were distinct gaps noted regarding the supportive services and care provided to these families. Particularly, the study explored supportive strategies that are used to improve behaviours and environments in this population.

4.7.1 Strategies used to assist with feeding behaviours: ABA

This study investigated the extent to which tools were used when addressing food behaviours and feeding environments in children with ASD. Specifically, the use of food

as a positive reward and positive reinforcement was explored to understand feeding outcomes. According to previous research, operant conditioning and the use of reinforcement and reward is a well-known approach that assists with changing and controlling behaviours in children with ASD (Gulick & Kitchen, 2007). Operant conditioning is the foundation of ABA, a highly successful and recognized approach used to assist with behaviours in children with ASD (Gulick & Kitchen, 2007). This approach has become an important tool in this population and the literature claims that it is effective at teaching life skills to children with developmental disabilities (Matson et al., 2012).

4.7.1.1 Edible Reinforcement (ER). In this research, positive reinforcement was defined as a stimulus provided to increase the likelihood that a behaviour would occur again (Gulick & Kitchen, 2007). The interview guide explored the use of reinforcement-referred to as edible reinforcement (ER). Specific questions asked if parents used ER, if it was effective, and if others used it and/or how often this strategy was used. In this study, reinforcement was defined an immediate stimulus that is given to participants within 0-5 seconds after a behaviour. The participants were asked about the use of ER with their children with ASD.

4.7.1.1.1 Edible Reinforcement (ER): is it used in these families? Two parents reported that using foods to increase positive behaviours was not effective. Kayla's son was "hypersensitive" to foods and this approach negatively influenced his feeding behaviours;

I think that's bogus [laugh] because if you've got a child who's very hypersensitive, like Tom is to touch, new experience, and sights, and smells, and gets very overwhelmed very easily. Food is so [pause], how do I say it. Food is the

devil, food just has all of those things wrapped up in one little cool cookie, right....For instance, there are these chips ahoy cookies that I love and they've got rainbow chocolate chip things on it, and my son just totally thinks that they're the devil. Like he looks at them and he's like "uhh what's that, get it away from me, it stinks, it looks bad, it's all-bland". Like if food reinforcements, it's so wrong because you're rewarding somebody with food, where food should be a basic right for everybody.

Kayla did not use ER and also disagreed with using ER strategies on children, with and without ASD. Julie stated that her family did not use reinforcement because it was ineffective. She felt that her family was more likely to provide rewards for eating. Importantly, both of these parents believed that ER was not effective when used on their children.

Other individuals (2) reported being unsuccessful when attempting to use ER; however they would use it if their child became interested. Pam reported, "not having a problem with it" and Bonnie would use it if her son were responsive to food "in that way," and if it would help her son; "I would be all in favour of using food, as positive reinforcement but there isn't much that he's excited about eating." It is important to consider that participants that had a child with pre-existing feeding challenges were selected for this study. Therefore, the reason ER was not often used may have been influenced by the sample population studied.

In this study, half of the parents reported using ER on their children. Specifically, positive reinforcement was used to help control and/or improve behaviours in children with ASD (Gulick & Kitchen, 2007). The parents in this study used preferred food items

to increased different behaviours in their children. Sasha reported using ER to encourage positive eating behaviours;

The only time I've ever used a positive reinforcement is when it was related to food. You know, so if he tries something new I would give him something that he wants, that he likes. So if he were to take a bite of celery then I would be like, awesome, and he can have a couple goldfish crackers and then it's like, okay take another bite of this celery.

Other parents reported trying this behaviour modification method to increase positive behaviours in the home. In the literature, toilet training was one common example that used ABA principles to help parent's toilet train their children with ASD (Kroeger & Sorenson, 2010). In this study, three parents used this approach to toilet train their children; "We've tried [using ER], sometimes it works, it's how we potty trained her. We gave her anything that you can think of, um and it worked," elaborated Claire. Liz and Fiona also reported using ER to potty train their son's. This ABA approach was used in many families to improve essential qualities that increase one's ability to live independently (Matson et al., 2012).

Other family members, school employees, and supportive programs used ER to develop skills and teach behaviours to children with ASD (Matson et al., 2012). Interview questions explored the use of these methods. All participants reported that other individuals attempted to use ER with their children. Supportive care and services offered by the SCO taught Fiona about this behaviour modification method and she now uses it on behaviours at the home;

Cause he seems to love that sweet taste. So those are only given to him in those areas, so he recognized that if I do what I'm told at ABA or when I'm with

[another supportive service] I get my cookie. When he was doing the potty training with [another supportive service] he knows and he'd follow to process to go to the bathroom, and he would get the Smartie. So I have no problem with using positive reinforcement sometimes, even when I am feeding him at home and he refuses to eat it [certain foods].

Over half of the parents reported supportive services using or recommending this approach for behaviours. This strategy was used by individuals associated with these services and has also been included in behaviour-changing interventions that are applied to individuals to help them develop skills, follow instructions, lower negative behaviours, and inflict motivational variables (Gulick & Kitchen, 2007). During the interviews, ER was used to understand the effect these environmental factors had on children with ASD. The use of edible reward was also considered in these families.

4.7.1.2 Edible Reward. Reinforcements and rewards are two different types of ABA principles used to modify behaviours. According to the work of Satter (1999), reward foods are often used in families to teach children appropriate feeding habits. Interview questions were developed to gain insights into the extent to which rewards were used when working with children with ASD. Rewards were discussed as a food item that is presented to a child after a desirable behaviour has occurred and edible rewards would be given to a child after a behaviour is achieved. Edible rewards are long-term stimuli that have to be given more than 5 seconds after a desired behaviour occurred or an entire activity is completed. According to the majority of the participants in this study, food rewards were not the best way to teach feeding behaviours to children with ASD.

4.7.1.2.1 Edible Reward: Is it used in these families? When speaking to parents about the use of rewards on children with ASD, parents were unsure of how beneficial this approach was. Among one of the parents was mother, Sasha stated:

Um, the food that he would want as a reward are just foods that he would get anyways [laugh]. Since his diet is so limited, it's kind of hard for me to do that but I mean in other instances I can see where it might be like effective. But for him particularly, I feel like food is not like a great reward thing for him.

Sasha then proceeded to explain how she felt that her son would be much more rewarded by, “a big hug and getting tickles... for doing something good, rather than food.” Other parents were unaware if their child understood the use and purpose of food rewards.

Bonnie explained how she was not sure if her son has made the connection between reward and food, and “I’ve done this and now I’m going to get this piece of food.” The majority of the mothers reported that they were unsure if their child was able to make the connection between what they just did and why they were receiving a desired food item.

Kayla elaborated on her experience when attempting to use edible rewards with her son; “Um, I tried using that but Tom, Tom doesn’t get that concept. He’s not into that whole sequencing thing. He doesn’t understand sequence, so he would never get that.” Similar to ER, edible reward may not have been as effective, due to evident challenges with feeding and eating in this sub-population of children with ASD.

Edible reward is a common approach used in therapy to increase food selectivity (Kodak & Piazza, 2008). Although the majority of parents reported that rewards were unsuccessful when used on their children, there were a minority of parents who used edible rewards. Parents discussed combining desired edible rewards

with non-preferred foods. Fiona explained using this approach to getting her son to eat:

So I have no problem with using positive [reward] sometimes... even when I am feeding him at home and he refuses to eat it and then I'll show him something else he wants to eat and I said you're going to first finish this and they you're going to get that. Doesn't work sometimes, he will scream, he will take a fit. But he knows that what I just told him and he doesn't finish it, he's not going to get it. So he knows he has to finish it.

Fiona understood the use of reward with her son; however she also felt her son may not respond positively to rewards if they were used over a long period of time. The duration of the reward when offered to children with ASD needs to be further explored, to understand the effectiveness of timing and the use of edible rewards. Liz also reported using food rewards to get her son to complete certain behaviours; "Um when he follows direction. Like Maddox please put that toy away or like Maddox if you have five more bites you could have this."

4.7.1.3 Parental Knowledge of the use of ABA approaches. Many different techniques are used on children with ASD (Marcason, 2009; Whiteley et al., 2013). As the literature suggests, families have a significant role in developing behaviours in their children (Ha et al., 2010). Therefore, parents should be knowledgeable of all approaches used when teaching their child. During the interviews questions were asked to explore parents' understanding and the frequency to which ER and edible rewards were used on their child with ASD.

When specifically asked about the use as food rewards, the minority of parents felt that the approaches were not used on their children. However, when asked indirectly,

some parents provided mixed responses. Parents were asked about their thoughts on the statement “if you don’t finish your dinner you don’t get your dessert.” Claire reported not using food rewards “that often” with her daughter, Elyse. However, when asked about withholding dessert from Elyse, her response was much different:

I’ve said it [laugh]. I have said it, I don’t necessarily like it but there are times when I know she’s holding out for something else. Or she might be sitting there and she’ll say, I don’t like this or this is gross or this is whatever... And then she’s like but I want ice-cream. Well you’re not getting it, if you have room for ice-cream then you have room for, pork chops or corn or something. Cause she used to love corn so what happened all of a sudden that you don’t like it today or just not even today maybe she had something for lunch and there were leftovers and she won’t touch, and it’s just so frustrating. So ya I have said that.

Feeding challenges result in parental and family stress (Sharp et al., 2014). Study participants were under a lot of pressure to get their child to eat, therefore parents may use desired food items to increase eating patterns. When a second participant was asked about rewards, Julie first stated that her son would not understand the use of rewards. However he was always given a cookie after he finished his dinner and the mother felt very strongly that her children should not receive dessert if dinner was unfinished. Julie did not recognize that withholding dessert was an example of using food as a reward. Therefore, she does use edible rewards as a strategy with her son. To conclude, some parents were not always aware of their use of rewards, reinforcement, and restriction of food with their children.

Parents were asked to estimate how often these approaches were used by other family members, school employees, and supportive programs. Almost half of participants reported other individuals attempting to use ABA approaches with their child that has

ASD, even if they were unsuccessful. Importantly, parents often found it difficult to quantify the number of times that ER or edible reward was used, per day or per activity. Sasha, questions who was using this approach with her son; “I think my mom has maybe done it like once or twice....That’s a good question...they may do it at school; I’m not sure how they would do that.” Therefore, a knowledge gap was evident between the parents of this study and other family members, school employees, and supportive programs that used these techniques on children with ASD. More research is required to alleviate the knowledge gaps experienced in these parents, and their families.

4.7.1.4 Misconceptions in ABA Approaches. Misconceptions are terms used when referring to a “disconnect” in parental perceptions (Doolen et al., 2009). When exploring food behaviours and feeding environments, misconceptions were evident between parents and family members, school employees, and supportive services. These misconceptions were experienced when using ABA strategies on children with ASD, including reward and reinforcement.

Parents, who reported that they were unsuccessful when attempting to use ER with their children, stated that other individuals tried to use this approach. For example, Julie reported that her son would get lollipops in therapy. Claire stated that her daughter has come home from school with chocolate and other foods that she did not give Elyse. Kayla elaborated and reported individuals who had attempted to use ER on her son, including grandparents and service providers; “behaviour management, um [another supportive service] use cookies and chocolates and candies. Even [another supportive service], they take a Smartie and they slice it as many times as possible so that they reinforce the action...and the behaviour.” Miscommunications regarding approaches used

to care for this population led to misconceptions between parents and others, including family members, school employees, and service providers.

When asked about certain feeding approaches and techniques, Kayla, Julie and Liz reported that they were the ones most likely to use ER or edible reward and fathers used the approach, if it were required. However, the minority of the participants (2) reported an information gap between themselves and their child's fathers. Sasha is a single mom and when asked about certain experiences, for example food rewards, she was not sure how her son's father approached or used this strategy;

Um, honestly I don't know. We have very small group of people in our family. So it's my mom, my sister, and then Kale's dad. And Kales' dad, I don't know what he does at his house with him... so I couldn't say.

This created a knowledge gap in this family that influenced strategies that were used on Kale. An information gap was also experienced with Claire and the father of Elyse (child with ASD). When asked about her experiences with these ABA approaches she was under the impression that Elyse's father and his family used it, however she was unaware of how much it was used. As stated in the literature, there are 5 key principles that are required for ABA to effective (Gulick & Kitchen, 2007). If information gaps are evident it is difficult to determine how consistent this approach is used, which influences the effectiveness.

Understanding what is successful and what is ineffective is crucial when attempting to improve the behaviours in each individual child with ASD. The ABA approach consists of a practical and theoretical framework that is used to teach behaviours (Gulick & Kitchen, 2007); however, it is not successful in all children. It is

important that parental perceptions are acknowledged between family members, school employees, and service providers, before ABA approaches are attempted on their children with ASD. Misconceptions surrounding the use of ABA strategies were one issue identified in this study; however other supportive service gaps were also evident.

4.7.2 Waitlists

When speaking to parents about the services their children were receiving, there were an overwhelming number of children waiting for crucial services. These families reported that they were on multiple waitlists to receive assistance and care for a variety of challenges experienced in their children with ASD. The literature available has expressed issues with wait times and waitlists in this population, therefore increased wait times reported in this study contributed to the frustrations experienced by the families. Bonnie elaborated on the services her son was on a waitlist for multiple services. Her explanation helps to put the term “waitlist” into a perspective that parents of children with TD may not understand.

He's on the waitlist for ABA and IBI, and I guess that's it. Everything else is waitlist yes...He's waitlist for ABA at [the SCO] and he is approved for um IBI thorough [another supportive service]. So he is on it that waiting list too...Oh ya actually he's on the waitlist for [Occupational Therapy] at [the SCO] ...Um what else? Everything else is just like [two other supportive services]...and he's on a waitlist for those too.

These participants were on a variety of waitlists to receive assistance and care for their children. Additionally, the amount of time parents are asked to wait to receive each

service was extremely long. Participants have to wait years for assistance with challenges that they are currently experiencing. Long wait times were an issue expressed by many families, including Liz; “He is on a waitlist for [another supportive service], it’s a 5-year waiting list. And he is on some waitlist at [the SCO] too.” This concern was also explained by Pam; “Um, IBI um they’re saying 4-years but it could be less cause they say they got funding, it could be 2.... Um but ABA you’re looking at over a year.” Wait time was a crucial gap experienced in the care and supportive services offered to these families.

The parents were also apprehensive because they worried that they may never receive help from some service providers. As stated by Fiona;

He’s getting IBI, that’s what we pay for, three days week. And then I receive, paid for by the government, speech and ABA from [the SCO]. And I still am currently, I don’t know if it makes a difference, on the waitlist for [another supportive service] but that is probably 3-years from now, if they ever do call my name.

Fiona expressed a lack of faith and some frustration because she felt her son would never receive help from some services. Fiona and Liz reported reaching out to private services to get the help required to assist their child during preschool development.

As expressed in the literature, wait times for ASD services are extremely long and wait times can have detrimental effects on each child’s developmental process (Popli et al., 2013). Preschool is a time period where children begin to personally and socially develop life skills (Knight & Lee, 2009). Long wait times cause participant and their children to miss out on assistance with challenges during critical areas of development.

4.7.2.1 Critical Window for development. The children in this study, aged 2-5, were in the preschool developmental period. According to the literature, during childhood

growth there are critical time periods for children to develop certain essential life skills (Popli et al., 2013). There is a theory within the literature that suggests there is a critical time period to introduce solid foods to children; which if missed, can cause difficulties with chewing (Dijk et al., 2012; Udall, 2007). In this research, multiple (4) children experienced difficulties with chewing and eating solid foods. Unfortunately, due to long waitlist, not getting access to services and not receiving timely assistance regarding these issues can be detrimental to areas of development, particularly chewing. According to the literature, children have a small ‘window of opportunity’ to be introduced to solid foods and parents expressed a higher degree of difficulty with feeding once this opportunity was missed (Dijk et al., 2012; Udall, 2007). The theory of “a critical window for development” was a belief that was clearly stated in this study by Kayla, when asked if she would like to add anything to the interview:

Tom doesn't chew, he lost his ability to bi-lateralize a long time ago, we missed that window, and... if we identified Tom earlier maybe we could have changed the course. However, we didn't and it took us so long to get to where we are now that I don't know if we'll ever be able to, to go back and teach him how to chew. And chewing is part of enjoying food right.... Like, we've missed the window... my family feels we've missed the window in terms of having the nutrients come into his body and having him develop um so that he's able to keep up with his peers. Like, if Tom was diagnosed earlier... around the 9-month mark when we started to notice that big plateau, we could probably get him, if he was diagnosed at that time we could have probably gotten him some help with chewing food, with becoming more exposed to food, and from there he could have developed some basic eating habits that could have carried him on up until this point. And who knows how that would have affected his processing.

The waiting time that is required of parents to receive a diagnosis and to then receive care and services may have an influence on the development of children with ASD. Children develop essential life skills during specific times of growth and waitlist can influence all areas of childhood development (Popli et al., 2013). Therefore, when families of children with ASD experience serious feeding difficulties, not receiving immediate professional support can be detrimental to development. During the interviews, parents expressed concerns with waitlist times, which contributed to the frustrations of families when they did not get the assistance that they required to help their child with ASD. Further exploration is required to develop appropriate and early feeding interventions on this population. Participants were also asked if they would like to receive help from other services.

4.7.3 Where or who participants wish to receive sources of help

It is important for this research to acknowledge areas where parents feel additional assistance is required to help their children with ASD. During the interviews, participants discussed whether they felt it would be beneficial for them to speak to other supportive service providers. Kayla stated that; “Autism is very different from other developmental disorders and other types of disabilities, so...I need somebody who actually understands autism.” Parents in this study, who wanted to receive assistance from other individuals and health professionals, needed them to recognize the dynamics and characteristics of ASD.

When speaking to parents about services they wished to receive, parents expressed uncertainty when addressing the question. There have been many supportive services assisting these families; however some parents were unsure of whom and where

to seek assistance. Kayla explained how she would have loved to receive help from other supportive services, yet experienced a knowledge gap with where to go to receive help;

Ya, I would love to speak to a nutritionist. I would love to speak to... a homeopathic person in terms of organic foods. There are a lot of things out there that I haven't even tried because I don't know where to start.

Participants experienced gaps in services because parents were unaware of how and where to obtain the information related to receiving care and support. Therefore, services should be made available, in order for these families to reach out to for assistance.

Other parents experienced some confusion between the types of services that were available to their family. When Bonnie was asked if it would benefit her to speak to a nutritionist, regarding questions about feeding or eating behaviours, she responded; "Oh, isn't that, dietitian and nutritionist the same thing?" Confusion between supportive roles can limit the number of services that families feel are available to them. When provided clarification on the types of services that are offered by each professional, she confirmed that she would be more interested in speaking to a nutritionist and dietitian to discuss her issues. Claire also expressed uncertainty with the role responsibilities of a dietitian. Parents need to be familiar with the types of services they are receiving and the role each service will be providing, when attempting to improve the challenges experienced in their child. Additionally, to decrease the knowledge gaps on services available to families, parents should be provided with more information on services that are available to them.

There is a paucity of research available regarding food behaviours and feeding environments in this population (Matson & Nebel-Schwalm, 2006). This research verified that parents would like to consult with a variety of health care professional

regarding the feeding challenges experienced in their children with ASD. Parents specifically indicated a desire to speak with a: homeopathic doctor, nutritionist, feeding clinics and similar families with picky eating experiences. One participant, Pam, shared a positive experience when meeting another mother with a child that had similar behaviours to her son. She expressed how this experience made her think that talking to families that have children with ASD may be helpful:

... I was actually surprised cause I met a lady last weekend and her son is autistic and he was 8 and she said he just got off baby cereal not that long ago and I thought oh my gosh so I'm not the only one [laugh]. So it was interesting, I thought it would be interesting to talk to more [parents and] I found it very interesting just talking to that one saying that oh her son was the same way... gagging on food and everything. So at least I know my sons not the only one that's picky [with] texture...so it was interesting to hear what she had to say.

It is important to acknowledge gaps in care and services available to these families. Feeding is an opportunity for parents to offer love, care, and attention to a child (Slaughter, 2000). To address feeding challenges, resources need to be made available that provide families in this study with the required and/or suggested services. Being aware of the wants and needs of the families in this study was important when attempting to understand the service identified to assist children with ASD. Additionally, increased education and awareness from service providers is important to help children with ASD and their parents understand what services are already available to them.

4.7.4 Knowledge gap: Registered Dietitian ‘Disconnect’

According to Canadian best practice guidelines for children with ASD, an interdisciplinary approach is ideal when working with this population (Nachshen, 2008);

amongst the health professionals recommended were Registered Dietitians. Unfortunately, not all supportive organization offer the services of a Registered dietitian and according to the ASD Provincial Needs Assessment survey; findings suggest that dietitians require increased training and education on children with ASD (PCDS, Faculty of Medicine, Memorial University, 2012). In this study, questions explored specific services that are provided to these families. Parents were asked if it would be beneficial to speak to a Registered Dietitian to discuss feeding challenges in their children. Results from this interview suggest that parents rated their previous experiences with Registered Dietitian as unsuccessful and/or did not understand what a Registered Dietitian could contribute to the challenges that they were experiencing.

Supportive organizations, including the SCO, offer a variety of services available to families of children with ASD. A very limited number include the services of a Registered Dietitian. Parents had mixed opinions when asked if it would be beneficial for them to speak to a Registered Dietitian to discuss food behaviours and feeding environments in their children. In this study, over half (5) of the parents felt that speaking to a dietitian would not be beneficial. Two parents had previously spoken with a dietitian and they did not believe it would be constructive to speak to a dietitian again. One participant, Kayla, described her experiences with a dietitian; “I would welcome the opportunity to speak to a [another] dietitian actually, I’ve spoken to a dietitian I’m just not sure that maybe her and I see eye-to-eye on things and I think that’s the challenge.” Parents expressed concerns with the approaches used by dietitians in the past and questioned their specific knowledge of children with ASD.

Additionally, parents who did not wish to seek support from a dietitian also suggested that the Registered Dietitian's knowledge and professional skills may not match the care that their children the ASD required. The range of strategies available to help the children in this study was a major concern of these families. When asked about speaking to a dietitian, Claire voiced her opinion;

No, I would go to a nutritionist over a dietitian.... They don't think as much as a nutritionist does and I feel that they just look at the food guide and then hammer that out and that doesn't work for everybody.

The above quote also suggests that Claire was not completely knowledgeable and aware of the types of services that are offered by a dietitian. Confusion and uncertainty pertaining to role responsibilities were previously discussed when asking parents where they would like to receive service support. Knowledge gaps of dietitians were expressed by over half of the participants in this study, regarding the approaches of the dietitian and their knowledge of the population. According to ASD Provincial Needs Assessment there is a high-need for dietitian education on 'dietary complaints and solutions' when caring for children with ASD (PCDS, Faculty of Medicine, Memorial University, 2012). Fiona reported that the issue was the physical action of getting her son to eat and she was not sure if her son's issue was relevant to the services offered by a dietitian; "... they're [dietitians] going to say, you know, stay away from this or stay away from that. But if he's not going to make an attempt to eat it then what is the difference they're [dietitians] going to make." Pam also stated that the problem is getting her son to put food into his mouth and she was not sure what service would be the best to assist her son. Registered Dietitian assessments of nutritional adequacy is an important step when attempting to

understand the feeding challenges experienced in children with ASD, however not all challenges may require assistance solely from a Registered Dietitian. Therefore, it is important for participants and services to be educated on the appropriate services that should be provided to each child with ASD.

The minority (3) of participants were receptive to speaking to a dietitian, yet were uncertain, that there would be positive outcomes. One of three of participants who had previously been referred to a dietitian was receptive to speaking to one again, yet was hesitant that the dietitian's suggestions would successfully improve her child's feeding challenges; Sasha reported:

We saw a dietitian and the paediatrician, and they basically said at his age it's hard enough with a, with a 5-year-old to get them to try new foods. But with autism on top of it, it just makes it that much harder, so just keep trying and be persistent...and as he gets older, if you're still persistent, then hopefully it gets better.

According to Sasha, the dietitian provided suggestions that were successful at assisting Sasha's family, yet she was still open to speaking to one again if they had alternative advice. Dietitians may require more information on the extent to which feeding issues are experienced in these families. Other parents (2) in this study who had not been referred to a dietitian in the past and were willing to be referred, expressed similar concerns that this service would not add new successful strategies, and were worried that the dietitian's may not be educated on about characteristics of their child with ASD. According to the literature, children with ASD have different dietary patterns and individual characteristics that effect growth, weight, and nutritional status, in comparison to children with TD (Xiong et al., 2007). Different approaches are required to manage, therefore, dietitians

should be educated on the issues in children with ASD, in order to approach and resolve the issues experienced. There is limited literature available to health professional, including dietitians, on how to appropriately approach and assist the population of ASD with feeding difficulties. Importantly, all supportive services that offer care to children with ASD need to become involved and aware of the feeding challenges experienced in this population. Additionally, future research is necessary to determine the proper nutritional or behavioural approaches used to assist with the eating challenges in children with ASD. Lastly, parental knowledge was further considered when exploring the knowledge gaps experienced in the services provided by dietitians.

Environmental factors, including perceptions of roles, influences, values, and experiences of parents play a big part in the dietary behaviours of children with ASD (Ha et al., 2010). Information discrepancies were evident between parents and how they perceive their child's environment and how dietitians attempt to solve the issues. To conclude, gaps in supportive services were experienced in these families; when further exploring this study, misconceptions in parental knowledge was another gap determined.

4.7.5 Information gap: Parental knowledge

Gaps appeared in supportive services; and information gaps were evident when exploring how knowledgeable parents were about the types of care and supportive services their children were receiving. Parental knowledge and their ability to recognize environmental factors that influenced their child were explored and discussed throughout this research. Information gaps were apparent regarding parental knowledge and understanding of ABA approaches and if they used rewards, reinforcement, and

restriction of food with their children; and how often others may be using these approaches with their children with ASD. Misconceptions were experienced when ABA approaches were used on children with ASD by others, including: supportive services, school employees, and other family members.

To conclude, ABA approaches, and other supportive strategies cannot be successful without full support and understanding from all individuals that provide care to children with ASD. To improve the outcomes of strategies used to assist children with ASD, information gaps in family members, school employees, and services should be acknowledged. Future research is required to increase the understanding regarding the parental knowledge gaps experienced by the families of children with ASD.

5.0 Conclusions, Recommendations, and Personal Reflections

5.1 Conclusions

The objectives of this study had two components: the first was an examination of feeding environments of children aged 2-5 years, diagnosed with Autism Spectrum Disorder (ASD), as well as an inquiry into the experiences of the children's parents' regarding food behaviours when having a child with ASD. All children were diagnosed using the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) and/or 5th edition (DSM-V) (APA, 2013). The conclusion summarized the parents' experiences, and ensured that the major research questions (See Appendix A) were answered in the study. Categories from the World Health Organization-International Classification for Functioning Disability and Health (WHO-ICF) framework (WHO, 2002) were used to understand the relationships that emerged between the health condition of ASD and the related behaviours and environments experienced by this population. These categories were discussed in this chapter to summarize and outline the findings that emerged in the data. From this study, the findings were used to develop recommendations to improve care and service gaps that emerged from the data, while concluding with personal reflections on the part of the researcher.

5.1.1. Participation

Participation refers to what one 'does' and/or their involvement in life situations (WHO 2001). The parents' experience of the food behaviours and feeding environments was influenced by the participation of their children in this study. The child's involvement had a major role on the different types of feeding challenges what were experienced by each family. The children in this study experienced an increased variety

of feeding challenges that varied in severity and type, in comparison to children without ASD. Children with typical development (TD) experience fewer issues with food selectivity, or what is referred to as picky eating, than children with ASD (Rogers et al., 2011). In this study, the children's dietary preferences were unpredictable and multifaceted, making it extremely difficult to determine consistent feeding challenges in the study.

5.1.2 Personal Factors

Personal factors and the characteristics of each child influence how one experiences disability from the individual, institutional, and social level (WHO, 2002). Contextual, including personal, factors had an important role on the health condition of ASD. Parents were the primary source of information in this study, therefore their experiences regarding the personal factors that influence their child were also considered. In this study, parents expressed multiple concerns and emotions, such as failures, frustrations, and little/lack of control, regarding the health of their child with ASD. These concerns and emotions arose when the parents experienced food selectivity, dietary preferences, and feeding challenges in their child with ASD. Parents' expressed concerns with the weight status of their children, particularly if their child's feeding problems progressed as they aged. Children with ASD have a greater risk of deviating from a normal weight (Emerson, 2005; Lloyd et al., 2012); and underweight status were a concern of parents in this study. The height and weight measurements, provided by the SI, were used to calculate the Body Mass Index (BMI) of the majority of the participants in this study; all children were classified in the normal range, for their age. Therefore, a misconception was present in parent's perceptions of their child's current health, in

relation to the serious feeding challenges experienced. This provided evidence that feeding/eating challenges may also require behavioural assistance. However, the findings from this study require further investigation to understand what specific services should be utilized to meet the needs of each individual child with ASD. Participants also reported that they felt the degree of feeding challenges experienced by their child was strongly influenced by the severity of ASD. The behaviours and environments of children with ASD shaped the individuals that provided care to this population. Parents' reported experiencing a lot of uncertainty with the onset of feeding challenges in their child with ASD. This uncertainty was connected to the health of their child, and the feeding problems they experienced; resulting in feelings of failure and frustration, and little or lack of control over the situation.

5.1.3 Environmental Factors

Environmental factors include the social and physical environmental influence on an individual with a disability (WHO, 2002). This contextual factor also contributed to the health condition of each child. Feeding environments were explored to help understand the environmental barriers and facilitators to children with ASD.

5.1.3.1 Facilitators. In this study, a limited number of positive environmental factors were acknowledged in the family feeding environment, such as screen time and role models. Environmental facilitators also include care and services from the Supportive Community Organizations (SCO) used in this study and specific Supportive Individuals (SI) that are a valuable lifeline to children with ASD and their parents. Supplementary research is required to understand the positive impact that the SCO and

SI's can have on these families, as well as the influence that screen time and roles models have when creating positive feeding environments for children with ASD.

5.1.3.2 Barriers. Although facilitators were evident, multiple gaps emerged in the supportive services and other individuals that provide care to children with ASD. Therefore, environmental barriers were experienced in this population. Supportive service strategies, specifically ABA and the use of edible reward and edible reinforcement (ER), have been used to assist families with the behaviours of children with ASD (Gulick & Kitchen, 2007; Matson et al., 2012). The study results conclude that these strategies were not as effective and/or understood as well as it was anticipated from the literature. Although this was a significant finding, it is important to consider that the sample of the population used in this study had previously experienced feeding challenges. Other environmental barriers experienced included waitlists for services, finding information about access to service and available services, and knowledge gaps in dietitian services meant to provide care and support to children with ASD and their parents. Although gaps were revealed in this study, evidence from the data collected further suggests that the feeding/eating challenges experienced in children with ASD might be a behavioural issue, and not solely a nutritional issue. Further research is required to differentiate what supportive services will be the 'best' approach to assist each child when experiencing feeding/eating challenges. Importantly, information gaps were evident in parental knowledge. Each parent's ability to adapt and understand the services and care provided to their child had a major influence on the environmental factors present in the family and the health condition of ASD. Parental knowledge and their ability to participate in environmental factors that assist their child with ASD were

considered in this study. Lastly, the lack of communication and coordination of services between parents, family members, school employees, and service providers had a large impact on the care provided to children with ASD. Increased communication and collaboration is required to improve the barriers experienced by parents and increase the success of strategies utilized to assist this population.

To conclude, this study explored and determined multiple factors that influence the food behaviours and feeding environments of a sub-population of children with ASD that experienced a wide variety of feeding challenges. The engagement and involvement of parents in this study was extremely beneficial to understanding the degree to which food behaviours and feeding environments are experienced in this population. This study has been successful at exposing multiple characteristics of participation, personal and environmental factors that influence of the health condition of ASD. There are many challenges experienced when raising a child with ASD; therefore, further research is required to develop strategies, including early interventions, to prevent feeding/eating from becoming a greater issue in these families (Lockner et al., 2008); in order to close the gaps experienced when exploring the food behaviour and feeding environments in children with ASD and their parents.

5.2 Recommendations

As a result of this study, recommendations have been developed for the parents that have a child with ASD, the SCO used in this study and other supportive services available to children with ASD, Registered Dietitians, and Government and Policy Makers; along with recommendations for future or continuing research about this population. It is hoped that recommendation will considered by all.

5.2.1 Recommendations for consideration by parents of children with ASD

This study was conducted to understand and gain insights into parents' experiences with food behaviours and feeding environments in children with ASD. Therefore, these recommendations may assist parents of children with ASD navigate the food behaviour and feeding environment challenges.

- Parents are encouraged to take an active role in accessing supportive services to assist with feeding issues for their children with ASD. If parents demonstrate a consistent demand for more supportive services in this area, specifically targeted to assist with feeding issues, for children with ASD, this issue will gain more attention by service providers.
- It is recommended that parents further familiarize themselves with the services that are provided to their child with ASD, for example Applied Behavioural Analysis (ABA) and the use of edible rewards and reinforcements. Parents can reach out to supportive services to ask for assistance when trying to understand the techniques used, or increase their participation by educating and involving themselves in the tools or approaches used with/on their child. This will assist with decreasing parental knowledge gaps and help parents familiarize themselves with care and supportive services used with/on their child with ASD.
- Similarly, it is recommended that parents of children with ASD are aware of the roles and responsibilities provided by each health care professional, specifically a Registered Dietitian. This is important to ensure that parents know why they are being referred to a dietitian and the type of care they will be receiving. This will help to establish positive and trusting relationships between supportive services and parents.

- Parents are encouraged to continue to share their experiences with service providers, medical professionals, and others regarding the food behaviour and feeding environment experiences when having a child with ASD. Parental knowledge of children with ASD is a valuable resource that is only present in those that experience daily feeding/eating challenges with this population. When parents share their experiences it can help to increase and improve approaches used by families and services, helping to develop a strong relationship with all individuals that provide care to their children. This can result in positive outcomes of the lives of children with ASD, including the development of feeding/eating support groups for families with similar problems; Registered Dietitians and Behavioural Therapists should be included in these groups to help further assist parents.

5.2.2 Recommendations for consideration by the SCO and Registered Dietitians who offer support to children with ASD and their parents

Supportive services are a valuable resource to these families, however there is always room for improvement. Recommendations are provided to service agencies to assist with the gaps that were identified in this study. Specific recommendations for Registered Dietitians are also discussed.

- Future research should investigate the knowledge and understanding of professionals who work with children with ASD (e.g. Behaviour Therapists, Registered Dietitians) regarding the food and feeding problems that commonly occur in this population.

Based on the gap analysis resources should be created to educate and inform these individuals about the food behaviour and feeding environment challenges that are experienced by many children with ASD and their parents. It is further recommended

that these professionals work in interdisciplinary groups to best serve these children and their parents when dealing with challenging food and feeding issues.

- It is recommended that all supportive services work together to help children with ASD. Evidence from this study suggests that the feeding challenges experienced in children with ASD may be a behavioural issue, and not solely a nutritional issue. Therefore, feedings challenges may not require in-depth assistance from a Registered Dietitian. To ensure each child is provided the right care, the role responsibilities of each health care professional should be established to help mandate what supportive position will be ‘best’ at assisting with the challenges experienced in each child with ASD.
- Recommendations for consideration by Registered Dietitians
 - The results of this study indicate that it would be beneficial for Registered Dietitians to increase their knowledge of the feeding issues experienced in population of children with ASD. It is important for dietitians to understand the dynamics and characteristics of ASD, as well as the traditional therapies commonly used with ASD, in order to utilize the right tools and approaches to assist these families. Increasing their knowledge and understanding of the population will positively influence the relationship between dietitians and parents of children with ASD. A desirable goal would be for families to be able to confidently collaborate with a dietitian to create positive food behaviours and successful feeding environments.
 - To address this gap, Registered Dietitians are strongly encouraged to voice their opinions on where they require assistance when providing care to individuals with

ASD. More research and understanding is required on the specific challenges experience by dietitians when serving these families, and how to best support them in their practice.

- The preliminary evidence from this study suggests that it is possible that the food behaviour and feeding environment challenges experienced by children with ASD may not be strictly a nutritional issue. For example, once a Registered Dietitian has determined that the child's intake of nutrients is sufficient and/or provided the parents with strategies to improve nutrient intake, the child should then also be referred to a behavioural consultant for a possible behaviour problem surrounding feeding and eating. It is therefore recommended that other supportive services for children with ASD, including Behavioural Therapists, increase their knowledge on the feeding issues experienced in children with ASD and their families. Education will help to develop a more collaborative relationship between all individuals providing care and support to children with ASD.

5.2.3 Recommendations for consideration by government and policy makers

Existing policies were at the root of the overall lack of supportive services available to the families in the study. In addition to this research, previous research has provided evident gaps in care and supportive services. Overall lack of services and the need to increase funding for supportive services provided to individuals with ASD is evident to governments, at all levels. This section will focus recommendations provided to individuals at the local level.

- Local public health initiatives need to address current gaps when assisting families dealing with challenges in children with ASD. Public health programs targeting the

food and feeding challenges experienced by children with ASD and their families might reduce the burden on the supportive service agencies.

5.2.4 Recommendations for future research

It is essential for researchers to become further aware of and familiar with the areas that require improvements relating to supportive care of children with ASD, with specific reference to the challenges presented by food behaviours and feeding environments. This study was able to bring forth preliminary evidence about the feeding challenges families experience; although important issues have been brought to light, there is need for future research on this population. During analysis of the findings, the researcher specified areas where future research would be beneficial.

- Future research is required regarding the degree of feeding challenges experienced by the parents of children with ASD. Research on this population is critical to understand the extent and severity to which each child with ASD experienced these issues, and the influence that food behaviours and feeding environments can have on the families of this population, specifically the stress on the parents. Additionally, future research about feeding challenges experienced in each family should include, but are not limited to, parents' concerns and feelings regarding the regression of eating habits and parental perceptions regarding their child's weight and health status.
- Specific to the findings of this study, future research is required on the care and services provided by Registered Dietitians. Further research on knowledge gaps experienced by dietitians regarding food behaviours and feeding environments of children with ASD is recommended. Additionally, this research should incorporate parents' opinions on where assistance is required to address the feeding challenges

experienced. Collaboration between both dietitians and parents will be beneficial to developing appropriate, effective, and successful treatment plans for children with ASD.

- Alternatively, future research is necessary to understand if the feeding challenges experienced in children with ASD require nutritional and/or behavioural assistance. Further investigation is required to understand the role Behavioural Therapists can have when attempting to address the food behaviours and feeding environments in children with ASD.
- Similarly, future research is required on the care and supportive services, specific to feeding and eating, provided by all health care professionals. Education is required to establish early and successful intervention services for feeding issues in children with ASD. Therefore, it is important to understand the services that each health professional can offer and what service should be utilized to meet the needs of each individual child with ASD.
- Future research is required to determine the knowledge gaps that are present in parents and families of children with ASD. This will allow supportive services to become aware of and target knowledge gaps. It is important to understand where further education is required to assist community members so that they understand the feeding challenges that can be experienced with the disorder, in order for parents and families to provide the appropriate care to children with ASD. In this study, some of the parents had a lack of familiarity with the services available to families and training about the tools used to assist children with ASD, specifically the use of ABA and edible reinforcements (ER) and rewards. Additional research is necessary

regarding knowledge gaps in individuals involved with children with ASD at all levels. However, the research required is not limited to these specific areas.

- In this study, screen time and role modeling were valuable tools used to assist with feeding challenges in the home; however the literature was extremely limited on each topic. Future research is required to learn more about the positive influence screen time can have on feeding environments for children with ASD; in particular, the influence of screen time on decreasing environmental stress and creating a distracted feed in the children of this population. As well as the relationship specific role models have in influencing positive eating behaviours and health mealtime manners in children with ASD.
- Findings from this study suggest parental concerns are focused on increased risk of future underweight issues due to their child's current food and eating challenges. Further research is necessary to evaluate feeding challenges and the influence these challenges can have on weight and long-term health outcomes. Future research would be beneficial to determine whether the food behaviour and feeding environment challenges in children with ASD had an effect on weight throughout development.
- Regarding health issues related to weight and children with ASD, future research is required to look at the severity of feeding challenges experienced in each child and the effect it has on one's weight outcome. Children with ASD are at increased risk of deviation from a normal weight (Emerson, 2005; Lloyd et al., 2012); and the majority of these children experience feeding challenges that are greater than children with typical development (TD) (Rogers et al., 2011). Therefore, additional research is

required to determine the effect of feeding severity on obesity and overweight or underweight health issues in children with ASD.

5.3 Personal Reflections

Upon completion of an undergraduate degree in Health Science, the researcher developed a passion for community health. The researcher had the opportunity to develop a health promotion program at the University of Ottawa, and through this endeavor, became aware of the role of nutrition and food had on influencing the health of individuals. Upon completion of her Honors Bachelor's degree in Health Science, the researcher began a Master's of Health Sciences at the University of Ontario Institute of Technology (UOIT) with her research supervisor, Dr. Ellen Vogel. Both the researcher and Dr. Vogel shared similar interests, which was beneficial in guiding and increasing the researcher's passion about this community health subject.

Initially the researcher was planning to explore the effect and use of local community gardens, when another opportunity arose through a member of her supervisory committee, Dr. Meghann Lloyd. Dr. Lloyd specializes in research on children with developmental disabilities and had noticed a specific area of this population that was lacking research and fit with the interests of Dr. Vogel and the researcher. After Dr. Lloyd highlighted this area of need, it was decided that the researcher would conduct a study exploring parents' experiences with food behaviours and feeding environments in children with ASD.

Although, the food behaviours and feeding environments in children with ASD was not the initial population of study, the researcher also had a passion and interest in this area. The researcher had some experience working with children with disabilities and

has an older sister who has always been very involved with behavioural therapy. Her sister has worked in respite care with children that have ASD, and is currently a Behavioural Therapist, while in school obtaining her Master's degree in Applied Behaviour Analysis (ABA). Given her sister's background, the researcher has always been familiar with and captivated by children that have ASD. Additionally, the opportunity to follow in her sister's footsteps increased the researcher interest in the topic. With advice and guidance from her sister and an extensive literature review, the researcher enhanced her knowledge of children with ASD, while noticing the paucity of research available regarding this population.

In an attempt to understand and provide parents with the opportunity to discuss the feeding challenges that were experienced in each family, the researcher developed a qualitative exploratory study to gain insights into parents' experiences with food behaviours and feeding environments with a child with ASD. The researcher was immersed in parents' concerns throughout the data collection process and was deeply exposed to the challenges these families faced.

Post-interview, the researcher documented insights and feelings that were experienced during data collection in a field note journal (Guba, 1981; Wolfinger, 2002). This allowed her to reveal and reflect on the roles, characteristics, and observations of each interview, and how the lives of the participating families influenced and changed expectations and perceptions held prior to data collection.

The researcher was able to establish a trusting relationship with each participant and capture their experiences during the interview process. Upon completion of the interviews, the researcher described that the literature review had not prepared her for the

extreme severity of the feeding challenges which were described. The number of food behaviour and feeding environment issues experienced by children with ASD were often multifaceted and overwhelming to the researcher. At the end of each interview, the researcher noticed that she felt mentally and physically drained after listening to the some of the struggles that the participants experienced in this study.

When asking parents about the services available to their children, the overwhelming number of families waiting for assistance was quite shocking to the researcher. Families have to wait years to receive many different services to assist their child, or they have to pay out of their own pocket for the services if they want it immediately. The researcher experienced confusion when trying to understand how these services would be effective with children that have to wait up to five-years for assistance with an issue; especially when the specific behaviours and/or challenges were already present.

From the findings in the literature, the researcher hypothesized that excessive body weight in children with ASD would be an issue faced by the parents. However, the data revealed that being underweight was actually a greater concern to the parents in this study. The severity of potential underweight status was a major concern to many of the parents of this study; yet all children were of normal weight range (Table 4). As such, the researcher felt that more investigation was required to understand how the severity of ASD and the degree of different feeding challenges in ASD influenced the weight outcomes of children of this population, as well as how this affected the long-term health and weight status of children. Lastly, the researcher also felt that future research is important to understand the types of services, specifically a Registered Dietitian and

Behaviour Therapist, that these families should seek assistance when experiencing feeding problems in their child with ASD.

Lastly, the degree of difficulties experienced in these families and the number unanswered questions support the need for more research on food behaviours and feeding environments experienced in children with ASD. Due to time constraints associated with completing a Master's thesis, the researcher was unable to further explore the unanswered questions that have emerged from the findings of this study. As stated in the recommendations for future research, there are many opportunities that can be conducted to further the information available about this population. Additionally, similar research could benefit and support the findings from this data. It is hoped that this work will be helpful in understanding and increasing the knowledge available regarding the experiences of parents and families of children of this population, as well as acknowledging the gaps experienced in the care and services required to establish positive food behaviours and feeding environments in children with ASD.

"Research is creating new knowledge" –Neil Armstrong

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Appendices

Appendix A: Major Research Questions

Major Research Question

The primary goal of this study was to explore the food behaviours and feeding environments experienced by children with ASD and their families. Over the past three decades, the diagnosis, awareness, and prevalence of ASD has increased dramatically; however, there is a paucity of research available on parents' experiences with food behaviours and feeding environments with regards to this population (Matson & Nebel-Schwalm, 2006).

Research Questions

Research questions explored the population of children with ASD and gaps evident in the literature. Exploring the food and feeding environments of children, aged 2-5 years, with ASD was the primary objective of this study. Examining the feeding behaviours from the perspective of parents who have a child with ASD was the secondary objective of this research. This research explored:

1. What are the parents' experiences with food selectivity, including variety and choice?
2. What are parental concerns about food and dietary preferences during meal times?
3. What are the food-related challenges parents' (including the family) experience when having a child with ASD?
4. What are parents' experiences with using edible rewards within the family environment?
5. What are parents' experiences with treatment approaches that incorporate edible reinforcement and/or rewards?

Appendix B: Interview Guide

Semi-structured Interview Guide: one-on-one interviews (i.e., conducted with a parent of a child with ASD)

Interviewer:

Name of Parent:

Location of the interview: _____

Interview date:

Time interview started and ended: _____

Signed consent form received [add date]:

Transcribed copy of interview requested by parent: yes no

* Contact information will be included on the consent form*

Study: *An exploratory study of parents' experiences with food behaviours and feeding environments in children with autism spectrum disorder (ASD).*

Thank you for volunteering your time to participate in this interview. *The primary goal of this study is to explore the food behaviours and feeding environments experienced by children with ASD and their families.* Your participation in this study is much appreciated and your insight and experiences will be greatly valued. It is hoped that this research will gather information about feeding behaviours experienced in the home. Please keep in mind that you are free to withdraw from the study at any time. This will not result in consequences of any kind for your child and his/her care at the Supportive Community Organization (SCO).

Key Concept	Rationale	Interview Questions
General Questions that will address characteristics of the participants (i.e. parent) of a child with autism spectrum disorder.		
<p>Interviewer (I): I would like to begin this interview by asking you general questions about your child.</p> <p>I: from here I would like to then ask about health issues in relation to their child with autism (Don't Say)</p> <p>I: From here I would like to explore parents' views on weight issues (Don't Say)</p>	<p>These questions will start off general and transition into questions that are more topic related: ASD and health</p> <p>Further discussion of ASD, with possible discussion of comorbidities and or medication</p> <p>Specifically looking for weight related comments or statements.</p> <p>The ability for parents to recognize a weight issue.</p>	<p>Can you provide me with information about your child with autism spectrum disorder (ASD)? For example,</p> <ul style="list-style-type: none"> • How old is your child? • What is the gender of your child? • What is the approximate height of your child? • What is the approximate weight of your child? <p>What else can you share with me about your child?</p> <p><i>Disorder:</i></p> <p>Is there anything further you would like to tell me about the diagnosis of your child?</p> <p>[YES and state a diagnosis] Can you help me to understand this diagnosis?</p> <p>[NO diagnosis mentioned] Has your child ever been diagnosed with another disorder?</p> <p>How old was your child when he/she was diagnosed with ASD?</p> <p>How would you describe your child's overall health?</p> <p>Do you have any other health-related concerns regarding your child with ASD?</p> <p>Has your child ever been classified as having or being-at-risk of developing other health issues (e.g. high blood pressure, high/low weight, etc.)?</p> <p>[If YES and state] Does your child take medication to assist with any health issues? (This is more of a yes or no answer...I don't need to know the specifics but if they state them, I will note medications)</p> <p>Does your child take any medications to assist with symptoms of autism? (e.g: anti-psychotics, serotonin reuptake inhibitors (SRI), and stimulant medications)</p>

	Inquire if children are receiving intervention services.	<p>Do you think your child is at a healthy weight for children his or her age? Can you explain your answer?</p> <p>Do you think your child with ASD is at increased risk of developing a weight issue later in life? Can you explain your answer? Is your child with ASD currently receiving any type of intervention service?</p>
Moving on: From this section I would like to move on from asking you general questions about your child with ASD, and explore the family feeding environment when having a child with autism.		
I: In this section, I would like to ask you about feeding patterns and dietary likes and dislikes. (Don't say)	<p>Preferences</p> <p>Dietary Manipulation</p> <p>How picky is picky and food selectivity and allergies</p> <p>Experiences</p>	<p>What can you tell me about your child's overall diet?</p> <p>Is your child on any kind of special diet (GFCF)?</p> <p>[If YES] Can you describe the special diet in more detail?</p> <p>[If NO] Has he/she ever been on a specific diet in the past?</p> <p>If YES: Can you tell me a little bit about the diet that they were on?</p> <p>Are there specific foods or food groups that your child cannot eat?</p> <p>Would you describe your child as a picky eater?</p> <ul style="list-style-type: none"> • Has your child been diagnosed with a specific food allergy? When I say allergy I mean, does your child have an immune response if they were to eat to a specific food (e.g. being allergic to peanuts. If one was to eat any food with peanuts, their throat would swell up and your body goes into a immune "shock" response (anaphylaxis)) • Does your child have any food sensitivities? When I say sensitivity I mean a food of intolerance. Where if your child eats a specific food that just doesn't sit right with them (e.g. having an intolerance to milk. If you drink milk one may have a hard time digesting the protein in milk and get

	<p>Early childhood: bottle or breast-feeding</p> <p>Transition into estimating the amount of milk/juice consumed in a day.</p> <p>What is the environment like a home during meals and snacks.</p>	<p>stomach cramps. In mild cases milk may only effect the individual if eaten in large portions)</p> <ul style="list-style-type: none"> • Does your child have any other food sensitivities? <ul style="list-style-type: none"> ○ Texture sensitivities ○ Colour sensitivities ○ Separation sensitivities • Are there any foods your child refuses to eat? <p>Was your child bottle-fed and/or breast-fed?</p> <ul style="list-style-type: none"> • When did he/she stop breastfeeding and/or taking a bottle? • If NOT on the bottle: Does your child like to drink milk or a milk substitute (e.g., soy milk)? <ul style="list-style-type: none"> ○ IF a milk substitute Could you specify the milk substitute you use (e.x. name/ brand/ type of substitute) ○ If YES: What type of milk (whole, 2-percent, etc.) • How much milk would he/she drink in an average day? (USE food models to estimate ounces) • Does your child like to drink juice? <ul style="list-style-type: none"> If YES: What type of juice and how much juice would he/she drink on an average day? (USE food models to estimate ounces) • What are some of his/ her favourite mealtimes foods? • What are some of his/her favourite ‘snack’ foods? <p>Does your child refuse to try new foods?</p> <p>Can you explain how you would introduce new foods to your child with ASD (what works and what doesn’t work)?</p> <p>Can you help me to understand what a typical mealtime is like at home with your child?</p> <ul style="list-style-type: none"> • What about snack times?
--	--	--

		<p>Is “screen time” (TV, iPad, etc.) used to assist with feeding challenges during meal times?</p> <p>OR “screen time” (TV, iPad, etc.) time ever used to assist with food or eating challenges in the home?</p> <p>Are there any other challenges associated with food or eating in the home?</p>
From here I would like to move on from discussing the family feeding environment and move on to talk a bit more about treatment approaches and services that your family may have or are currently receiving.		
I: I will begin by asking you about intervention services.	Potential services that these families, and children with ASD, may be enrolled in, including ABA or IBI. Seeking or getting assistance	<p>Continuing on to discuss services I would just like to clarify again....</p> <p>Your child IS/ IS NOT currently enrolled in any supportive programs and/or services that assist children with ASD?</p> <p>[If YES] What are the services that they are receiving?</p> <p>[If NO] Is he/she on a waiting list to receive a service?</p> <p>If YES: What services is he/she on a waiting list to receive?</p>
I: I would like to continue by exploring what you know about ABA		<p>Does your child participate in Applied Behavioural Analysis (ABA) or Intensive Behavioural analysis (IBI) programs for children with ASD?</p> <p>[If NO]</p> <ul style="list-style-type: none"> • Has your child received ABA/ IBI in the past? • [If NO] Is your child on a wait list to receive one of these specific services?
I: I would like to end this portion by asking if you use edible reinforcements and or rewards (I will provide an explanation . . .)	Reinforcement usage Edible REINFORCEMENT (using food to alter a behaviour)	<p>Next, I would like to ask you about the use of reinforcement and reward. These strategies may also be used in interventions and/or other services.....</p> <p>Can you explain to me your understanding of positive reinforcements?....In this study we are referring to positive reinforcement as an IMMEDIATE stimulus that is given to your child if they do something positive – or desired (I like to think of it as giving the child a item, 1 to 5 seconds after a good behaviour). For</p>

	<p>example: In therapy if a child does something positive, like following an instruction (sitting at the table), the therapist may give them a toy or sticker right after the behaviour. (Importance of Immediacy***). This is different from a REWARD, which is what we will discuss after this.</p> <p>What are your thoughts about using food as positive reinforcement (promoting a desired behaviour within 1 to 5 seconds)?</p> <ul style="list-style-type: none"> • Can you think of any examples, at home, where you use food as reinforcement with your child? • Can you explain how other family members may use edible reinforcements with your child? • Can you tell me about other individuals that may come in contact with your child and how they may use edible reinforcements with your child? <p>Has a clinician ever told you to use food as reinforcement for behaviours at home? [If YES] Can you tell me a little bit more about this?</p>
Others using edible reinforcement	<p>Roughly, how often would you say you use FOOD reinforcement?</p> <ul style="list-style-type: none"> • Per/day and/ or per/activity?
Accumulation Factors	<p>NOW I would like to ask you about the use of REWARDS when parenting your child with ASD. This is a little bit different than reinforcement. A reward is a stimulus that can be provided to your child at ANY TIME, in response to a desired behaviour. If your child does something positive they can get a reward for it. For example, in therapy, if a child is well behaved and follows instructions all day the therapist may let him/her play in their favourite room at the end of the session. * A reward is not always provided immediately (1-5 seconds) after the positive behaviour.*</p> <p>Do you ever use food as a reward with your child with ASD?</p>
Edible REWARD	

	<p>Others using edible reward</p> <p>Accumulation Factors</p>	<p>What are your thoughts about using food as a reward?</p> <ul style="list-style-type: none"> • Can you think of any examples, at home, where you use food as reward with your child with ASD? • Can you explain how other family members may use edible rewards with your child with ASD? ? • Can you tell me about other individuals that may come in contact with your child and how they may use edible rewards with your child with ASD? <p>Has a clinician ever told you to use food as REWARDS for behaviours at home?</p> <p>[If YES] Can you tell me a little bit more about this?</p> <p>Roughly, how often would you say you use FOOD rewards with your child?</p> <ul style="list-style-type: none"> • Per/day and/ or per/activity? <p>What are your views on this statement: “if you don’t finish your dinner you do not get your dessert?”</p> <p>Do you have any additional thoughts as to why you would use food as reinforcement?</p> <p>Do you have any additional thoughts as to why you would use food as a reward? (Potential answers: e.g. do not know what else to do, convenient, money)</p>
Coming to a close: In this section I would like to ask the interviewee for suggestions they have that could assist with improving the food related environment in the home (and elsewhere)?		
I: In this section I would like to discuss your ideas that might be helpful moving forward ...	Focusing attention	<p>Are there things that your family could do to help in changing your child’s eating behaviours?</p> <ul style="list-style-type: none"> • What areas of feeding and eating are most important for you and your family to consider when trying to have a healthy lifestyle? • What areas of feeding and eating are most important for your child with ASD to have?

	<p>Have you ever sought help or advice for feeding or eating behaviours in your child with ASD?</p> <p>If YES: Where have your sought help or advice?</p> <p>Do you think it would be beneficial to speak to a registered dietitian to ask them questions about feeding or eating behaviours in your child with ASD?</p> <ul style="list-style-type: none"> • If YES: What would you like to discuss with them? <p>Do you think it would be beneficial for your family to speak to anyone else about specific feeding or eating questions?</p> <p>What strategies have you, and your family, found that work at getting your child to eat? In the past, what have you found works for you and your family when addressing your child's food-related challenges?</p> <p>Winding down with the interview... Is there anything else you would like to add? Is there anything else that should be considered in exploring feeding behaviours and food environments in children with autism? Any additional thoughts or feelings you have about the study? Any additional questions you have regarding the details of the study?</p>
Interviewer: I would like to take the opportunity to thank you for participating in this interview. If you have requested for a transcript of this interview session, we will mail them to you as soon as they are available. Please be advised that due to study time constraints, it will be requested that transcripts are returned within two weeks of receiving them.	

Appendix C: Ethics Approval Letter



RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

Date: January 24th, 2014

To: Sarah Prosser (PI), Ellen Vogel (Co-I), Meghann Lloyd (Co-I) and Caroline Hunt (Co-I, [REDACTED])

From: Manon Lemonde, REB Vice-Chair

REB File #: 13-050

Project Title: An exploratory study of parents' experiences with feeding behaviours and food environments in children with autism spectrum disorder (ASD)

DECISION: CHANGE REQUEST APPROVED

CURRENT EXPIRY: November 18th, 2014

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the above research proposal. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and the UOIT Research Ethics Policy and Procedures.

Please note that the (REB) requires that you adhere to the protocol as last reviewed and approved by the REB.

Always quote your REB file number on all future correspondence.

Please familiarize yourself with the following forms as they may become of use to you.

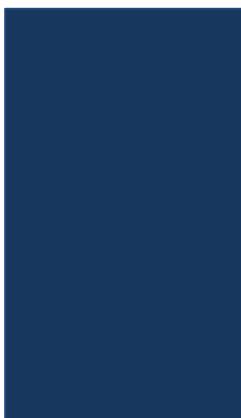
- **Change Request Form:** any changes or modifications (i.e. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or unexpected Events Form:** events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol. (I.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** must be completed when the research study has completed.
- **Renewal Request Form:** any project that exceeds the original approval period must receive approval by the REB through the completion of a Renewal Request Form before the expiry date has passed.

All Forms can be found at <http://research.uoit.ca/faculty/policies-procedures-forms.php>.

REB Vice-Chair Dr. Manon Lemonde, Health Science manon_lemonde@uoit.ca	Ethics and Compliance Officer compliance@uoit.ca
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University of Ontario, Institute of Technology
2000 Simcoe Street North, Oshawa ON, L1H 7K4
PHONE: (905) 721-8668, ext. 3693

Appendix D: Letter of Support



September 13, 2103

UOIT Research Ethics Board
2000 Simcoe Street North
Oshawa, Ontario
L1H 7K4

Dear UOIT Research Ethics Board:

I am pleased to provide a letter confirming our participation in the Master's Thesis research project of Ms. Sarah Prosser, under the supervision of Dr. Ellen Vogel, Dr. Meghann Lloyd and Dr. Carolyn Hunt. This research project will encompass an exploratory study of parents' experiences with feeding behaviours and food environments in children with Autism Spectrum Disorder (ASD).

We understand that recruitment of approximately 6-8 participants will take place through the medical clinic of [REDACTED]. We understand [REDACTED] will be contacting parents of children with documented food/feeding issues in their child with ASD on her case load and asking them if they would be interested in a voluntary research project where they will be interviewed by Ms. Sarah Prosser on this topic.

We are pleased to be hosting and collaborating with these researchers.

Sincerely,



Executive Director

...leading the way to excellence in services for children and youth with special needs and their families in Durham Region.



A Registered Charitable Organization

Appendix E: Study Inclusion and Exclusion Criterion

In this study, the paediatric doctor at the Supportive Community Organization (SCO) will select participants. The paediatrician and Supportive Individual (SI), has expert knowledge of families and their characteristics that will allow her to make appropriate decisions on participants that best suit the study. Participation characteristics include:

- Parent that has a child diagnosed with ASD (Diagnosis using DSM-IV and/or DSM-V)
- The child is between the ages 2-5 prior to the study commencement
- Families are enrolled in services at the SCO or on a wait list for services

Study characteristics include families that have previously expressed at least one concern to the SI, regarding:

- Food issues in their child with ASD
- Feeding preferences in their child with ASD
- Feeding patterns in their child with ASD
- The family and feeding environment
- Increased risk of developing a weight problem
- Existing weight issues in their child with ASD
- Treatment approaches utilized that are affecting the food behaviour and feeding environment

Study characteristics that exclude specific characteristics, include:

- Children with severe feeding deficits, resulting in the utilization of medical assistance for the child to meet the dietary needs (e.g. GI tube)
- Children with severe oral-motor deficiencies that impact food behaviours

Appendix F: Consent Form

Informed Consent:



UNIVERSITY OF ONTARIO
INSTITUTE OF TECHNOLOGY

2000 SIMCOE STREET NORTH
OSHAWA, ON, CANADA L1H 7K4

PH905.721.8668
www.uoit.ca

Study: *An exploratory study of parents' experiences with food behaviours and feeding environments in children with autism spectrum disorder (ASD).*

Investigators:

Sarah Prosser Faculty of Health Sciences
University of Ontario Institute of Technology
905-242-6820
sarah.prosser@uoit.ca

Dr. Ellen Vogel Faculty of Health Sciences
University of Ontario Institute of Technology
905-721-8668, ext. 2518
ellen.vogel@uoit.ca

Background and Rationale:

You have been selected to participate in an exploratory study of food behaviours and feeding environments experienced in children with autism spectrum disorder (ASD). The present exploratory study will be carried out by a researcher from the University of Ontario Institute of Technology (UOIT), as a part of the Masters in Health Science Program. We ask that parents' of the child with autism voluntarily participate in an in-depth semi-structured interview. With this research, it is hoped that the interviews will provide useful information about feeding behaviours experienced in the home environment.

Why is this study important?

There is increased prevalence of feeding issues in children with autism spectrum disorder (ASD). To understand factors that may influence these issues, research is required.

Feeding behaviors and food environments of children with autism will be explored from the perspective of the parent. When looking specifically at childhood development, parents have an important role in caring for their child. Through one-on-one interviews parents' will have the opportunity to express their knowledge, understanding, and issues that they, or their family, experience when caring for a child with autism. This study will provide useful insight based on parents' experiences and how these experiences may be different from other populations.

Study Procedures:

One-on-one interview will be conducted and last approximately forty-five to sixty minutes in length. Interviews will take place, in an office setting, at the University of Ontario Institute of Technology (UOIT), or off-site in the homes of the participants. The researcher will ask the participant general question to guide the interview, as well as open-ended and probing questions to gain insight on the topic of study. Participants have the right to refuse to answer questions that will be asked. The interview will be audio recorded. Recorded interviews will be transcribed to allow the researcher to appropriately analyze the data. Once transcripts are available, copies will be sent, via mail, to participants who request them to allow for member checking. This study has been designed to explore parents' experiences with food behaviours and feeding environments when having child with ASD. The qualitative interviews will provide parents the opportunity to openly express information and insights about the topic.

Risks and Benefits:

There is minimal risk associated with this research. During the interview parents will be asked questions regarding the food behaviours and feeding environments of their child with ASD and their families. It is stressed that this interview will be used to understand parents' experiences regarding this topic. This interview does not intend to place blame or judge any responses made by the participant. By signing this consent form you are in no way waiving your legal rights or releasing the investigator and the sponsor from their legal and professional responsibilities. Additionally, withdrawing yourself from the interview will have no effect on any services that you may be currently receiving.

There are many benefits that can result from the study at hand. Parents will have the ability to express, inform, and or explain their child's eating behaviours. This allows the researcher to observe this population through the eyes of parents, who have personal experience on this topic. Experiences can help the researching community increase their knowledge and information about children with ASD. Increasing awareness about the population is important to understand eating behaviours that are occurring in children with ASD, which may be different from children with typical development. The ultimate goal of this research is to understand and gather information about feeding behaviours in the home environment; in hopes to improve knowledge and awareness regarding experiences in this population. It is projected that a peer-reviewed paper will be published in academic literature from this study.

Confidentiality:

During the data collection, the participants' information will be contained within a paper file folder to ensure confidentiality and safety. During analysis all of the data will be kept on a locked computer that requires a password for access. Audiotapes will be converted to the appropriate format to allow for transcription. These files will be stored on an encrypted USB and kept with the rest of the data. All notes, audiotapes, transcripts, and study information will be stored without identifiers in a locked filing cabinet in a locked office. During transcription, participant information will be made anonymous. Direct identifiers and names of participants will be removed from the data and will not be used in the research findings. Direct quotes used from interviews will not be connected to specific individuals. If publication were to result, data will only contain unidentified group data. The principal investigator and the faculty supervisors will be the only individuals with access to data. The University of Ontario Institute of Technology (UOIT) Ethics Board will have access to the records for auditing purposes. Limits of confidentiality include situations of subsection child abuse, concerns of harm to self or others, or any request for information by court order.

Contact Information:

If you have questions about this study, please contact:

Principal Investigator

Sarah Prosser

Masters in Health Science candidate

University of Ontario Institute of Technology

2000 Simcoe St. North

Oshawa, ON; L1H 74K

905-242-6820

sarah.prosser@uoit.ca

Co-investigator & Supervisor

Ellen Vogel, PhD, RD, FDC

Dean of Health Science

University of Ontario Institute of Technology

2000 Simcoe St. North

Oshawa, ON; L1H 74K

(905) 721-8668 (ext. 2518)

ellen.vogel@uoit.ca

This study has been reviewed by the University of Ontario Institute of Technology Research Ethics Board (REB# 13-050). The goal of this committee is to ensure the protections of the rights and welfare of people participating in research. If you have any questions about your rights as a research participant please contact the University of Ontario Institute of Technology Research Ethics Board at 2000 Simcoe St. N., Oshawa, ON, L1G 7K4, 905-721-8668 (ext. 3693) or compliance@uoit.ca.

Informed Consent: Interview Participants

SECTION 1

Study: *An exploratory study of parents' experiences with feeding behaviours and food environments in children with autism spectrum disorder (ASD).*

I, (Please Print)

(Participant/Your Name)

- I have read and understand the information regarding the study: *An exploratory study of parents' experiences with feeding behaviours and food environments in children with autism spectrum disorder (ASD).*
- I understand this study is exploring feeding behaviours experienced by parents' that have a child with ASD.
- I understand that I have volunteered to participate in an interview to discuss my child's feeding behaviours. I am aware I will be asked questions about my child's dietary lifestyle, as well as any impacts it may have on my own lifestyle and my families.
- I understand this interview will last approximately 45-60 minutes in length, and will be audio recorded.
- I understand that everything I say will be confidential and will remain anonymous.
- I understand all data collected will be stored safely in a locked cabinet at UOIT, until it is destroyed.
- I recognized that my participation in this study is voluntary and that I am able to withdraw from the study at any time during the interview, if necessary.
- I understand that this study is being conducted for research purposes and may be published in academic journals at some point in time.
- I am aware that post-interview I have the opportunity to request to review a transcribed interview.
- I have been fully informed of the details of the study and understand I can discuss any question or concerns I have with the researcher.

I,, (Please Print)

(Participant/Your Name)

1. Have read and understand the information concerning this research project
2. I understand I am free to ask questions as necessary
3. I indicate free consent to participating in this research by signing the consent form.

Name of Parent/Guardian

Contact phone number

Email

Signature of Parent/Guardian

Date

Investigator's signature

Date

SECTION 2

It is requested by the research to gain more information on the height and weight of your child. If you allow the researcher to do so, please sign below. If not, please move onto the next section.

I _____ (Please print) give my permission for the Supportive Individual (SI) to provide the researcher with the height and weight measurements of my child with ASD.

SECTION 3

I would like to receive a copy of the transcribed interview (circle one):

Yes

No

Request for Transcript

If you circled YES and wish to receive and review a copy of the transcribed interview, please sign BELOW and provide your contact information. If you do not wish for a copy of the interview, please sign the transcription release form that will be given to you.

I, (Please Print)

1. Would like to receive a copy of the transcribed interview.
2. Once, received I will review and return it to the research with suggestions (if applicable).
3. A signed transcript release form will be provided with the returned interview, to allow the researcher to analyze the approved transcribed data.

Signature of Parent/Guardian

Date

Contact Information (please PRINT)

Name: _____

Address: _____

City/ Province: _____

Postal code: _____

Email: _____

*Due to study time constraints, respondents will be asked to return the transcript within two weeks of receiving the document. Reminders, via email or mail, will be sent out two weeks after mailed date, to ensure participants return transcripts to allow for data analysis. *

Appendix G: Transcript Release Form (mailed)

Transcript Release Form (mailed)



UNIVERSITY OF ONTARIO
INSTITUTE OF TECHNOLOGY

2000 SIMCOE STREET NORTH
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Ph 905.721.8668
www.uoit.ca

Study: *An exploratory study of parents' experiences with food behaviours and feeding environments in children with autism spectrum disorder (ASD).*

Investigators:

Sarah Prosser	Faculty of Health Sciences University of Ontario Institute of Technology 905-242-6820 sarah.prosser@uoit.ca
Dr. Ellen Vogel	Faculty of Health Sciences University of Ontario Institute of Technology 905-721-8668, ext. 2518 ellen.vogel@uoit.ca

I, (Please Print)

1. I have received a copy of the transcribed interview.
2. I have had the opportunity to review the transcribed interview and have made changes (if applicable).
3. By signing this transcript release form I am aware that I am agreeing to the information stated in the interview.
4. By signing this release form I am allowing the researcher to begin the analysis of this reviewed and corrected interview.

Name of Participant (please print)

Signature of Participant

Date

*Due to study time constraints, respondents will be asked to return the transcript within two weeks of receiving the document. Reminders, via email or mail, will be sent out two weeks after mailed date, to ensure participants return transcripts to allow for data analysis. *

Appendix H: Transcript Release Form (not mailed)
Transcript Release Form (NOT receiving an interview COPY)



UNIVERSITY OF ONTARIO
INSTITUTE OF TECHNOLOGY

2000 SIMCOE STREET NORTH
OSHAWA, ON, CANADA L1H 7K4

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Sarah Prosser	Faculty of Health Sciences University of Ontario Institute of Technology 905-242-6820 sarah.prosser@uoit.ca
Dr. Ellen Vogel	Faculty of Health Sciences University of Ontario Institute of Technology 905-721-8668, ext. 2518 ellen.vogel@uoit.ca

I, (Please Print)

1. I have chosen to NOT receive a copy of the transcribed interview.
2. By signing this transcript release form I am aware that I am agreeing to the information stated in the interview.
3. By signing this release form I am allowing the researcher to analyze this interview.

Name of Participant (please print)

Signature of Participant

Date

Appendix I: Statement of Confidentiality (2 forms)

Statement of Confidentiality for Investigator, Co-investigator, and Supervisory Committee

Study: *An exploratory study of parents' experiences with food behaviours and feeding environments in children with autism spectrum disorder (ASD).*

Name of investigator, committee member, and supervisory committee (Please print):

PLEASE READ

Confidentiality and respect of privacy are crucial in research to ensure protection of the rights of research subjects. *Respect for human dignity also implies the principles of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are considered fundamental to human dignity. Thus, standards of privacy and confidentiality protect the access, control and dissemination of personal information. In doing so, such standards help to protect mental or psychological integrity. Further, they are consonant with values underlying privacy, confidentiality and anonymity.* [Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans, 1998].

As it has been laid out by the Tri-Council Policy Statement, this current study will ensure anonymity and confidentiality for all research subjects, as well as ensuring confidentiality off-site. Once the interviews are recorded, any identifiers in the data collected will be removed. All notes, audiotapes, transcripts, and study details will be stored without identifiers in a locked cabinet in a locked office when the researcher is not analyzing the data. The only individuals with access to this data will be the research and the research supervisor. All raw data will be destroyed 7 years after it is collected, in accordance with the UOIT policy. Transcripts will be available for participants to review and validate the statements made during their interview. No names of participants will be presented in the research findings. Direct quotes used in the final study will only include anonymized data, to ensure that there will be no connections to specific individuals. If publication were to result, data will contain de-identified group data.

In signing below you are agreeing to respect the right to privacy of all participants in this study as well as that of other individuals who may be identified through the data collection and/or analysis process. As an investigator, committee member, or co-investigator all information shall not be shared in a public environment or with friends or family members to respect the confidentiality and anonymity rights that the participants deserve. The study and its participants are to be discussed only during research meetings.

In signing below you are indicating that you understand the following:

- I understand the importance of providing anonymity and confidentiality to research participants;
- I understand that the raw data may contain references to the individual and/or other individuals, I understand that this information will be kept strictly confidential;
- I understand that the raw data are not to be discussed outside of research meetings;
- I understand that data files (electronic and printed versions) are to be secured at all times (i.e., not left unattended). Further, data files will be stored as outlined in the Letter of Information and Consent approved by the UOIT Research Ethics Board.

In signing my name below, I agree to the above statements and promise to ensure the participants in this study anonymity and confidentiality.

Signature of the investigator, co-investigator, and supervisory committee:

Signature

Date

Statement of Confidentiality



PLEDGE OF CONFIDENTIALITY

I have read and understand the [Supportive Community Organization (SCO)] policy on confidentiality (Personnel Manual, #1-30).

I understand that all clients, staff and financial information to which I have access is confidential and is not to be communicated to anyone, in any manner, except as outlined in the policies identified above.

I further understand that any infraction of this policy may result in disciplinary action, up to and including dismissal.

Employee Name (please print): _____

Signed: _____

Witnessed: _____

Dated: _____

Appendix J: Telephone Recruitment Script

Verbal telephone script for participant recruitment (Provided to the SI, Supportive Individual)

Purposeful sampling will be the only method used to gather participants for the study. The paediatrician, the SI, has expert knowledge of families and their characteristics that will allow her to make appropriate decisions regarding participants that best suit the study. The SI will be calling potential participants, via telephone, to ask them if they would like to participate in this study. Parents who wish to participate will verbally volunteer themselves for the study and will allow the SI to release their contact information to the researcher. The researcher will then get in contact with the participant to establish a time to conduct the interview. A verbal script will be provided to the SI to assist her with recruiting participants. The SI will be making telephone calls to families that meet eligibility criteria and are enrolled at the Supportive Community Organization (SCO) or on the facility's wait list. The verbal script is as follows:

Verbal script

Hello, this is the SI from the SCO and I am calling to ask if you (or one of the primary caregivers in your family) would be willing to participate in a study that is being conducted by a Master's student at the University of Ontario Institute of Technology (UOIT). We are asking specific families to participate in this study to learn more about children with ASD. As part of this study we are interest in parents' experiences with food behaviours and feeding environments. This research will be carried out by a UOIT student, as a part of the Masters in Health Science Program. It is hoped that this study will increase information and awareness regarding how parents and families who live with a child with ASD experiences feeding outcomes in the home. Are you interested in hearing more about this study?

[If NO] Thank you for your time. Have a great day.

[If YES] We are seeking one parent to participate in a 45-60 minute in-person interview. The researcher will be asking parents to discuss and answer questions regarding their child with ASD, feeding behaviours, and feeding outcomes experienced in the home. Interviews will take place in an office setting at UOIT. You will be provided with directions to the facility and parking is complimentary; if you request it, interviews can take place off-site in your home. In this case, the researcher, along with a member of the research team, will travel to your families' home to

conduct the interview. It is important to understand that this study does not intend to place blame or judgment on parents' responses. This study was developed to explore the experiences of parents in order to gather more information about children with ASD and their families. Upon completion, you will be given a \$20 gift card to thank you for your time and contribution to the study. Would you like to participate in this study?

[If NO] All right, no problem. Thank you for your time and have a great day.

[If YES] Great! In order to create a time for the interview I would need to provide your contact information (telephone number) to the researcher, Sarah Prosser. Do I have your verbal permission to give your telephone number to the researcher, in order for her to contact you directly to set up an interview time?

[If NO] Thank you for your time. Have a great day.

[If YES] Perfect. The researcher, Sarah Prosser, will get in contact with you shortly to establish a time and place to conduct the interview. Do you have any questions?

[If YES] Answer questions.

[If NO OR after questions answered] Thank you for choosing to participate in this study and you will be hearing from the researcher shortly. Have a great day!

Appendix K: Research Recruitment Script

Verbal telephone script to create an interview time (For the Researcher)

Participants that agree to participate in the study will allow the SI to give the researcher, Sarah Prosser, their telephone number. She will use this number to contact the participant and establish a time and place for the interview. The interview will last approximately 45-60 minutes and take place at UOIT or off-site within the homes of the participants. A member of the research team will accompany the research to off-site interviews and will not be required for on-site data collection.

Verbal script

Hello, my name is Sarah Prosser and I am a Master's student at the University of Ontario Institute of Technology (UOIT). The SI from the Supportive Community Organization (SCO) has informed me that you are interested in participating in my study exploring how parents and families of children with ASD experience feeding outcomes in the home. Does this sound familiar?

[If NO] Thank you for your time. Have a great day.

[If YES] We are seeking **one** parent to participate in a 45-60 minute in-person interview. The researcher will ask parents to discuss and answer questions regarding their child with ASD, feeding behaviours, and feeding outcomes experienced in the home. Does this work for you?

[If NO] Thank you for your time. Have a great day.

[If YES] Perfect. I would like to arrange a time that we could meet up to conduct the interview. If possible, we would like parents' to come to UOIT. Directions will be provided and parking is complimentary. If you are unable to come to UOIT, and you make the request, interviews can take place off-site in your home. Would you be willing to come to UOIT to participate in the interview?

YES TO UOIT	NO TO UOIT
[If YES] Perfect, I would	[If NO] Not a problem. Would you like to conduct the interview at your home?

<p>now like to establish a time to conduct the interview (Use schedule and determine a date and time.</p> <p>During this time I will also provide directions). Do you have any questions?</p> <p>[YES] Answer questions</p>	<p>[If YES] When conducting the interview in the home, a member of the research team will accompany me. The member of the research team will not ask any questions, and will only be present to provide support to me. During the time of the interview, it is asked that you are able to provide an environment that allows for undisturbed conversation. How does that sound?</p> <p>← [If NEGATIVE] Refer to asking them to come to UOIT again.</p> <p>[If YES] Great, I would now like to establish a time to conduct the interview. (Use schedule and determine a date and time. Receive address and directions) Do you have any questions?</p> <p>[YES] Answer questions</p>
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[NO more questions] Thank you for your time and for helping me with my research project – I look forward to meeting you!

Appendix L: Thank you Letter (With Gift card and list of services inside)



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Sarah Prosser
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BaHSc, MHSc Candidate
University of Ontario Institute of Technology (UOIT)
2000 Simcoe Street North
Oshawa, ON
L1G 7K4

Dear interview participant,

I would like to thank you for your participating in the study: *An exploratory study of parents' experiences with food behaviours and feeding environments in children with autism spectrum disorder (ASD)*.

Your participation in this research and the insight you provided is much appreciated. Your ability to express, inform, and explain your experiences is valued. Providing personal insight is important to allow researchers to see through the eyes of parents and those that have experience and expertise in caring for children with autism. Your contribution to the study will be utilized to understand feeding behaviours, food environments, and the health of children with autism. It is my hope, as a researcher, that the valuable information obtained in this study will be a great addition to literature, specifically studying children with autism spectrum disorder.

Thank you again for your participation, time, and consideration.

Sincerely,

Sarah Prosser

"Research is creating new knowledge" –Neil Armstrong

Appendix M: List of Contacts

List of Contacts

Specialty: Supportive Services

Contact: **Lake Ridge Community Support Services (LRCSS)**

Phone number: 905-666-9688

Email / website: <http://www.lrcss.com/ContactUs.html>

Address: 900 Hopkins Street Unit 8

Whitby, Ontario

L1N 6A9

Specialty: Supportive Services

Contact: **Resources for Exceptional Children and Youth – Durham Region**

Phone number: 905-427-8862

Email / website: <http://www.rfecydurham.com/>

Address: 865 Westney Road South

Ajax, Ontario

L1S 3M4

Specialty: Finding Assistance

Contact: **Ontario Ministry of Children and Youth Services** (Programs & services for children with autism)

Phone number: 1-8666-821-7770 (Toll free)

Email / website:

<http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/index.aspx>

Address: M-1B114, Macdonald Block,
900 Bay Street, Toronto ON
M7A 1N3

Assistance: Finding a Dietitian

Contact: **Dietitians of Canada**

Phone number: 416-596-0857

Email / website:

<http://www.dietitians.ca/About-Us/Contact-Us/Overview.aspx>

Address: 480 University Avenue,
Suite 604 Toronto, Ontario,
M5G 1V2

Assistance: Online Tools

Contact: Health Canada (Food guide)

Email / website: <http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>

Services offered: Access to the Canadian food guide, can request a copy or the guide, and can create your own food guide, etc.

Specialty: Networking Tools

Contact: Family Networking Services

Phone number: 905-728-2281

1-800-6180-2281

Email / website: andrea.belanger@grtc.ca

Service Offered: Connect with families dealing with similar challenges to you own.

There is a family resource center located in the atrium of the Supportive Community Organization (SCO)

Specialty: Online Search Tools

Contact: Information Durham: Organization and Program Search

Phone number: 905-434-4636

1-866-463-6910 (Toll-free)

Email / website: <http://www.informdurham.com/>

Address: 144 Old Kingston Rd

Ajax, ON

L1T 2Z9

Assistance: Online Tools

Contact: Autism Canada

Email / website:

<http://www.autismcanada.org/index.html>

Services Offered: About Autism, Treatments, Research, Involvement, and Conferences

Specialty: Networking Tools

Contact: Ontario Telemedicine Network- Video Conferencing

Email / website:

http://www.lrcss.com/videoconferencing2/Training_Events_list.asp

Services Offered: Video conferencing used in link LRCSS that is expanding on providing care to increase access.