

# **Feeding problems and current dietary practices in children with autism spectrum disorder in England**

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March 2012

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## **Abstract:**

**Objectives:** Children with autism spectrum disorder (ASD) are known to have feeding difficulties. This study gathered information from parents/caregivers with children diagnosed with ASD. The following aspects were investigated: early feeding history, food preferences, sensory issues, current dietary practices and the use of nutritional supplements and special diets. The study also gathered information regarding these families' experience with dietitians in supporting them with advice related to dietary problems.

**Methodology:** An online questionnaire was used and the link to the study was placed on the National Autistic Society (NAS) of the United Kingdom's website to recruit participants. Parents/ caregivers of children aged between 3-16 years and diagnosed with ASD, who resided in England, could take part in the study.

**Results:** Three hundred and twenty five parents/ caregivers participated in the study. The mean age of children was 9.5 years. The majority of children were male (85%). The most common feeding problem was the transition from stage 1 weaning foods to more textured food (55.6%). Sensory problems played a large role in food acceptance. Clear preferences were made for crunchy (81.5%) or dry foods (79%), followed by food with a smooth consistency (69.8%) such as yogurt. Food appearance and presentation (64%) was the main determinant of food acceptance and specific brands and packaging played a major role. Habitual food intake and continually choosing the same foods for meals were present in the majority of children (75.6%). Specific preference was given to the following foods: starchy vegetables (62.6%), refined carbohydrates (81%), processed meat products (69.2%) and dairy products (68.6%). The use of 'special' and exclusion diets were not popular. However, where specifically gluten and/ or casein were excluded (19%, n=55), it was generally excluded for more than one year. Reported observations with these exclusions were: improvement in bowel habits, sleep, concentration, behaviour and social communication. The use of nutritional supplements were significantly higher ( $p < 0.5$ ) where exclusion diets were used. A large number of children (43.4%, n=23) on exclusion diets, have not been consulted by a dietitian. Most parents /caregivers (58.1%) had the perception that dietitians were lacking knowledge of ASD and had inadequate knowledge of current dietary interventions for children with

ASD (61.7%). However, parents felt that it was reassuring to consult a dietitian, that practical advice was given to improve dietary intake and that generally it reduced their concern regarding their child's dietary intake.

**Conclusion:** The study highlights the complexity of ASD and the variable effect it has on eating, behaviour and dietary intake. The use of the gluten and casein free (GFCF) diet may improve general wellbeing in some children with ASD when used appropriately and warrants further investigation. It is concerning that only a minority of children on exclusion diets are consulted by dietitians to ensure nutritional adequacy. Due to the complexity of ASD and in the absence of clear guidance for dietary interventions, dietitians who work with children with ASD need to be supported by continued training opportunities in order to enhance their competencies and optimise their service delivery.

## Opsomming:

**Doelwitte:** Kinders wat aan Outismespektrum-steuring (OSS) lei is geneig om voedingsprobleme te hê. Die studie het inligting ingesamel van ouers en versorgers met kinders wat met OSS gediagnoseer is. Die volgende aspekte is ondersoek: vroeë voedingsgeskiedenis, voedsel voorkeure, sensoriese probleme, huidige eetgewoontes en die gebruik van nutriëntaanvullings en spesiale diëte. Die studie het ook inligting ingesamel aangaande gesinne se ondervinding met dieetkundiges en ondersteuning met dieetprobleme.

**Metodologie:** 'n Elektroniese vraelys is gebruik en die skakel na die studie was op die webwerf van die *National Autistic Society (NAS)* van die Verenigde Koninkryk geplaas om deelnemers te werf. Ouers/ versorgers van kinders tussen die ouderdomme van 3-16 jaar, met 'n diagnose van OSS en woonagtig in Engeland, kon deelneem aan die studie.

**Resultate:** Drie honderd vyf en twintig ouers/ versorgers het deelgeneem aan die studie. Die gemiddelde ouderdom van die kinders was 9.5 jaar en 85% was manlik. Die mees algemene voedingsprobleem vir kinders met OSS was die oorgangsfase van gladde speningsvoedsel na growwer voedsel (55.6%). Sensoriese probleme het 'n groot rol gespeel in voedselaanvaarding. Daar was duidelike voorkeure vir bros (81.5%) en droë voedsel (79%), gevolg deur voedsel met 'n gladde tekstuur soos jogurt (69.8%). Die voorkoms en aanbieding van voedsel het grootliks bepaal of voedsel aanvaarbaar (64%) is. Spesifieke handelsmerke of verpakkings het 'n groot rol gespeel (64.7%). Die meeste van die kinders (75.6%) het vaste eetgewoontes gehad en dieselfde kos tydens maaltye gekies. Die volgende voedselsoorte was verkies: styselryke groente (62.6%), verfynde koolhidrate (81%), geprosesseerde vleis produkte (69.2%) en suiwel produkte (68.6%). Die gebruik van spesiale en uitsluitingsdiëte was ongewild. Waar gluten- en kaseïen-uitsluitingsdiëte (19%, n=55) gebruik is, is dit meestal vir langer as een jaar gebruik. Met die gebruik van uitsluitingsdiëte is verbeteringe waargeneem in stoelgang gewoontes, slaap, konsentrasie, gedrag en sosiale kommunikasie. Die gebruik van nutriëntsupplemente was beduidend hoër ( $p < 0.5$ ) in die groep waar uitsluitingsdiëte gebruik is. 'n Hoë persentasie kinders (43.4%, n=23) wat op uitsluitingsdiëte was, is nie deur dieetkundiges gekonsulteer nie. Die meeste ouers /versorgers (58.1%) het

gevoel dat dieetkundiges gebrekkige kennis oor OSS en dieetverwante probleme het, asook onvoldoende kennis van huidige dieet intervensies vir kinders met OSS (61.7%). Ouers het wel gevoel dat dit gerusstellend was om dieetkundiges te gaan spreek vir praktiese raad om dieet inname te verbeter. Dit het ook hul kommer verminder aangaande kinders se diëte.

**Gevolgtrekking:** Die studie benadruk die kompleksiteit van OSS en die wisselende effek wat dit op eetgewoontes, gedrag en voedsel inname het. Die gebruik van die gluten- en kaseïenvrye diëte kan moontlik die gesondheid en welsyn van sommige kinders met outisme verbeter mits dit reg gebruik word, maar vereis verdere navorsing. Dit was kommerwekkend dat 'n minderheid van die kinders op uitsluitingsdiëte deur dieetkundiges gekonsulteer word om voldoende nutriëntinname te verseker. Aangesien OSS 'n komplekse toestand is en daar 'n gebrek is aan duidelike riglyne vir dieet intervensies, word dit aanbeveel dat dieetkundiges wat met kinders met OSS werk ondersteun word deur opleidingsgeleenthede om hul vaardighede te verbeter en dienslewering te optimaliseer.

## LIST OF DEFINITIONS

Asperger Syndrome	A form of autism and includes the three main areas of impairment such as with ASD and autism. <sup>1,2</sup> People with Asperger syndrome usually have fewer problems with speech development and have average or above average intelligence. <sup>3</sup>
Autism	Part of the collective term ASD's and also called 'autistic disorder' or 'classic autism'. <sup>1</sup>
Autism Spectrum Disorder (ASD)	ASD is a complex developmental disorder and causes delays or problems during the developmental period between infancy and adulthood. The term is used to cover the range of conditions that include all of the following: impairment of social interaction, social communication and social imagination. <sup>1</sup> The word 'spectrum' is used as people with autism share all three main areas of difficulty; however their condition will affect them in very different ways. <sup>2</sup> ASD included: autism, and Asperger syndrome. <sup>1,3</sup>
Casein	One of the two cow's milk proteins.
Exclusive breastfeeding	Breastfeeding exclusively from birth without the use of any supplemental feeds such as infant formula. <sup>4</sup>
Gluten	Main protein found in wheat, rye and barley.

Omega 3 and 6 fatty acids	Long chain polyunsaturated fatty acids that play an essential role in brain development and function. <sup>5</sup>
Pervasive Developmental Disorder (PDD)	A broad term used by some to describe autism. These include the ASD's, Childhood disintegrative disorder and Rett syndrome. <sup>1</sup>
Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)	Also called 'atypical autism'
Rickets	A disorder in growing children causing newly formed bone to be inadequately mineralised. This causes bone deformities, especially on weight bearing limbs. Causes are: Vitamin D deficiency, calcium deficiency, or phosphate deficiency. <sup>6</sup>

**LIST OF ABBREVIATIONS:**

AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
GFCF	Gluten and casein free
LRNI	Lower recommended nutrient intake
NAS	National Autistic Society (UK)
PUFAs	Polyunsaturated fatty acids
RNI	Recommended Nutrient Intake
UK	United Kingdom



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## **Contributions by principle researcher and fellow researchers**

The principal researcher, Leanie Huxham, developed the idea and the protocol. The principal researcher planned the study, undertook data collection and captured the data for analyses. Data was analyzed with the assistance of a statistician, Prof DG Nel, who interpreted the data and was drafted in the thesis. Mrs M Marais and Mrs E van Niekerk provided input at all stages and revised the protocol and thesis.

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# CHAPTER 1

## LITERATURE REVIEW

## 1. LITERATURE REVIEW

### 1.1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a condition where children present with a cluster of symptoms associated with communication and behaviour during an important developmental age (usually before the age of three years). These children present with impaired interaction and communication with others, and impaired imagination skills.<sup>1</sup>

The term ASD refers to the following diagnoses:

*Autism or classical autism*, also known as Kanner's syndrome and infantile autism.<sup>7</sup> Characteristics may be present from two and a half years of age. Children with autism have difficulties in communication and forming relationships with other individuals. They cannot comprehend what other people feel and many prefer to remain isolated. They also have difficulties in speech development and understanding abstract concepts. Repetitive behaviour and stereotyping is common. Children with autism find any type of change extremely difficult to cope with; therefore routine is an important aspect of the condition. Approximately 50% of children with autism have learning difficulties; however, some may have exceptional intelligence and talent.<sup>8</sup>

*Pervasive developmental disorder not otherwise specified (PDDNOS)* or atypical autism is when children's behaviour are similar, but not identical to all the characteristics of typical autism.<sup>3,7</sup>

*Asperger Syndrome (AS)* incorporates similar social communication difficulties to ASD and PDDNOS. However, as speech is present, it is sometimes considered to be a milder form of autism.<sup>7</sup> Generally children with AS will achieve developmental milestones for childhood, sometimes before typical children.<sup>9</sup> Characteristics include a lack of interest in other people, disordered social interaction and communication, overformal styles of speech, and fixation on specialized interests or hobbies (such as timetables). Intelligence levels can be above average.<sup>8,10</sup>

For the purpose of this study, the term ASD will be used to include children with various autistic conditions and characteristics that fall under the umbrella term of ASD (i.e. autism, PDDNOS, and AS).

There are limited epidemiological studies in this area and therefore it is difficult to predict an accurate prevalence. Problems arise with studies using different diagnostic criteria. There is currently no central register of people with ASDs and therefore current projections are based on epidemiological studies done in the UK. The estimated current population in the UK in 2009 was 61.8million and data from the National Autistic Society (NAS) show that there may be over 500 000 people in the UK with autism. Research also suggests that there may be over one in 100 children on the autism spectrum, indicating that approximately 1% of children in the UK may have a level of ASD.<sup>9</sup>

The term 'Autism spectrum disorder' is relatively new to the medical world and only became an official diagnosis in 1980.<sup>11</sup> As awareness increases about the disorder, more speculation is raised to what the actual cause is, and how the condition can be treated and prevented. There is currently no known single cause of ASDs. Current theories suggest that there may be an underlying genetic predisposition. Post-mortems have showed abnormal levels of neurotransmitters, in particular serotonin, and other abnormalities in the cerebellum, frontal lobes and brain stem – suggesting there may be a biological cause. Other possible factors may include viruses, metabolic and immune dysfunction during pregnancy. Research by Whiteley et al has indicated that ASD may be linked to the incorrect metabolism of casein and gluten in the diet and thus eliminating these proteins from the diets of children with ASD is beneficial.<sup>9</sup> Despite the lack of evidence of its efficacy this remains the most commonly requested dietary intervention used as a 'treatment' for autism or related gut problems.<sup>12</sup>

There is limited scientific information available to parents on dietary interventions for ASD. Different dietary interventions recommended on the internet or from various professionals can be overwhelming and often conflicting in advice.<sup>13</sup> Parents are also increasingly turning to alternative dietary interventions and supplements such as omega-3 fatty acid supplements, high dose vitamins and yeast free diets.<sup>12</sup>

Healthcare professionals rely on sound evidence from high quality trials in order to recommend dietary interventions. Unfortunately the evidence linked to diet as a treatment in autism is anecdotal and there have not sufficient good quality trials done to advocate the use of these interventions.

## **1.2 NUTRITIONAL RECOMMENDATIONS IN CHILDREN**

Children need adequate diets to meet their nutritional requirements for growth and development. Growing children need a healthy and balanced diet that is rich in fruit vegetables and starchy foods.<sup>14</sup> Therefore it is important to ensure that all children, including children with ASD, have nutritional intakes that are adequate for optimal growth and development.

Current literature suggests that children with autism may have abnormalities in their nutritional and metabolic status, compared to children of neurotypical development. However, the causes of these abnormalities are not yet understood. It has also been reported that some vitamins, minerals, amino acids and other biomarkers are associated with the variations of the severity of ASD.<sup>15</sup> However, until we have more research specifying that there are definite differences in nutritional requirements for children with ASD, dietary guidelines for the general paediatric population are used.

## **1.3 FEEDING PROBLEMS AND NUTRITIONAL INTAKE IN CHILDREN WITH ASD**

Feeding problems occur frequently among all children. Feeding difficulties in children with ASD may be similar in nature to those in typically developing children. However, such feeding difficulties are at significantly higher rates (estimated prevalence as high as 90%) in children with ASD compared to children of typical development and in the absence of ASD as a diagnosis.<sup>16</sup> A study by Schreck *et al* in 2004 compared the eating behaviours between children with ASD and children of typical development. The study confirmed what has previously been hypothesized by other researchers that children with ASD present with significantly more eating and meal-time problems than those of typical development.<sup>17</sup>

The social and communication difficulties experienced by children with ASD affects their everyday life activities including eating. Difficulties coping with unpredictable situations and change play a role in food selection and acceptance. A meal is a complex sensory experience consisting of foods and their characteristics including appearance, odour, texture, taste and auditory components.<sup>18</sup> Due to the complexity of ASD, most of the current literature available on this topic is based upon relative small study populations and thus results need to be interpreted with caution. A review of feeding problems in children with autism spectrum disorders gives possible reasons for the high prevalence of feeding problems in this group. Concentration on detail, fear of novelty, sensory impairments, problems with social compliance and biological food intolerance may also contribute. Other possible causes may be reinforcement of negative feeding patterns, parental anxiety and communication difficulties. It is further suggested that characteristics of ASD may manifest as selective eating as part of restricted interests and activities.<sup>19</sup>

Current criteria for autism diagnosis and other pervasive developmental disorders does not include feeding problems, however, there have been many reports of feeding problems in this group.<sup>16</sup> A study by Nadon et al that documented the high prevalence of food selectivity and sensory problems within this group, proposed that assessment of mealtime behaviours and sensory profile should be part of the diagnostic process.<sup>17</sup> The main feeding problems will be discussed in more detail.

### **1.3.1 Sensory Problems:**

Sensory problems are not exclusive to the population of ASD; however, many researchers agree that they exist in this population.<sup>20</sup> The NAS explains the 'sensory world of autism' as difficulty with processing everyday sensory (sight, sound, touch, taste, smell, balance (vestibular) and body awareness) information.<sup>21</sup> People with ASD may be over or under sensitive to any of the sensory areas and this is referred to as hypo- or hypersensitivity. Children who present with hyposensitivity may prefer foods which have stronger tastes, generate sound when eaten (i.e. coarse texture and crunchy) or are very hot/cold.<sup>2</sup> In contrast to this, ASD children with hypersensitivity may present with eating habits that can severely limit their dietary intake. Hypersensitivity has an effect on taste, smell, visual perception of food, auditory (sound of food when eaten) and touch. These children will often have an

aversion to strongly flavoured food, food that makes a noise when chewing, mixed food textures or even cutlery in the mouth.<sup>7</sup> Depending on the severity of oral sensitivity, children may have very limited diets.<sup>18</sup>

Children with ASD may become distressed when they are presented with food that is not acceptable and appealing to their sensory difficulties. Problems may arise from the early age of weaning where children find it difficult to progress to age-appropriate foods. Clear preferences for specific food colour, presentation and texture are common.<sup>18</sup>

### **1.3.2 Desire for familiarity and routines**

Children with ASD normally find it hard to cope with change such as new environments, experiences and people.<sup>2,18</sup> Parents and caregivers of ASD children report that these children prefer having familiar foods in specific settings compared to children of typical development of the same age.<sup>22</sup> Food is preferred in an ordered manner, such as having different food items separately on a plate.<sup>7</sup> Meals that are offered out of the normal routine or presented in a different way often cause anxiety and meal refusal is common.<sup>7,18</sup> To establish a new routine may be a lengthy process as the child's anxiety needs to be addressed.<sup>16<sup>2,16</sup></sup> Food refusal, failure to eat the usual family diet, inapt rate of eating, obsessive eating patterns, failure to accept new foods and inappropriate mealtime routines complicate mealtime for parents. Ledford and Gast reported that 46% to 89% of children with ASD may have mealtime problems.<sup>23</sup> This behaviour may have a negative impact on family life as parents and caregivers need to allocate more time to feeding rituals as opposed to other important activities.<sup>24</sup>

### **1.3.3 Selective eating:**

'Selective eating' or 'picky' and 'fussy' eating can be described as *eating a limited variety of food and refusal to eat or taste new foods.*<sup>23</sup> The presence of *neophobia* (fear of new things or experiences) may cause difficulty to accept new foods. This may also be associated with the desire for routine and fear of change in daily activities. Any changes during mealtimes may therefore heighten anxiety.<sup>25</sup> These behaviours may interfere with the child's daily routine and integration to the social environment.<sup>19</sup> Parents/caregivers of children with ASD are more likely to report their

children are 'fussy eaters' and resist trying new foods.<sup>22,26</sup> A cross-sectional study by Nadon et al compared mealtime problems in children with ASD with their typically developing siblings. They found that children with ASD showed significantly more problems during the transition from puree to textured foods as infants.<sup>23</sup> The frequency of selective eating by food type or texture is significantly higher in children with ASD than in children with typical development, and these problems may persist from infancy throughout adulthood.<sup>20,23,27</sup>

Results from an audit by Cornish concluded that children with autism had very prescriptive eating habits. Food preferences were categorized by 'wet'/'dry' food, colour, shape, specific brands and packaging.<sup>26</sup> Higher incidence of food cravings, pica and other related eating problems have also been reported in children with ASD than in children with typical development.<sup>27</sup>

#### **1.3.4 Effect of limited dietary intake on nutritional status in ASD:**

The following studies that will be mentioned are restricted in sample size. Cornish investigated the dietary intake and food-related behaviour of children (n =17) diagnosed with autism spectrum disorder (aged 3.5-10 years) in South Derbyshire (England). Diets were assessed using a 3-day dietary recall method and a food frequency questionnaire. Main concerns expressed by parents regarding their children's dietary intake included: little/no fruit and vegetables taken, little/no meat eaten, lack of fibre and problems with constipation, too much sugar, too many unhealthy foods eaten, and generally very restricted dietary intakes.<sup>26</sup>

Overeating and excessive weight gain can be a problem in children with ASD. The prevalence of obesity in this group is not necessarily higher than for the rest of the population. However, management of overweight can be more difficult in these children due to selective eating habits and preference for carbohydrates or foods and drinks with a high energy density. As in the general population, sedentary lifestyles can be a problem in this group and may cause excess body weight. However other contributors to weight gain in ASD may be medication, impaired mobility, and/or continually eating due to sensory issues for example enjoying the feel/taste or sound of food when eating.<sup>24,28,29</sup> Other reasons for overeating in children with ASD may be physical (E.g. problems with the hypothalamus therefore lacking the ability to know when they are full). Overeating could also be one of the obsessive behaviours

presented in children with ASD. Eating may turn into an obsessive and repetitive pattern leading to overeating and weight gain. Overeating may also present as a coping strategy for children to deal with stress or low self esteem.<sup>30</sup>

Although low body weight and growth may not be the main problem in this group, nutrient deficiencies may still occur due to the lack of variety in the diet. Another study by Cornish, amongst members of the National Autistic Society in South Leicestershire and Derbyshire assessed 3-day food diaries for children (n=37) with autism (aged 3-16 years) by means of a postal questionnaire. Forty two percent of the total sample had dietary iron intake below the Recommended Nutrient Intake (RNI) due to poor intake of red meat. Of the 29 children who were not following a special diet, 32% had an intake below the Lower Reference Nutrient Intake (LRNI) for iron, zinc, calcium, vitamin A, vitamin B12 and riboflavin.<sup>31</sup> Eight (22%) of these children were following gluten/casein free diets. Of these children 50% had intakes below the LRNI for zinc and calcium.<sup>31</sup> Deficiencies of these particular vitamins and minerals may have detrimental effects on a child's health. **Iron** deficiency is associated with poor growth, loss of appetite, lethargy, poor memory and slower learning.<sup>32</sup> Low **zinc** levels in typically developing children are associated with learning problems, mental retardation and hyperactivity. A case control study (n=86) comparing children with ASD with typically developing children revealed that children with ASD appear to have lower serum zinc levels ( $p<0.05$ ).<sup>32</sup> **Calcium** is particularly important for healthy bones and deficiency may lead to bone abnormalities in later life, such as osteoporosis.<sup>13</sup> Studies investigating **Vitamin A** deficiency in children with ASD found that severe deficiency caused impaired and loss of vision, however these symptoms were reversed when adequate dosages of Vitamin A were administered.<sup>32</sup> These findings were not specifically focusing on children with ASD, but highlight the detrimental effect nutrient deficiencies can cause. A case report of 60 children investigating the effects of Vitamin A supplementation in children with ASD found improvements in eye contact, vision, socialization and language, with no adverse effects noted.<sup>32</sup> Vitamin A supplementation needs to be carefully monitored by healthcare professionals to prevent toxicity. **Vitamin B12** is required for normal cell division and helps to maintain healthy blood and nerve cells. Vitamin B12 deficiency is most commonly caused by inadequate absorption from the gut. Deficiency can cause megaloblastic anaemia and peripheral neuropathy. Treatment



involves intramuscular injections of Vitamin B12.<sup>13</sup> **Riboflavin** is important for processes involved with the release of energy from proteins, fat and carbohydrates. Low intakes and deficiency could impair growth in children and cause scaliness and lesions around the mouth.<sup>13</sup>

A case report by Stewart in South Wales identified symptomatic nutritional rickets in a teenager with autism spectrum disorder, caused by **Vitamin D** deficiency. The 15 year old boy's diet had been poor since infancy. Dietary intake at the age of 15 consisted mainly of chips and gravy with refusal of all dairy products.<sup>28</sup> Although the incidence of rickets is rare in this group, this case report highlights the effect of inadequate nutrition in autism and the severe nutritional deficiencies that may develop in some children.

The nutrient deficiencies listed above may affect general health, normal growth and development in children. It is important for children who have very restricted dietary intakes to have access to a dietitian to identify possible nutrient deficiencies and to find ways to prevent and correct them.

## **1.4 DIETARY INTERVENTION**

A recent clinical review showed that ASD may be linked to the incorrect metabolism of casein and gluten in the diet.<sup>33</sup> Therefore, parents of children with ASD may exclude these from their children's' diets, to assess whether there are any positive effects on their autistic behaviours.

### **1.4.1. Gluten and casein free diet:**

The National Autistic Society (UK) as well as Members of the Mental Health Group of the British Dietetics Association reviewed the evidence for the use of gluten and casein free (GFCF) diets. Although some studies found benefits to following a gluten and casein free diet for autism, there is still limited data available to advocate this as a treatment for ASD.<sup>18,34</sup> The evidence recommends the need for more randomized controlled trials of adequate sample size.<sup>34</sup> However, in practice, many parents report significant improvements in a child's behaviour and health related outcomes

from following a strict GFCF diet and paediatric dietitians in the UK still get numerous requests from parents who want to trial this diet.<sup>18</sup>

Urinary peptide abnormalities have been reported in children with ASD for almost 30 years. Proteins in the diet are broken down to peptides and amino acids in the gut are then absorbed from the intestinal lumen.<sup>35</sup> Peptides may be present in the urine due to incomplete breakdown (due to under activity of peptidase enzymes) of proteins derived from gluten, gliadin and casein in the gut.<sup>7,36,37</sup> Gluten and gliadin are proteins found in food containing wheat, rye and barley. It forms a large part of most families' staple diets and sources include bread, pasta and flour. Casein is a protein found in cow's milk and other cow's milk based products. Casein's chemical structure is very similar to that of gluten.<sup>36</sup>

The so-called 'opioid effect' is attributed to the similarities found in behaviour when people are exposed to opioid drugs compared to characteristics of children with ASD.<sup>29</sup> Opioid activity in the brain could result in the abnormalities seen in ASD such as impaired cognition, abnormal perception, lack of appropriate emotions and other associated behaviours.<sup>31</sup> The justification for the 'opioid excess theory' is based on the fact that opioids are derived from insufficient digestion and absorption of gluten and gliadin in the gut lumen.<sup>38</sup> This is related to increased intestinal permeability known as the 'leaky gut syndrome' where the barrier between the gut and the blood system, as well as the blood and brain barrier, is impaired.<sup>6</sup> Therefore opioid substances are not only found in the urine of children with ASD, but also in their blood and spinal fluid.<sup>38</sup> It is hypothesised by Knivberg that the excess peptides present in the gut may become biologically active, enter the central nervous system, and alter signal transmission from the brain.<sup>35,37</sup> The opioids derived from gluten and casein in the gut may then affect the central nervous system and impair maturation of the brain.<sup>37</sup> A study by Reichelt found that children (n=15) with ASD who were treated with a gluten free and milk-reduced, or a milk free and gluten-reduced diet, had decreased urinary peptide secretion after the dietary intervention. They also found improvement in some autistic behaviours and decreased seizures.<sup>38</sup> The authors recommend that in order to prevent opioid excess in this population, children should be trialed on a GFCF diet for a minimum of 3 months, but recommended the use of GFCF for 12 months.<sup>18</sup> Knivberg's randomised controlled study (n=20) found a significant reduction in autistic behaviour in the gluten and casein free diet group

compared to the control group.<sup>35</sup> Even though Knivsberg's study was the only study included in the Cochrane review (2007) it was still stated that there is insufficient evidence to use GFCF diets for the treatment of autism, although this is an important area for future research.<sup>7</sup>

#### **1.4.2. Specific carbohydrate diet:**

The specific carbohydrate diet (SCD) was originally used by people with inflammatory bowel disease and other gut-related disorders. It has become popular to use in children with autism to improve symptoms of diarrhoea, constipation and food intolerances. The diet eliminates complex carbohydrates including rice, potatoes, sweet potatoes, corn and other wheat and gluten-containing grains (such as bread and baked products made from wheat, barley, rye and oats).<sup>39</sup> Complex carbohydrates (starches, lactose and sucrose) are eliminated from the diet in order to promote normal gut functioning by theoretically allowing simple carbohydrates (monosaccharide's) to be absorbed as they do not require further digestion. The bulk of the diet consists of unprocessed meat, eggs, fruits, vegetables, goat milk yogurt, nuts and seeds.<sup>39</sup> The aim of the SCD diet is to promote normal gut function. By doing so, it is anticipated that children with ASD will show improved behaviour and cognitive development.<sup>40</sup>

There is no evidence that this diet is effective or safe to use in children with ASD. To date there have been no research studies published in peer reviewed journals on the use of SCD in children or adults with ASD.<sup>40</sup> The Autism Network for Dietary Intervention (ANDI) state that there is insufficient data to support the diet's use.<sup>39</sup>

#### **1.4.3. Yeast free diet:**

The yeast free diet is related to the 'leaky gut' theory. It is believed that the 'leaky gut' in ASD is caused by yeast overgrowth and by the use of antibiotics that disturb the normal flora in the gut.<sup>7</sup> Overgrowth of yeast in the gut can be treated medically if necessary. When this diet is recommended, antifungal treatment is often used in conjunction with a yeast free diet (exclusion of fructose, sucrose and all other forms of refined sugars).<sup>7</sup> However, there is no evidence that a yeast free diet helps to control yeast overgrowth in the gut.<sup>41</sup>

#### 1.4.4. Omega 3 fatty acid supplementation:

More than 20% of the dry weight of the human brain consists of long-chain polyunsaturated fatty acids (PUFAs).<sup>42</sup> There are two categories of essential fatty acids (*omega-3 (n3)* and *omega-6 (n6)*) based on their chemical structures. A large proportion of the PUFAs in the brain are made up of long-chain *n3* fatty acids: docosahexaenoic acid (DHA) and arachidonic acid (EPA).<sup>43,42</sup> *Omega-6* fatty acids include linoleic and gamma-linolenic acids. Both *n3* and *n6* fatty acids are important for normal brain development.<sup>5,34,43</sup> They are also both derivatives of essential fatty acids (EFAs), therefore, they are not synthesized by the human body and needs to be consumed in the diet.<sup>42,44</sup> Dietary sources of *n3* fatty acids include fish, seafood, liver and egg yolk.<sup>5,39</sup> Dietary sources of *n6* fatty acids are vegetable oils, nuts, lean meat and eggs.<sup>39</sup> It is more likely for people to consume adequate amounts of *n6* fatty acids, than *n3* fatty acids.

Omega-3 fatty acids are also essential for sensory, cognitive and perception development.<sup>39</sup> As these characteristics are often impaired in children with ASD, researchers suggest that fatty acid deficiencies may be responsible for childhood neuro-developmental disorders, such as autism.<sup>44</sup> The effects of *n3* fatty acid supplements have been well documented for other neuro-developmental and childhood disorders such as attention-deficit hyperactivity disorder (ADHD) and dyslexia.<sup>2,38,39</sup> However, there is a need for more research specific to autism. There has only been one peer reviewed randomized control trial on the use of *n3* fatty acids specifically in children with autism by Amminger (2007).<sup>44</sup> The results of the study are promising; however, the sample population was very small as only 13 children (aged 5-17 years) with ASD participated in the study. The sample received *n3* fatty acid supplements for 6 weeks. The study concluded that the intervention group showed reduced symptoms of hyperactivity.<sup>34,44</sup> It also showed a reduction of stereotypical behaviour, such as repetition and lack of creativity or interest.<sup>44</sup>

The recommended dietary reference values for *n3* and *n6* fatty acid intake from food, are two portions of oily fish to be consumed weekly (such as salmon, mackerel, sardines, trout and herring) to provide <200mg/day of EPA.<sup>7</sup> There are no specific dosage guidelines for fatty acid supplementation.<sup>40,45</sup> The Autism Research Society

(UK) recommends using fatty acid supplements only within the dosage specified on the supplement packaging for age.<sup>34</sup>

#### **1.4.5. The use of other nutritional supplements:**

The use of nutritional supplements, such as vitamin and mineral supplements to prevent or treat nutritional deficiency where the diet is lacking may play a role. Other nutritional supplements may include fatty acid supplementation as discussed previously, as well as probiotic supplements, digestive enzymes or fiber supplementation. There is a large variety of different nutritional supplements available on the market and the use of these will be investigated in the study.

### **1.5. PROBLEM STATEMENT**

There are many factors that may influence adequate food intake in children with ASD. Feeding problems, selective eating and subsequent limited dietary intake are common concerns of parents and caregivers who have children with ASD. Feeding problems may be due to a range of factors including early feeding experiences, sensory problems, neophobia, anxiety, inability to deal with change within the mealtime environment, specificity of food appearance, and other presenting health complaints (e.g. constipation and gut related problems) that may affect food intake. Feeding problems may be an addition to numerous other difficulties associated with ASD that can increase anxiety for parents and caregivers. The main concern however, is the effect that feeding problems may have on the nutritional intake and consequently nutritional status of children with ASD.

The use of dietary interventions such as the gluten and casein free, yeast free and specific carbohydrate diets is becoming more popular. In addition to these, other nutritional supplements may also be used such as vitamin and mineral preparations and fatty acid supplementation. It is not known what percentages of ASD children are using dietary interventions and supplements. Current literature does not support the routine use of dietary interventions such as the gluten and casein free diet; however it is relevant to establish to what extent the use of exclusion diets and nutritional supplements are used by children with ASD. It is essential to review the

evidence of the use of these interventions, once the prevalence within this group has been established.

Dietitians are aware that many parents are turning to complementary and alternative therapies including exclusion diets for their children with autism.<sup>46</sup> Dietitians should have a good understanding of the impact of these interventions on the nutritional status of ASD children. A small number of dietitians, especially dietitians who are members of specialist groups for autism, such as *Dietitians in Autism* (a sub-group of the British Dietetic Association in the United Kingdom) who have an interest in working with children with ASD, may have good understanding of associated feeding/ eating problems and current dietary interventions.<sup>47</sup> It is important to acknowledge that dietitians may provide very useful dietary assessments and advice for parents and caregivers who have children with ASD. Therefore, current service provision should be evaluated and key areas identified to further improve dietetic support within this group.

## **1.6 MOTIVATION**

Dietitians frequently receive referrals to see children with ASD for various problems associated with dietary intake. However, the extent of the problem needs further investigation and the most common feeding problems and parental concerns need to be identified in order for dietitians to improve clinical practice and support within this group. Dietitians need to provide scientific information to parents enabling them to make an informed choice regarding the use of dietary interventions. An increased awareness of the extent of feeding problems and the range of dietary interventions available would enable dietitians to support this patient group efficiently.

It is important to find out from parents what experience they have had with dietitians and how services can be improved for this vulnerable patient group.

This study is for parents or caregivers of children with ASD. It aims to provide valuable information by sharing their experiences, observations and perceived benefits of using dietary interventions. In this way parents will contribute to autism research, and the study will provide detailed information about these children's dietary intake and related food behaviour associated with ASD.

# CHAPTER 2

## RESEARCH DESIGN AND METHODOLOGY

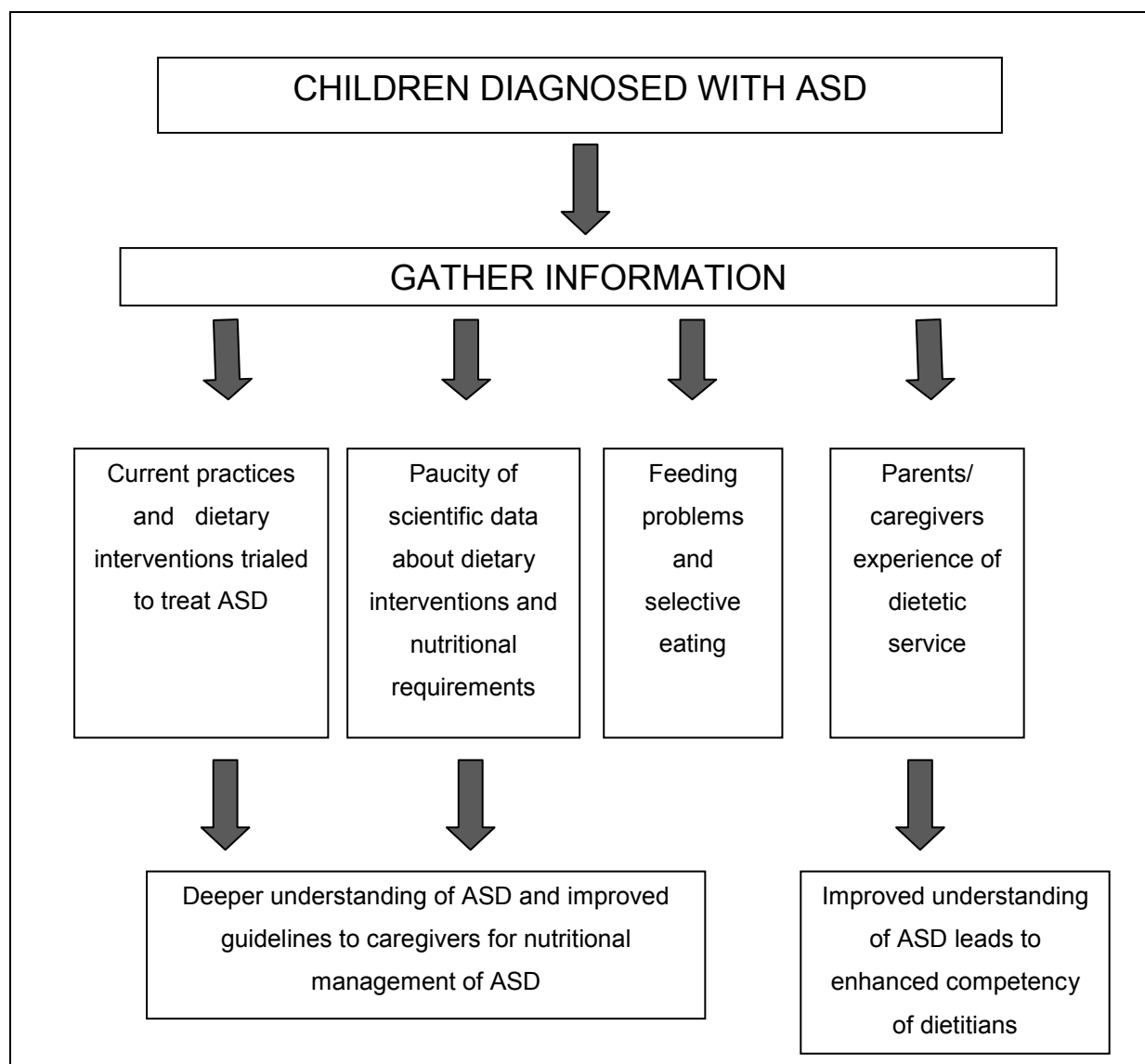


## 2. RESEARCH DESIGN AND METHODOLOGY

### 2.1 INTRODUCTION

In this chapter the research design and methodology for the study will be discussed.

### 2.2 OBJECTIVES AND CONCEPTUAL FRAMEWORK



**Figure 1: Conceptual framework for the study.**

### **2.2.1 Primary objective**

The primary objective of this study was to determine which factors influence the dietary intake and consequently the nutritional status of children with ASD. According to literature, poor dietary intake may negatively affect nutritional status. Nutritional status however requires a complex assessment including anthropometric indicators (such as weight and height), biomarkers (such as individual's blood results), and clinical assessment.<sup>48</sup> This study gathered information about common feeding problems and health related issues in ASD:

- Prevalence of early feeding problems between 0-1 year (prior to diagnosis)
- Selective eating habits
- Limited variety in diet
- Difficulty accepting new foods (neophobia)
- Anxiety around eating
- Specificity of the meal environment
- Difficult behaviour during mealtimes
- Sensory problems affecting eating
- Specificity of food presentation
- Constipation or other gut related problems

### **2.2.2 Secondary objectives**

The secondary objectives of this study were:

To determine the extent exclusion diets and dietary supplements are used for children with ASD and the observed outcome of the dietary interventions. The following exclusion diets and dietary supplements were assessed:

- Gluten free, casein free (GFCCF) diet
- Yeast free diet

- Fatty acid supplements
- Other special diets and supplements
- To make recommendations regarding appropriate advice and support to meet ASD patients' needs based on parents or caregivers' previous experience of the service they received from dietitians.

### **2.3 STUDY DESIGN**

This was a descriptive, cross sectional study design with a qualitative component.

### **2.4 STUDY POPULATION**

The study population included parents or caregivers of children aged 3-16 years, of both genders who have a diagnosis of Autism Spectrum Disorder (ASD), residing in England.

### **2.5 SAMPLE SIZE**

NAS has over 18 000 members across the UK (including England, Scotland, Wales and Northern Ireland) of which there are 12 017 members in England.<sup>40</sup> There are limited and inconclusive studies available about response rates for online website-based surveys. In order for the study to be statistically significant, the researcher aimed for a response rate of 2.06%. The total study population consisted of 325 participants with a response rate of 2.7%; therefore the sample population was statistically significant.

## **2.6 SAMPLE SELECTION**

Simple random sampling was used. The following inclusion and exclusion criteria were applied:

### **2.6.1 Inclusion criteria**

- Parents/ caregivers of children formally diagnosed with Autism Spectrum Disorder (including autism, Asperger Syndrome and Pervasive Developmental Disorder not otherwise specified)
- Parents and caregivers of children aged 3-16 years
- Both male and female participants
- Members of the National Autistic Society (NAS) England or non-members who are able to access the NAS website to participate in the study
- Access to the internet in order to register for the study and access the questionnaire
- Residing in England

### **2.6 2 Exclusion criteria**

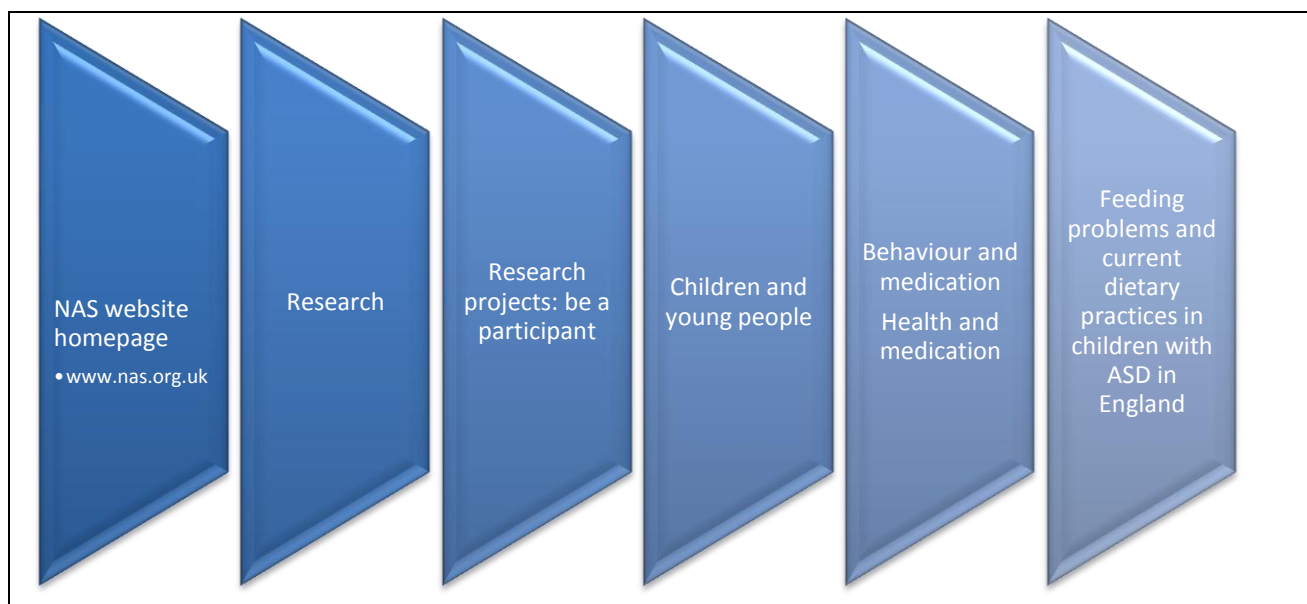
- Parents/ caregivers of children aged 3-16 years who have not been formally diagnosed with ASD
- Parents/ caregivers of children with ASD who are not English literate
- Members of NAS who reside in Scotland, Wales or Northern Ireland
- Parents/ caregivers of children with ASD who do not consent to take part in the study

## **2.7 METHODS OF DATA COLLECTION**

Following ethical approval for the study by Stellenbosch University Health Research Ethics Committee in July 2010, the researcher contacted the National Autistic Society United Kingdom (NAS) via email, to obtain permission to feature the study on their website, in order to recruit participants. An application form was completed and the aims and objectives of the study were stated. The study was approved by

the NAS (September 2010) and permission was granted to feature the pilot and main study on the organization's website. The link to the study was featured on the NAS website on the 10<sup>th</sup> January 2011 at the following website address: <http://www.nas.org.uk>.

To access the online questionnaire, participants had to navigate to the 'Research' section (Figure 2). From the research section, users were guided to the link; 'Research projects: be a research participant' and then to sections: 'Research projects: children and young people, Research projects: behaviour and medication, and Research projects: health and medication' where the study featured in all these categories. Participants then clicked on the main study: 'Feeding problems and current dietary practices in children with ASD in England.'



**Figure 2: Access to online questionnaire on the National Autistic Society website.**

The introductory page (Addendum 1) of the study explained the aims of the study and then directed respondents to the *informed consent* form. All the relevant information about the study was provided in the informed consent form, including the aim and purpose of the study and how the data will be used in the future. It was specified that the questionnaire was aimed at parents/caregivers who have children with ASD aged 3-16 years and living in England. Parents/caregivers then had to

decide if they were willing to participate in the study. Parents/caregivers who decided to participate in the study had three options in completing and returning the questionnaire to the researcher:

1. Completing the online informed consent form and survey directly on the website using the pre-loaded survey on the National Autistic Society's website
2. Via Email to the researcher - requesting a copy of the questionnaire in Microsoft Word format and then returning the completed questionnaire
3. Requesting a paper copy of the questionnaire by email from the researcher with a prepaid self-addressed envelope to be sent in the post for completion

All study participants chose to complete the questionnaire online. The researcher did not have any requests for hard copies of the questionnaire. In order to obtain a representative sample, it was decided during the planning of the research to keep the link open until the required number of participants was obtained. However, after three months, the researcher found that participation from the study link on the NAS website alone was not sufficient for the study to be statistically significant. The researcher then contacted all NAS local branches of England via email to raise awareness of the study and to ask for participation of those meeting the inclusion criteria. Following this process, the online questionnaire timeframe was extended, and the participation increased significantly to exceed the target of minimum 248 completed questionnaires. There were 352 study participants and 288 completed all sections of the questionnaire. The link to the study was closed on the 7<sup>th</sup> August 2011. The study was available for participation for seven months in total.

## **2.8 QUESTIONNAIRE**

### **2.8.1 Questionnaire methodology:**

The online questionnaire was developed using the web based survey program: 'Survey monkey'. The program allowed the researcher to choose settings to ensure participant confidentiality. The researcher chose for respondents' computer IP addresses not to be displayed, as well as allocating random numbers to each

respondent's questionnaire to ensure that all participants remained completely anonymous to the researcher.

The questionnaire (Addendum 2) was divided into various sections:

The initial part contained screening questions to ensure that the participant complied with inclusion criteria i.e. to determine if the child was between the ages of 3-16 years and that participants resided in England.

The questions were divided as follows:

- Section 1- 'Information about your child and diagnosis': demographic information including the diagnosis, age diagnosed, source of diagnosis and gender.
- Section 2- 'Early feeding experiences': feeding history as an infant (e.g. breastfed/ formula fed), any previous history of tube feeding as an infant, feeding experiences or problems when solids were first introduced, progression to more textured foods during the second and third stages of weaning, food preferences or behavioural feeding aspects noted from an early age.
- Section 3 – 'Food preferences': current feeding experiences and specific food and mealtime preferences and behaviour.
- Section 4 – 'Dietary interventions and supplements': use of exclusion diets and/or supplements and the perceived benefits and information regarding where ASD had been assessed
- Section 5 – 'Dietetic support': current or previous dietetic input, service evaluation and recommendations.

There were 33 questions: one open-ended and five were close-ended and numerical. Fifteen questions were closed-ended multiple choice of which there were ten open ended options as part of the questions e.g. 'other, please comment'. Twelve questions were closed-ended categorical, of which five had open ended options where comments/opinions could be added.

## **2.8.2 Questionnaire validity:**

### **2.8.2.1 Content validity:**

This specific questionnaire was used for the first time and therefore has not been formally validated. The questions were formulated to address the research objectives and the aim was to elicit answers that would adequately measure the variables. The questionnaire was specific to parents/ caregivers who have children with ASD in England and therefore would not be fully applicable to use in other population groups or demographic areas. The questionnaire was reviewed for content and face validity by two registered dietitians in England, both of whom have extensive experience in the field of ASD. The questionnaire was then adapted appropriately according to recommendations made by these dietitians.

### **2.8.2.2 Face validity:**

In order to assess the face validity of the developed questionnaire, the researcher tested ten questionnaires during the pilot study to ensure that the questions were clear, well formulated, non-ambiguous (to prevent interpretation error), relevant to the study population and appropriate to use as a research instrument.

### **2.8.3 Questionnaire reliability:**

The pilot study was conducted in two stages to make the questionnaires as reliable as possible. There was variation in answers to the same questions when repeated, and reliability was measured using statistical tests. The statistician used the Spearman Rank correlation test. It was not always possible to find a correlation between two variables due to limited responses, even when comparing continuous variables. A value of  $p < 0.05$  was used to mark significant correlations between the first and the second completion of the questionnaire by the same participants. For each question significance varied (p value ranged from 0.0001 to 0.65). For some questions, it was not possible to find a correlation due to limited responses.



## **2.9 PILOT STUDY**

The researcher contacted the NAS research coordinator to feature the pilot study on their website. There were two stages to the pilot study. The first pilot study was conducted in October 2010 to improve the quality of the instructions of the questionnaire and to test the process. The link to the pilot study was available on the website for 4 weeks. The researcher explained the reason for the pilot study to the participants and asked permission to contact them again via email to conduct a second pilot study. The researcher tested ten questionnaires for the pilot study. The second stage of the pilot study was repeated two weeks later to determine the reliability of the questionnaire.

Participants who agreed to share their contact information and to take part in both stages of the pilot study were contacted via email to complete the same questionnaire again. Personal and contact details were only used during this stage of the pilot study and then destroyed when the process was completed. Participants who took part in the pilot study agreed not to take part in the final study as this would have introduced bias to the responses.

## **2.10 DATA ANALYSIS**

### **2.10.1 Preparation and analysis of data**

The researcher compiled a Microsoft Excel (2007) spreadsheet numbered according to each completed questionnaire and divided into categories by allocating values for each question. Qualitative data was summarized according to the main themes and was reported in the results section of this thesis.

### **2.10.2 Statistical methods**

Computer software MS Excel was used to capture the data and STATISTICA version 9 (Stat Soft Inc. (2009) STATISTICA (data analysis software system), [www.statsoft.com](http://www.statsoft.com).) was used to analyze the data. Summary statistics was used to describe the variables. Distributions of variables were presented with histograms and frequency tables. Medians or means were used as the measures of central

location for ordinal and continuous responses and standard deviations and quartiles as indicators of spread.

Relationships between two continuous variables were analyzed with regression analysis and the strength of the relationship was measured with Pearson correlation or Spearman correlation when continuous variables were not normally distributed. Where one continuous response variable was related to several other continuous input variables, multiple regression analysis was used and the strength of the relationship measured with multiple correlation.

The relationship between two nominal variables was investigated with contingency tables and likelihood ratio chi-square tests. A p-value of  $p < 0.05$  represented statistical significance in hypothesis testing and 95% confidence intervals were used to describe the estimation of unknown parameters.

Friedman non-parametric test was used to assess differences among repeated measures of the same ordinal variable.

The Mann-Whitney non-parametric test was used to determine if significant differences existed between two ordinal variables.

## **2.11 ETHICS AND LEGAL ASPECTS**

Ethical approval was granted on the 1<sup>st</sup> July 2010 by the University of Stellenbosch (ethics approval number N10/05/153). Subsequently the National Autistic Society in England granted approval to feature the study on the organization's website.

Participants who took part in the study did so entirely on a voluntary basis. No incentives were offered for participation. The purpose of the study was explained and all participants had to sign the informed consent form before completing the accompanying questionnaire.

Data was handled in a confidential manner. All questionnaires were anonymous and unique codes were allocated to questionnaires in the order of which they were received.

# CHAPTER 3

## RESULTS

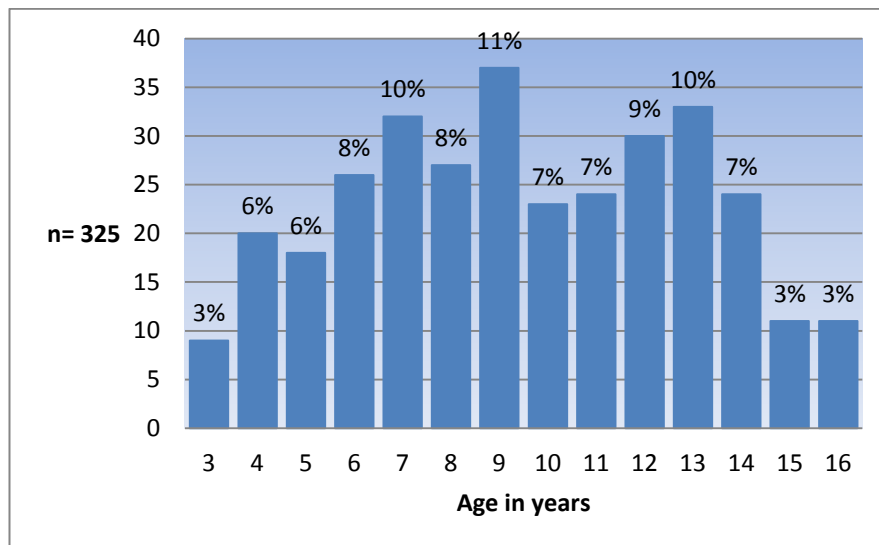
### 3. RESULTS

The response rate of 2.7% yielded a study population of 325 participants. The number of responses per section or question varied as it was dependent on whether it was applicable to the parent/ caregiver.

#### 3.1 DEMOGRAPHIC INFORMATION

##### 3.1.1 Age:

Three hundred and twenty five parents/caregivers participated in the study if their children were diagnosed with ASD and aged 3-16 years. The average age of children with ASD in this study was 9.5 years (Figure 3).



**Figure 3: Age range (in years) of children with ASD (n=325)**

##### 3.1.2 Location:

All participants resided in England. There was variation in the number of respondents from each county of England. Of all the 48 geographical counties (Figure 4) in England, Greater London had the highest response rate (13%, n=42) of the total study population (n=325).



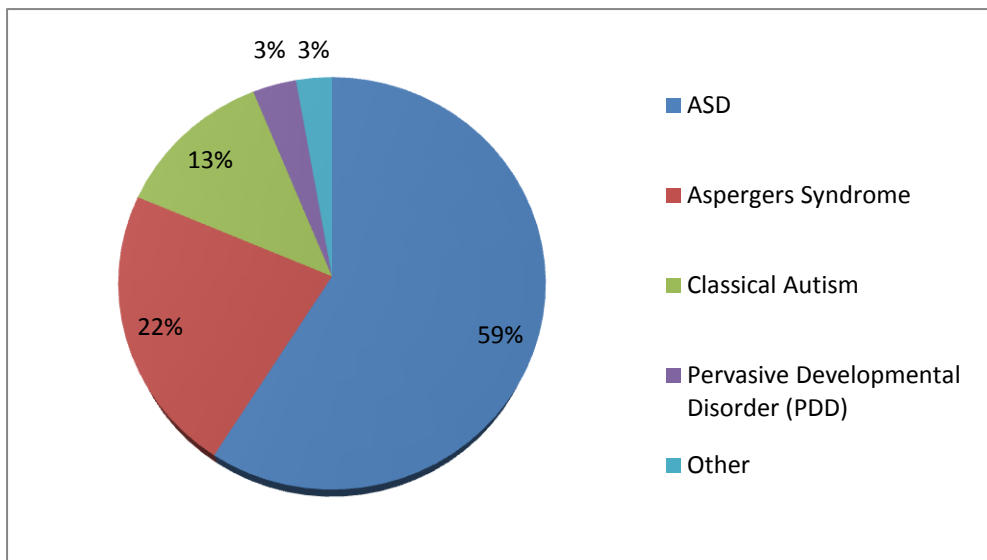
**Figure 4: Geographical counties of England.**<sup>49</sup>

### 3.1.3 Gender:

Eighty five percent of children were male (n=273) and only 15% female (n=49), representing a male to female ratio of nearly 7:1.

### 3.1.4 Diagnosis:

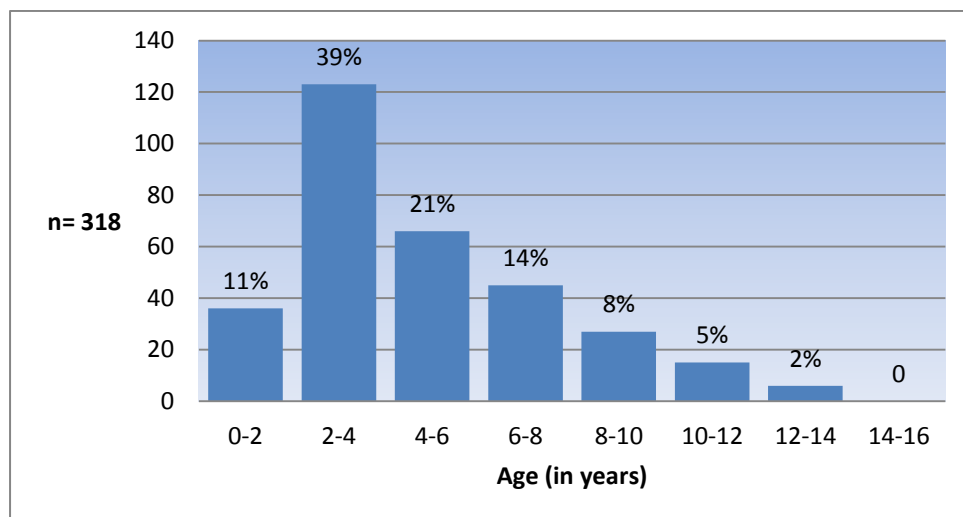
The majority of children (59%, n=190) had a diagnosis of Autism Spectrum Disorder (ASD), 22.4% (n=72) had Asperger Syndrome (AS), 12.4% (n=40) had classical autism (CA), 3.4% (n=11) had Pervasive developmental disorder not otherwise specified (PDD-NOS), and 2.8% (n=9) stated 'other' as a diagnosis without specifying (Figure 5).



**Figure 5: Diagnosis of children with ASD (n=322)**

### 3.1.5 Age when diagnosis confirmed:

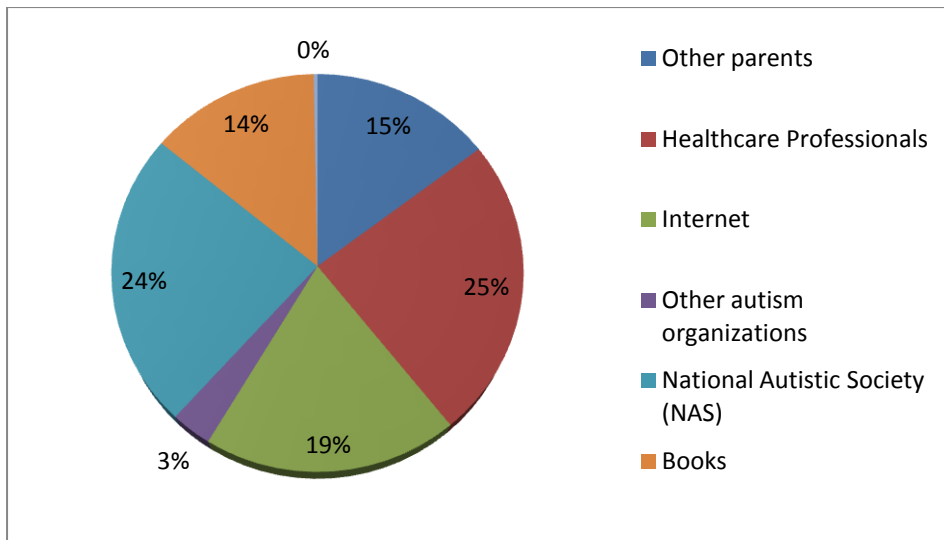
It was clear ASD was diagnosed at a young age as most children were diagnosed between the ages of 2-6 years (69.5%, n=221). Reportedly no diagnosis was made in this group of children after the age of 14 years (Figure 6).



**Figure 6: Age (in years) when a child was diagnosed with ASD (n=318)**

### 3.1.6 Supporting information about ASD at diagnosis:

Nearly equal numbers of respondents indicated that useful information was obtained from Health Care Professionals (Paediatricians, Speech & Language Therapists, Dietitians or other professionals within the healthcare team) and from the National Autistic Society UK (24.5%, n=78) and 24.1%, n=77) respectively). The third most popular source of information regarding ASD after a confirmed diagnosis was the internet (19.4%, n=62). Only 3.1% (n=10) of respondents indicated that they obtained information from other autism organizations (such as Autism File, ANDI, and The Autism Trust etc.) or the Autism Research Unit (0.3%, n=1) (Figure 7). Comments by parents suggested that information was obtained from many different sources including pre-school, nursery teachers working with children with special educational needs (SEN), as well as friends or family.



**Figure 7: Sources of information at diagnosis of ASD (n=319)**

### **3.2 COMMON FEEDING PROBLEMS AND HEALTH RELATED ISSUES ASSOCIATED WITH ASD**

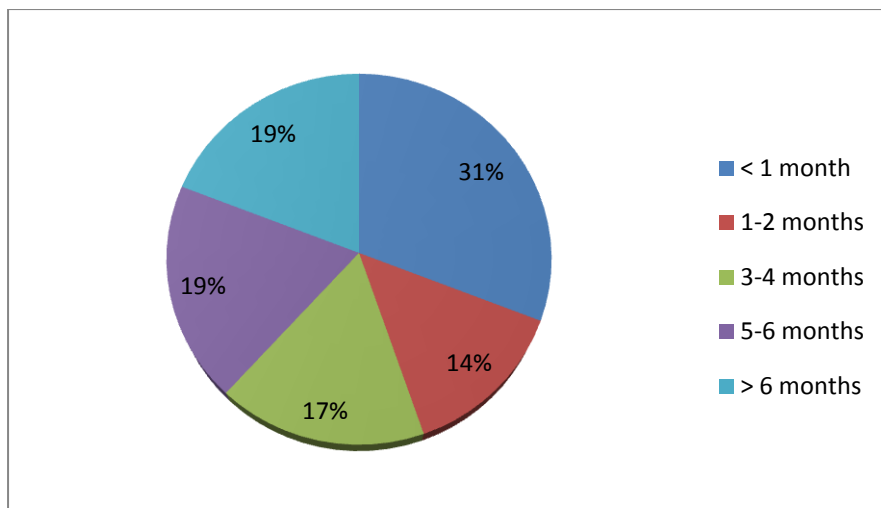
The primary objective of this study was to determine which factors affect the dietary intake and consequently nutritional status of children with ASD. The study identified common feeding problems in children with ASD as reported by parents /caregivers.

#### **Early feeding history:**

##### **3.2.1. Duration of exclusive breastfeeding in children with ASD (n=246):**

Two hundred and forty six parents (75.7%) confirmed that they exclusively breastfed their children. The remainder of parents did not breastfeed at all. Of the parents who breastfed their children, nearly one third (30.9%, n=76) indicated that their children were exclusively breastfed for less than one month while only 19.1% (n=47) of infants were exclusively breastfed for more than 6 months (Figure 8).





**Figure 8: Duration of exclusive breastfeeding in children with ASD (n=246)**

### 3.2.2 Feeding problems during breast or formula feeding (n=272):

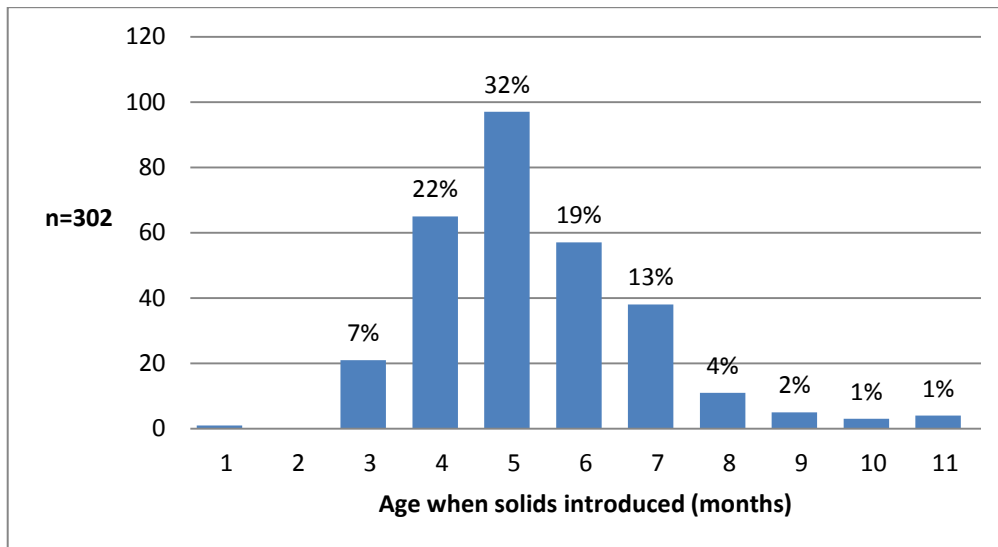
When asked if there were any significant feeding problems when infants were receiving breast or formula milk, 32.7% (n=89) parents/ caregivers had the perception that children struggled to take adequate volumes of breast or formula milk when they were infants, although this amount was not quantified. Fourteen percent (n=34) of parents/ caregivers indicated that children were not interested in feeds and 15.9% (n=38) reported that their children did not cry when hungry.

Infants were unsettled during feeds (18.5%, n=46) or after feeds (45.9%, n=122) for reasons unknown to parents/ caregivers at the time, and prior to the diagnosis of ASD. Parents/ caregivers (n=194) also commented on their experiences. Common themes indicated the following feeding problems: colic (n=29), gastroesophageal reflux (n=14), latching problems with breastfeeding (n=13), allergies to breast milk or cow's milk protein based infant formula (n=11) and excessive wind (n=6). A minority of parents/ caregivers indicated that children seemed very hungry and not satisfied with even large volume of feeds (15.9%, n=31). In contrast, double the number of parents/caregivers felt their children struggled to take adequate volumes of breast or formula milk (32.7%).

### 3.2.3 Introduction of complementary foods (n=302)

The mean age for introducing children to complementary foods was 5 months. Early weaning (before the age of 6 months) was indicated by 60.9% (n=184) of parents/

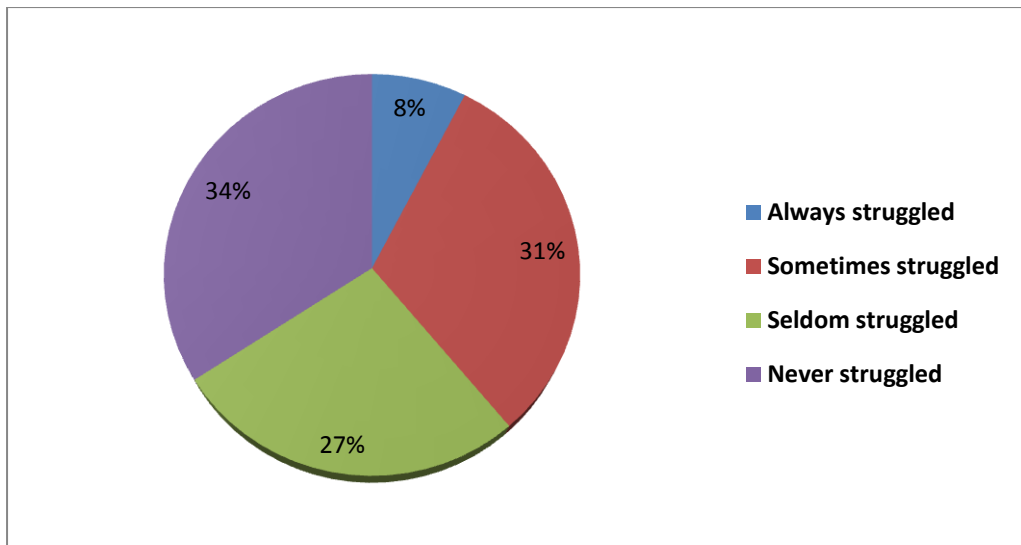
caregivers. Late weaning (from 7 months onwards) was indicated by 20.2% (n=61) of parents/ caregivers (Figure 9).



**Figure 9: Age (months) when weaning was initiated in children with ASD (n=302)**

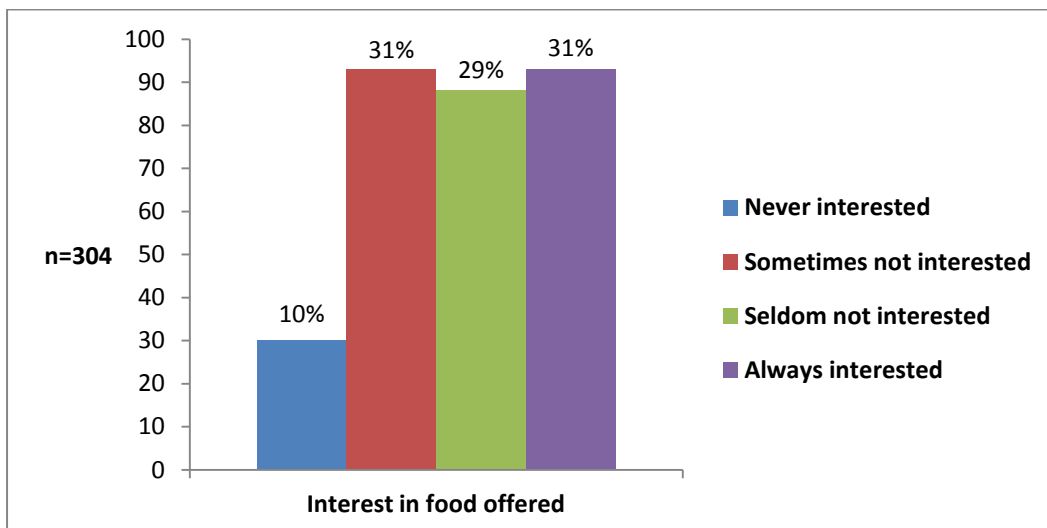
### 3.2.3.1 Weaning stage 1 – smooth pureed food (n=304):

The first stage of weaning is normally recommended at 4-6 months and consists of smooth pureed food. This would normally be accepted without major problems by children with typical development. Parents/ caregivers were asked if children struggled to take smooth pureed food from a spoon during the first stages of weaning. The majority, 61.2% (n=186) indicated their children *did not struggle*. More than one third (38.8%, n=118) of children *struggled* to take smooth pureed food from a spoon (Figure 10). Similarly, parents/caregivers reported that 70% (n=211) of children were *never upset* when smooth pureed food was offered.



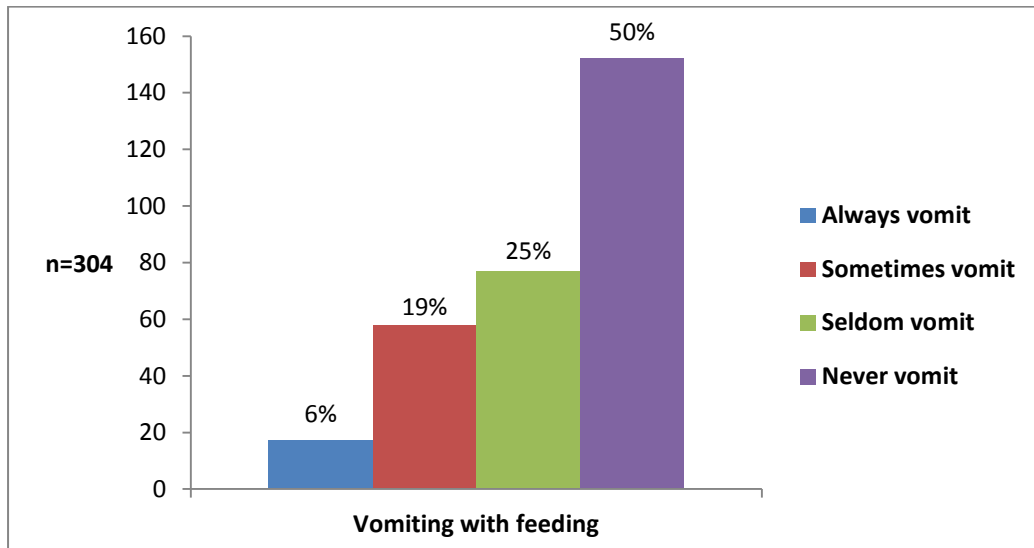
**Figure 10: Problems experienced when taking smooth pureed food from a spoon during the 1<sup>st</sup> stage of weaning, in children with ASD (n=304)**

Parents/caregivers were also asked if children showed interest in the food offered during the 1st stage of weaning (Figure 11) and it is clear that experiences varied for each child. Nearly two thirds of children were interested in food offered (60%, n=181), but 10% (n=30) of children showed no interest in food.)



**Figure 11: Disinterest in food offered during the 1<sup>st</sup> stage of weaning in children with ASD (n=304)**

In terms of vomiting or 'gagging' when food was offered, results showed that half of parents/caregivers (50%, n=152) felt children *never* experienced these symptoms, and only 5.6% (n=17) reported symptoms were *always* present when food was offered (Figure 12).



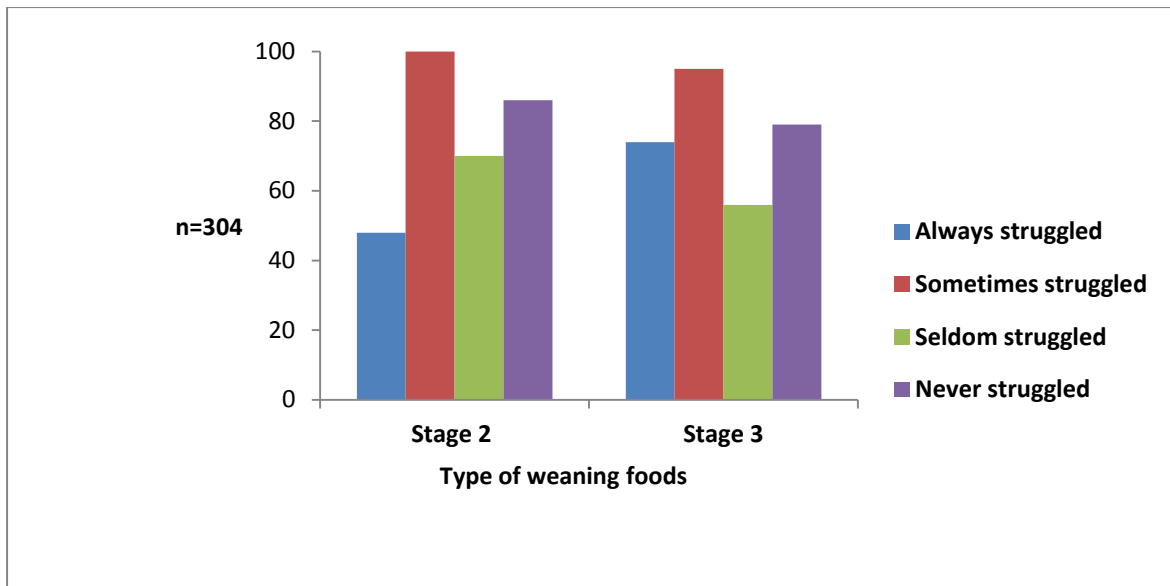
**Figure 12: Vomiting associated with feeding children in ASD (n=304)**

### 3.2.3.2 Progression of weaning: Stage 2 and 3 weaning foods (including finger foods) (n=304):

Current literature reports that the transition from stage 1 to the next stages of weaning, are often the most difficult for children with ASD. The researcher asked specifically about food acceptance during the introduction of coarser textures in this group.

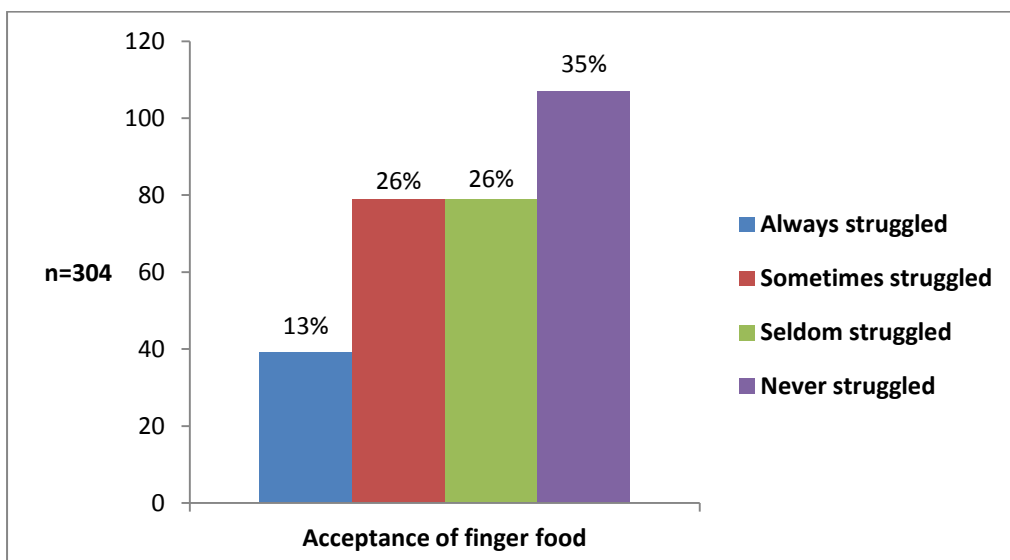
Stage 2 weaning foods include the progression from smooth pureed foods to food with a mixed texture such as pureed food with soft lumps (normally around 7-9 months of age). Results indicate that 48.7% (n=148) of children with ASD would *struggle* to accept foods with soft lumps. The remaining 51.3% (n=156) *did not struggle* to eat foods with soft lumps (Figure 13).

Stage 3 weaning foods have textured lumps and chunks (normally around 9-12 months of age). When asked about acceptance of food with textured chunks and lumps, 55.6% (n=169) *struggled* with this food texture, while 44.4% (n=135) *did not struggle* to take stage 3 weaning foods (Figure 13).



**Figure 13: Acceptance of stage 2 and 3 weaning foods in children with ASD (n=304)**

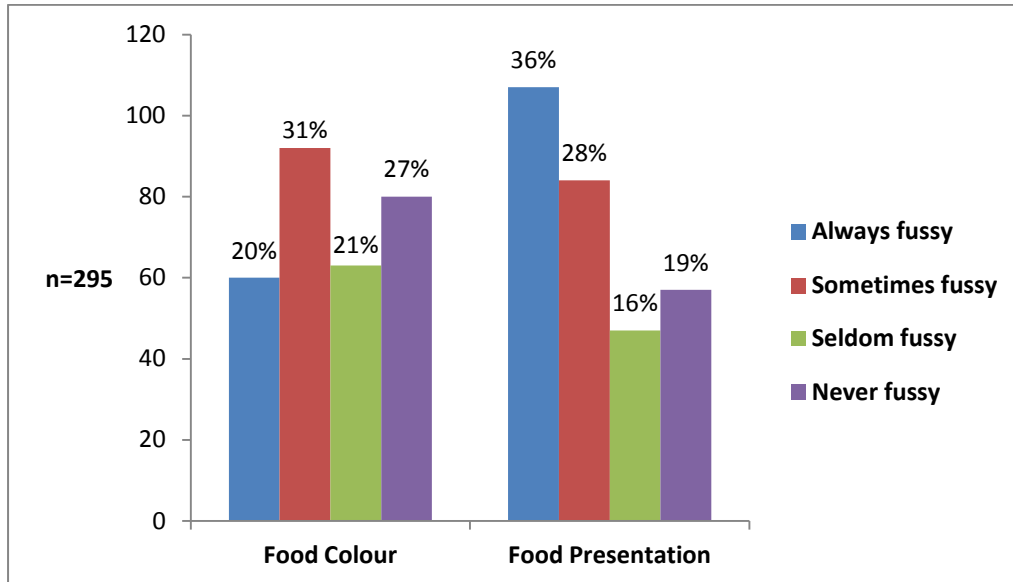
Finger foods: Stage 3 weaning foods include bite size finger foods. Only a small percentage of children (12.8%, n=39) always *struggled* to accept finger foods. On the contrary, the majority (61.2%) *seldom* or *never struggled* to accept finger foods (Figure 14).



**Figure 14: Autistic children's acceptance of finger foods (n = 304)**

### 3.2.3.3. Influence of food colour and presentation on food acceptance (n=295):

**Food colour:** The question pertaining to preference of food colours found that nearly half of children were *always/sometimes fussy* (51%, n=152) about the colour of food. One quarter (27.1%, n=80) of the parents/ caregivers indicated that food colour did not affect the child's food choice (Figure 15).



**Figures 15: Influence of food colour and presentation on food acceptance in children with ASD**

**Food presentation:** Results for food presentation indicated that 64.7% (n=152) of children were particular about food presentation, including specific brands of food and food packaging. Out of this group, more than a third (36.3%, n=107) of children were *always fussy* about food presentation and only 19.3% (n=57) were *never fussy*.

Additional comments from parents/ caregivers suggest that children would often *refuse* food if the preferred brand was not available. When a different brand of cereal was put in the same box/ packet as the preferred brand, children would identify the difference in taste and refuse the food. Food presentation also played a big role, apart from specific brands, the packaging was also important. Parents/ caregivers commented that any food that looked slightly different from what they were used to, would be refused. Specifics regarding presentation of food included having bread cut into squares, preferring whole foods rather than cut food, or preferring that certain food items were served in bowls with a specific colour.

Another common theme was the children did not like different food items to touch on the plate. It did not matter whether the textures were similar or different. One specific child preferred food arranged in individual groups on the plate and if any of these touched (such as a carrot that slightly touched gravy), then he/she would refuse all the food.

### **3.2.3.4 Food texture (n=295)**

The different textures investigated in this study were crunchy, dry, smooth, moist, soft and easy to chew.

#### **Crunchy food:**

Children with ASD seem to differ in terms of preferences to food texture. In this study, it was found that crunchy foods were popular as 81.5% (n=238) of the children would normally eat these and only 4% (n=12) of the children would always refuse crunchy food (Figure 16). Examples of crunchy foods in the question were apples, corn flakes and toast.

#### **Smooth food:**

Examples of smooth food in this questionnaire were smooth pureed food, yogurt, and custard. The majority of the children (69.8%, n=206) would normally eat smooth food and 16% (n=47) of the children would always refuse smooth food (Figure 16).

#### **Dry food:**

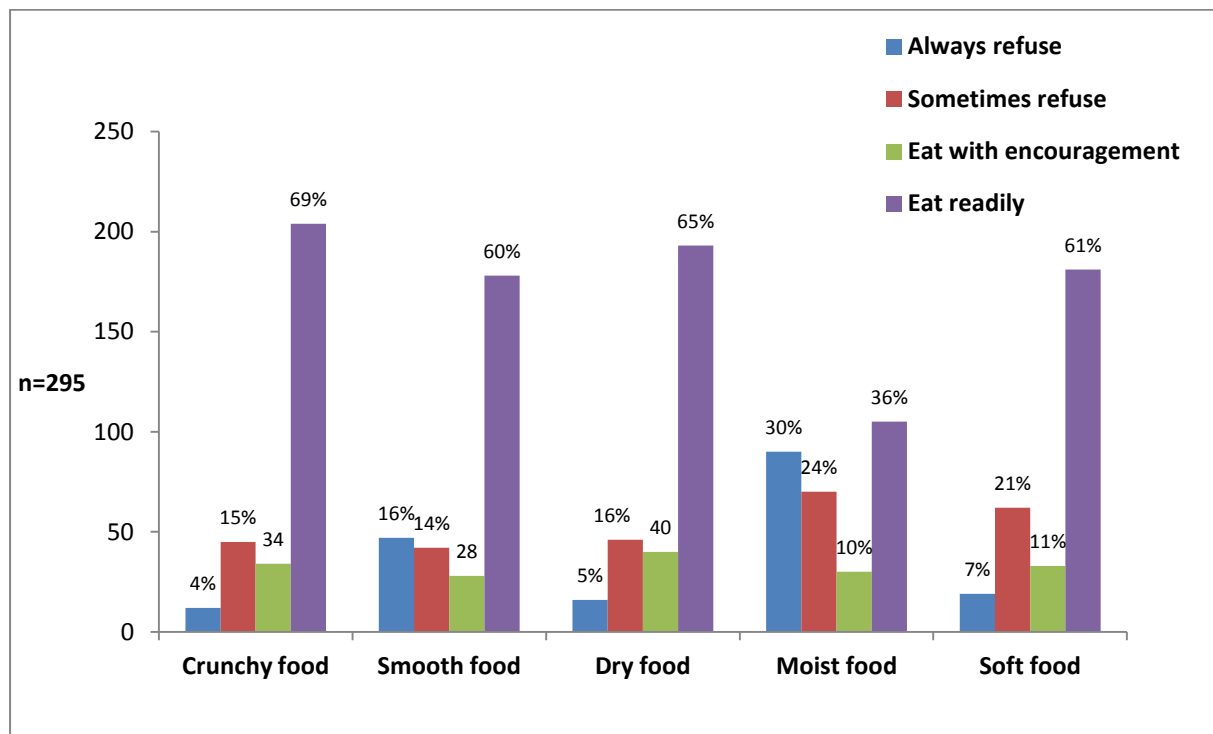
Dry food in this questionnaire referred to cooked food without any sauce or dry crackers, bread without spread. Dry food was a popular choice and 79% (n=233) of the children would normally eat these (Figure 16).

#### **Moist food:**

Moist food was explained in the questionnaire as cooked food with sauce or food with high water content such as fruit. The results indicate that moist food was less popular, only 35.6% (n=105) of children would readily eat this. More than half the children (54.2%, n=160) would sometimes/always refuse moist foods (Figure 16).

**Soft and chewable food:**

The majority of children (61%, n=181) would readily eat soft and easy chewable foods, only 6.4% (n=19) would always refuse these foods.



**Figure 16: The influence of texture on food acceptance in children with ASD.**

**3.2.3.5. Food temperature**

Questions investigated the response of ASD children to different temperatures included hot, warm/ lukewarm and cold options (Table 1).



**Table 1: Acceptability of different temperatures of food or drinks in children with ASD (n=295)**

Temperature	Always refuse	Sometimes refuse	Eat with encouragement	Eat readily
<b>Hot</b>	<b>27.7%</b> <b>(n=82)</b>	18.2% (n=54)	11.8% (n=35)	42.2% (n=125)
<b>Warm and lukewarm</b>	7.1% (n=21)	15.6% (n=46)	14.9% (n=44)	<b>62.4%</b> <b>(184)</b>
<b>Cold</b>	8.1% (n=24)	16.3% (n=48)	9.2% (n=27)	<b>66.4%</b> <b>(n=196)</b>

To assess the reaction to very warm food or drinks, examples included very warm cooked food or hot drinks such as tea, coffee or hot chocolate. Interestingly 27.7% (n=82) would *always refuse* hot food but only 7.1% (n=21) or 8.1% (n=24) would *always refuse* warm/ lukewarm or cold food respectively. One parent/ caregiver commented that tea or coffee has to be very hot before her child would drink it, and toast would not be eaten if it started to cool down, otherwise fresh toast would have to be made. Another parent/ caregiver commented that her child would not take hot drinks but loved to eat very warm food. Examples of cold foods given to parents/caregivers were yoghurt, cheese and chilled cooked food. Cold food was equally popular as warm and lukewarm food (66.4%, n=196) and 62.4% (n=184) respectively. However, comments from parents/ caregivers suggested that food refusal may be a combination of temperature and texture, for example a child may eat cheese which is chilled but not yoghurt.

### 3.2.4 Mealtime environment

Nearly a quarter (24.4%, n=72) of children with ASD were specific about the place where they would eat their meal, for example a specific area in the house. Some parents/ caregivers commented that their children preferred to eat alone or with only the main care giver present, disliked eating with other people and in public places. Other factors within the mealtime environment included: only eating in a specific chair (16.9%, n=50) and when a specific person was present (4.1%, n=12) (mean age 9.4 years and 9.9 years respectively). Other experiences shared by individual

parents/ caregivers showed that their child would not sit still during mealtimes or they would only eat when the set routine was adhered to, such as having fixed mealtimes. Parents/ caregivers also mentioned that their children disliked hearing other people chewing, while others preferred having certain distractions while eating such as reading books, listening to music or watching specific television programs.

### **3.2.5 Sensory problems**

Sensory problems are common in children with ASD. These problems often affect their food choice and dietary intake.

#### **Getting their hands or face dirty (n=294)**

In this study more than half of the children disliked getting their hands or face dirty (59.9%) and only 21.7% (n=64) of the children *never* disliked this. The example given was when the hands or face gets dirty or sticky (such as when eating finger foods and playing with clay) (Figure 22). To avoid this, one child would eat sweets with a fork. Gender comparisons in the study showed that overall males were more prone to disliking getting their hands and face dirty (60.9%, n=151) compared to females (54.3%, n=25), although the difference was small.

#### **Sensitivity to touch (n=293)**

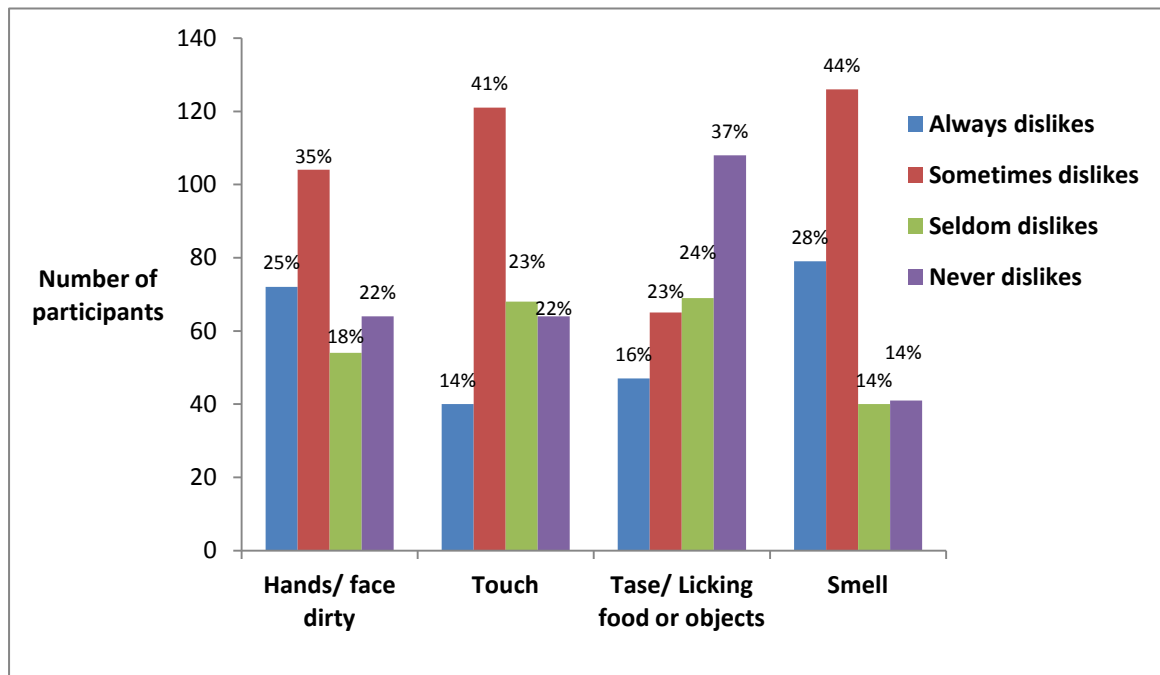
Tactile sensitivity such as touching around the face and giving or receiving a hug may also be prevalent in this group of children. This study found that more than half (55%, n=132) of children *disliked* touch (Figure 17). Parents/caregivers also shared that the hypersensitive child may not like being tapped on the shoulder or disliked the feel of wet clothes. One child liked giving hugs but did not want other people to touch her unless she asked. The opposite is true for children with hyposensitivity. One parent/ caregiver mentioned that her child needed to be hugged firmly and another parent commented that hyposensitivity to touch caused her child difficulty with using a knife and fork. Interestingly, gender comparisons showed girls disliked touch more (66.7%, n=30) than boys (53.8%, n=131), even though the difference between boys and girls was not significant.

### Licking food and objects (n=289)

Another aspect of touch sensitivity is the child's reaction to licking food or objects and parents/ caregivers were probed about related experiences. Most children (61.2%, n=177) did not have a problem with tasting or licking food or objects (Figure 17). Gender comparisons ( $p=0.557$ ) showed similar results where 60.4% (n=148) of boys and 65.9% (n=29) of girls like to taste and lick food or objects. One parent/caregiver commented that their child specifically liked to lick door handles.

### Sensitivity to smell (n=286)

Children with ASD may also be more sensitive to certain smells such as strong perfume, pet odours and odour of food. This study found that 71.7% of children would normally dislike strong smells (Figure 17).



**Figure 17: Response to sensory elements in children with ASD (n=286-294)**

Additional comments included: children would smell food before eating it (n=11), were very sensitive to food odours such as food in the process of cooking and that certain food smells may even cause nausea or vomiting (n=2). Where most children were found to be hypersensitive to smell, some children were hyposensitive, for example these children would like very strong flavours and odours such as vinegar, garlic, ginger, lemon and onion.

Children also appeared to be very sensitive to changes in taste and smell of known foods. Parents/caregivers commented that their children could recognize ‘incredibly subtle taste differences’ and would refuse foods if it didn’t ‘smell right’ (even fruit such as apples).

A few parents/caregivers also said that their children preferred very strong tastes such as spicy foods.

### **Preference to mealtime utensils and cutlery (n=268)**

Results show that the majority of children (71.3%, n=191) were not particular to use specific eating utensils and cutlery. However, 18.7% (n=50) of children would only take a drink from a specific cup, 16.4% (n=44) of children would only accept food from a certain spoon or specific cutlery and 11.2% (n=30) of children would only accept food from a certain plate. Parents/ caregivers commented that some children would only have drinks from a spouted cup or with a straw while others were either specific about having their own cup or would insist on drinking from a water bottle instead of a cup. Some parents/ caregivers also mentioned that their children would normally want to choose their own cutlery or utensils from the kitchen and would check if it was clean, or smell it before using it. The use of cutlery was not very popular with some parents/ caregivers saying that their children would rather eat with their hands. Another preference mentioned was the use of plastic forks and spoons rather than metal ones (n=3).

### **3.2.6 Food choice (n=295)**

Less than a quarter of children (24.4%) were not specific about their food choices but the majority of children (75.6%, n=223) would repeatedly choose the same type of foods for meals. The results obtained indicating children’s food preferences according to specific food groups are summarized in Table 2. Parents/ caregivers were asked to answer questions about each food group according to the following scale: ‘*Will always eat, will eat with encouragement, sometimes refuse, and always refuse*’.

**Table 2: Food preference of children with ASD according to food groups**

<b>Food group (number of children)</b>	<b>Always refuse</b>	<b>Sometimes refuse</b>	<b>Will eat with encouragement</b>	<b>Will eat readily</b>	<b>p-value</b>
<b>Fruit (n=291)</b>	19.2% (n=56)	21% (n=61)	18.2% (n=53)	41.6% (n=121)	p<0.001
<b>Fruit juice (n = 293)</b>	20.5% (n=60)	12.3% (n=36)	21.5% (n=63)	45.7% (n=134)	p<0.001
<b>Vegetables (n=294)</b>	25.5% (n=75)	23.8% (n=70)	23.8% (n=70)	26.9% (n=79)	p=0.855
<b>Starchy vegetables (n=291)</b>	14.4% (n=42)	23% (n=67)	21% (n=61)	41.6% (n=121)	p<0.001
<b>Unrefined carbohydrates (n=286)</b>	27.6% (n=79)	21.7% (n=62)	19.6% (n=56)	31.1% (n=89)	p=0.021
<b>Refined carbohydrates (n=289)</b>	4.8% (n=14)	14.2% (n=41)	16.6% (n=48)	64.4% (n=186)	p<0.001
<b>Eggs (n=287)</b>	44.3% (n=127)	15% (n=43)	17.4% (n=50)	23.3% (n=67)	p<0.001
<b>Unprocessed meat (n=287)</b>	27.5% (n=79)	14.6% (n=42)	22% (n=63)	35.9% (n=103)	p<0.001
<b>Processed meat (n=286)</b>	16.1% (n=46)	14.7% (n=42)	16.8% (n=48)	52.4% (n=150)	p<0.001
<b>Meat alternatives (n=282)</b>	57.1% (n=161)	15.6% (n=44)	16% (n=45)	11.3% (n=32)	p<0.001
<b>Dairy (n=290)</b>	14.8% (n=43)	16.6% (n=48)	17.9% (n=52)	50.7% (n=147)	p<0.001

Significant differences ( $p<0.05$ ) were found for children's food preferences for most foods except for unrefined carbohydrates ( $p=0.021$ ) and vegetables ( $p=0.855$ ).

## **Fruit**

All types of fruit were included i.e. fresh, tinned, frozen and dried fruit. The majority of children would always eat (41.6%, n=121) or would eat fruit with encouragement (18.2%, n=53), but 19.2% (n=56) would always refuse fruit (Table 2).

## **Fruit juice**

The questionnaire explained that fruit juice refers to all types of fresh or reconstituted fruit juice made from concentrate, as well as fruit smoothies. The preference for fruit juice followed the same pattern as fruit: 45.7% (n=134) of children would always drink fruit juice and 20.5% (n=60) would always refuse fruit juice in all forms.

## **Vegetables**

Examples of vegetables included carrots, tomatoes, sweet corn, green beans, peas, spinach and peppers. For this section, vegetables excluded starchy vegetables such as potatoes, which were covered in the following question. The results show an equal distribution between the four options (ranging from 23.8%-26.9%) thus equal amounts of children would eat or refuse to eat their vegetables.

## **Starchy vegetables**

Questions pertaining to starchy vegetables included potatoes, sweet potatoes, butternut squash, yams, cassava and all forms of these such as potato chips. Once again, a similar pattern was found as with fruit preference, 41.6% (n=121) of children would *always eat*, and only 14.4% (n=42) of children would *always refuse* to eat starchy vegetables.

## **Unrefined starchy or carbohydrate based foods**

For this question, unrefined carbohydrate based foods referred to grains such as bread (whole-wheat-/ brown-/ rye-/ oats- and seed based), oats porridge and high fiber cereal (such as bran flakes, muesli and shredded wheat), durum wheat based pasta (white or whole-wheat), brown rice and crackers (rye or whole-wheat). Surprisingly almost a third of children (31.1%, n=89) would *always eat* these, and similarly 27.6% (n=79) would *always refuse* to eat unrefined carbohydrate based foods.

### **Refined starchy or carbohydrate based foods**

Refined carbohydrate foods were explained as refined starchy foods and grains including white bread, cake, biscuits, pastries and refined cereals (such as rice krispies, corn flakes and sugar puffs). The majority of children (64.4%, n=186) would *always eat* these and a mere 4.8% (n=14) of children would *always refuse* to eat refined carbohydrates.

### **Eggs**

The question regarding the intake of eggs included all forms of cooked eggs such as boiled, scrambled, fried, poached and omelet. The majority of children (59.3%, n=170) refused to eat eggs.

### **Unprocessed meat or fish**

Unprocessed meat or fish referred to all varieties of meat such as chicken, beef, lamb, pork, fish and minced beef or lamb. Over a third (42.1%, n=121) of children refused to eat unprocessed meat or fish.

### **Processed meat**

Processed meat referred to meat that has been subjected to curing, further mincing, and mixing with other ingredients. Examples include breaded chicken, chicken nuggets, beef burgers, fish cakes/ fish fingers, Frankfurter sausage, pork sausage, sandwich meat (cold cuts including turkey, ham, chicken). In this case only 16.8% (n=46) of children would *always refuse* eating processed meat.

### **Meat and protein alternatives**

This question was included for families who are vegetarian or choose to exclude animal protein from their family's diets. Examples of meat alternatives were: soya protein (such as tofu, soya beans and derivatives), lentils and mycoprotein (such as quorn). Only 11.3% (n=32) of children would *always eat* these products and over half (57.1%, n=161) of children would *always refuse* meat alternatives.

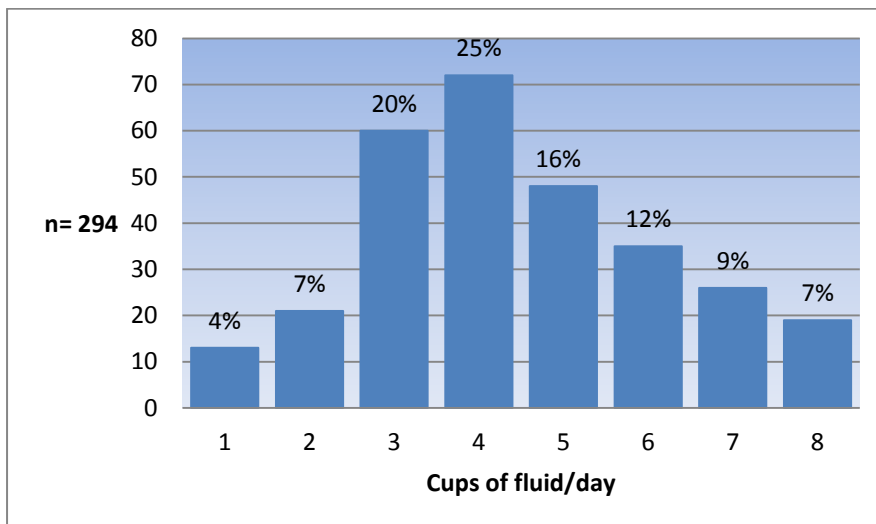
## Dairy products and dairy alternatives

Examples of dairy products included all forms of milk products (cow's and goat's milk, yogurt, cheese) as well as soya products (calcium enriched soya milk, yoghurt and cheese). Also included were other non-dairy products such as rice milk, almond milk and oat milk. At least half of the children (50.7%, n=147) would *always* eat or drink dairy products or alternatives but nearly one third (31.4%, n=91) would refuse to take these products.

## Fluid intake

Parents/caregivers were asked how many cups of fluid their child consumed on average per day. All types of fluids were included: cold drinks (such as water, fruit juice, squash, fizzy drinks, milk) and hot drinks (such as tea).

The majority of children (61.2%, n=180) had a fluid intake of 3-5 cups daily (Figure 18) equating to approximately 600-1000ml fluid daily (using 200ml as an average cup size). Furthermore it was found that nearly a third (31%, n=94) of children in this study had suboptimal fluid intake, by taking only 1-3 cups of fluid per day.



**Figure 18: Daily fluid intake (cups) of children with ASD (n=294)**

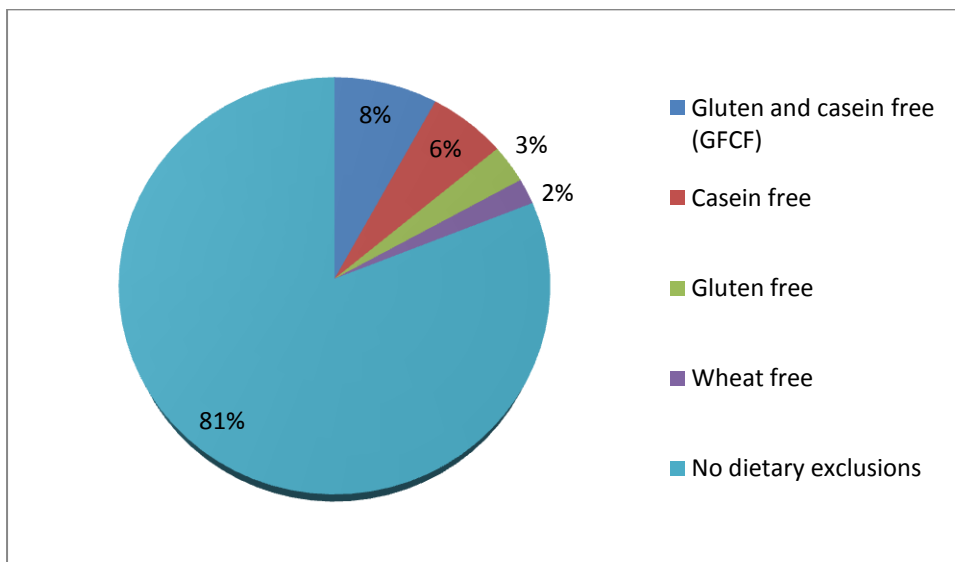


### 3.3 EXCLUSION DIETS

A secondary objective of this study was to determine the extent to which exclusion diets and dietary supplements are used for children with ASD and the observed outcome of such dietary interventions.

#### 3.3.1 Prevalence of exclusion diets

Parents/ caregivers were asked if they had before, or were currently excluding any wheat, gluten (including wheat, rye, barley and oats), casein (cow's milk protein), or both gluten and casein from their child's diet. The prevalence of exclusion diets in this study population was 19.1% (n=55). The most used exclusion diet was gluten and casein, 8.3% (n=24), followed by exclusion casein (5.9%, n=17), then by the exclusion of wheat and gluten (3.1%, n=9) and wheat exclusion at 1.7% (n=5) (Figure 19).

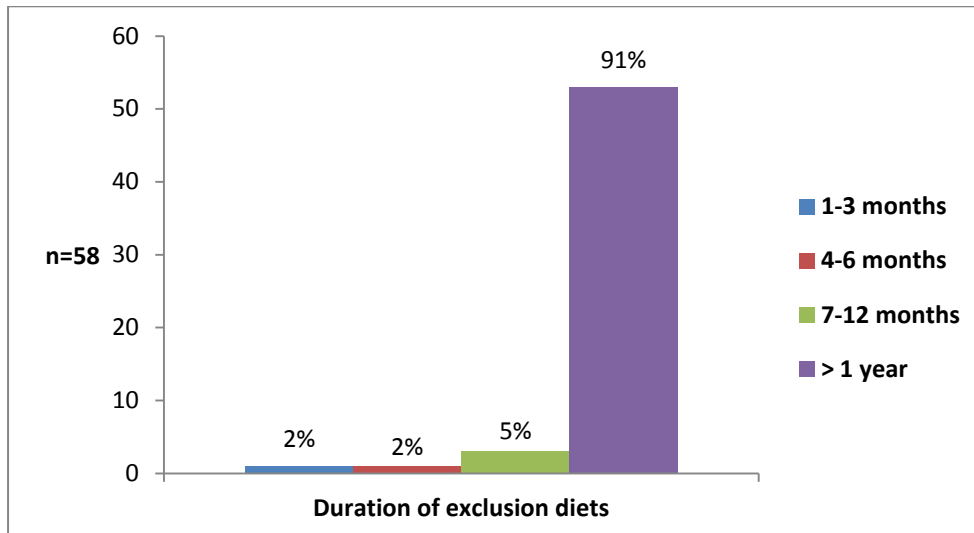


**Figure 19: Prevalence of exclusion diets in children with ASD (n=288)**

#### 3.3.2 Duration of exclusion diets

Parents/ caregivers who had excluded or were excluding gluten and/ or casein/ milk from their child's diet at the time of the study were asked about the duration of these exclusions. Although 55 (19%) respondents reported the use of gluten and/or casein exclusions, more parents answered the respective questions relating to the duration and effects of these as indicated in the next sections.

Fifty eight parents/ caregivers answered the question relating to the duration of gluten and casein exclusion diets and the majority (88.3%, n=53) reported that they have excluded these foods for more than a year (Figure 20).



**Figure 20: Duration (months) of gluten and / or casein free diets in children with ASD (n=58)**

### 3.3.3 Effect of gluten and/or casein dietary exclusions

This section reports on the following question: '*Have you noticed any significant improvement in your child when following a gluten and/ or milk free diet?*' Parents/ caregivers were asked to complete this question for various parameters including bowel habits, general health, disturbed sleep, undesired behaviour, poor concentration and social communication. Results are summarized in Table 3.

**Table 3: Impact of gluten and casein free diet on various parameters**

Parameter (number of children)	Worsened	Little improvement	Slight improvement	Significant improvement
<b>Bowel habits (n=54)</b>	<b>0</b>	<b>12.96%</b> (n=7)	<b>22.2%</b> (n=12)	<b>64.8%</b> (n=35)
<b>General health (n=55)</b>	<b>0</b>	<b>12.7%</b> (n=7)	<b>30.9%</b> (n=17)	<b>56.4%</b> (n=31)
<b>Sleep (n=52)</b>	<b>1.9%</b> (n=1)	<b>38.5%</b> (n=20)	<b>34.6%</b> (n=18)	<b>25%</b> (n=13)
<b>Behaviour (n=57)</b>	<b>1.8%</b> (n=1)	<b>28.1%</b> (n=16)	<b>33.3%</b> (n=19)	<b>36.8%</b> (n=21)
<b>Concentration (n=57)</b>	<b>1.8%</b> (n=1)	<b>24.6%</b> (n=14)	<b>35.1%</b> (n=20)	<b>38.6%</b> (n=22)
<b>Social communication (n=53)</b>	<b>0</b>	<b>28.3%</b> (n=15)	<b>35.8%</b> (n=19)	<b>35.8%</b> (n=19)

Overall, results indicate that exclusion diets can have a marked effect on improving the quality of life of some children with ASD.

#### **Effect on bowel habits of children with ASD (n=54)**

The majority of parents/ caregivers (64.8%, n=35) reported that they had observed a significant improvement in their child's bowel habits following the use of a gluten and/ or milk exclusion diet. Parents/ caregivers in this section reported symptoms of diarrhoea improved significantly, similarly children who had problems with constipation also appeared to benefit. Parents/ caregivers also mentioned that stomach cramps subsided with the use of a milk free diet or a gluten and milk free diet.

#### **Effect on general health of children with ASD (n=55)**

Most parents/ caregivers (87.3%, n=48) indicated general health improved in their children following the dietary exclusion. There were no reports of any deterioration in health. This section yielded interesting responses from parents in terms of improvement of general health. Comments from individual parents/ caregivers

included that children had less frequent occurrence of headaches (n=1), a reduction of dark circles under eyes (n=1) and an improvement in balance and coordination (n=1). Other health outcomes included less mucus production leading to a reduction in wheezing and a runny nose. One parent/ caregiver mentioned that her child “*did not communicate pain prior to the exclusion diet, and when casein was excluded, her child could communicate pain for the first time and cried*”. Two parents/ caregivers reported that since being on the exclusion diet, their children significantly ‘*recovered*’ from autism and were able to attend a mainstream school, which had not previously been an option. Another parent/ caregiver pointed out the significance of the exclusion diet for their family life, as the child seemed much happier.

### **Effect on sleeping patterns in children with ASD (n=52)**

Although one parent/ caregiver (1.9%) reported that their child’s sleep routine worsened when the exclusion diet was followed, the majority of respondents observed improved sleeping patterns (59.6%, n=31). Comments from parents/ caregivers suggested that sleep had improved due to improvements in other areas of health such as improved bowel habits and reduced headaches or stomach cramps.

### **Effect on concentration of children with ASD (n=57)**

A similar effect was reported on concentration, the majority (73.7%, n=42) reported improvement in the child’s ability to concentrate and only one parent/ caregiver reported that the child’s concentration levels worsened following an exclusion diet. Comments from parents/ caregivers suggest that the improved concentration enhanced performance at school. Another parent/ caregiver commented that his/her child was able to concentrate better as all other symptoms disappeared with the exclusion diet (such as stomach cramps and diarrhoea).

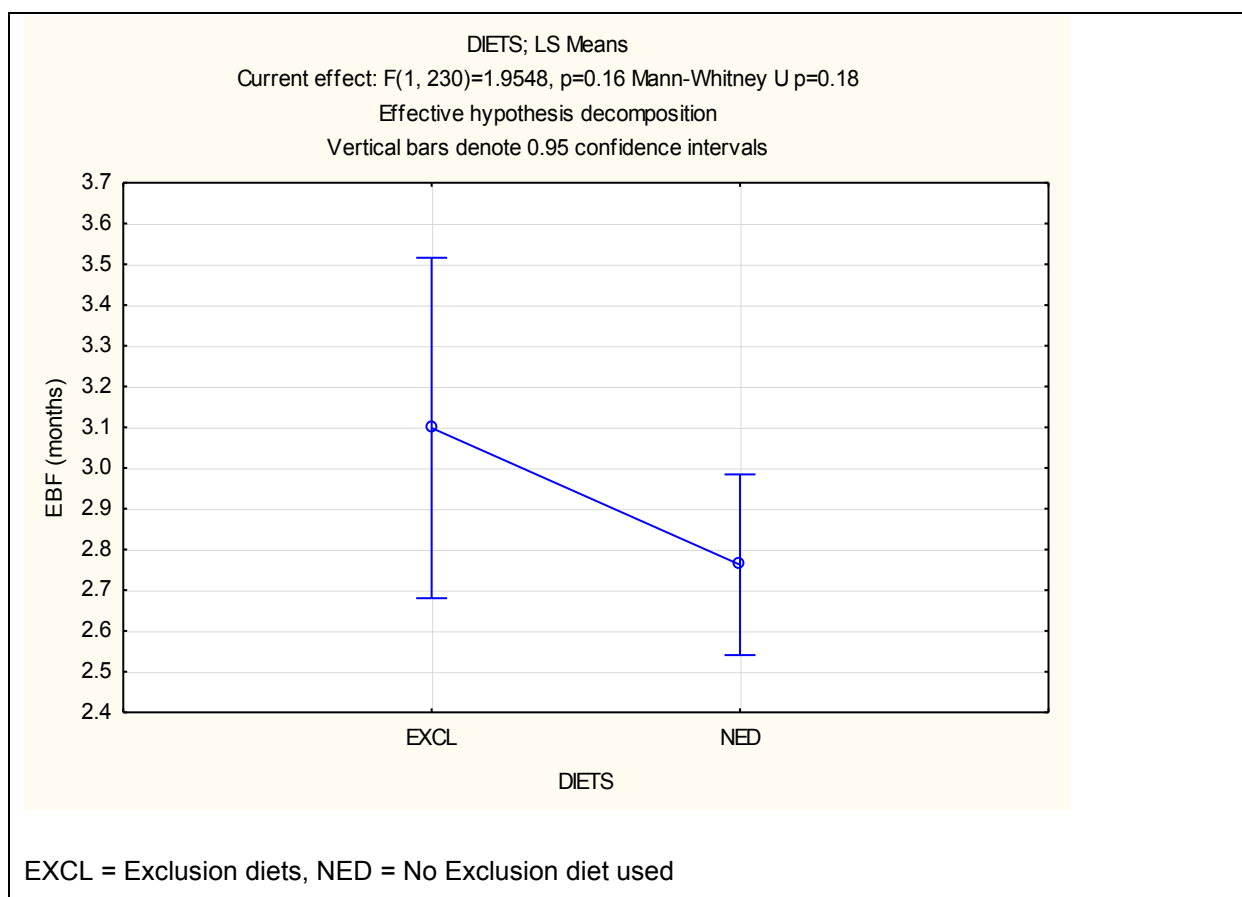
### **Effect on social communication in children with ASD (n=53)**

In this study social communication referred to speech, eye contact and facial expressions such as smiling. The majority of parents/ caregivers (71.6%, n=38) implementing exclusion diets said that their child’s social communication skills improved. There were no responses to indicate that social communication skills had worsened. One parent reported a ‘*huge difference*’ in social communication,

especially speech and eye contact. Another parent said that ‘*he came out of his own world and joined ours a little since starting the GFCF diet.*’

### Relationship of using exclusion diets and history of exclusive breastfeeding

The duration of exclusive breastfeeding during infancy was compared in children who were on exclusion diets (gluten and/or casein free) vs. those not following an exclusion diet. Although not statistically significant, results show that children who were placed on exclusion diets were breastfed for longer during infancy than those who were not using dietary exclusions (Figure 21).



**Figure 21: Relationship between using exclusion diets and history of exclusive breastfeeding (n=232)**

#### 3.3.4 Other exclusion diets

Parents/ caregivers were probed about the use of any other exclusion diets. Only 4.2% (n=12) of parents/ caregivers had tried the specific carbohydrate diet and a yeast free diet was tried by 5.3% (n=15) of parents/ caregivers.

Comments from parents suggested that they would also use sugar free diets and also exclude all forms of food additives, preservatives and colourants.

#### **3.3.4.1 Effect of specific carbohydrate, yeast free and other special diets**

Although only 27 parents reported that they used 'other exclusion diets' (section 3.3.4) a total of 61-65 parents/ caregivers reported on the effect of exclusion diets.

Improvements in various aspects were reported by a small number of respondents: bowel habits (n=15), general health (n=13), sleep (n=9), undesirable behaviour (n=20) and concentration (n=15). Fourteen parents/ caregivers noticed a significant improvement in social communication (such as speech, eye contact and smiling).

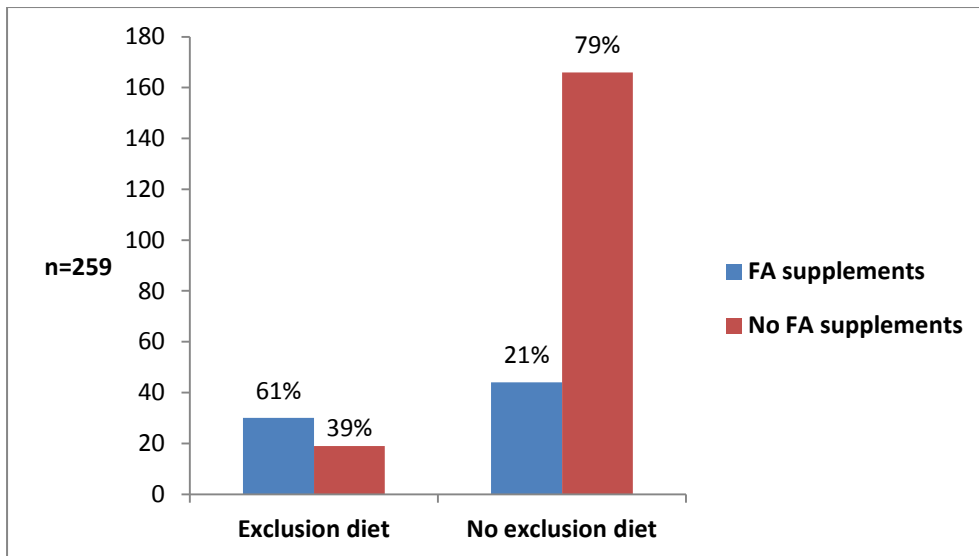
### **3.4 USE OF NUTRITIONAL SUPPLEMENTS**

Parents/ caregivers were asked to report which (if any) nutritional supplements they used for their children with ASD. Results show that the majority of parents/ caregivers did not use nutritional supplements (Table 4). Where supplements were used, omega-3 fatty acids appeared to be the most popular (28.3%, n=75). Parents/ caregivers who reportedly used supplements, used a range of multivitamin preparations (24.3%, n=61), including liquid preparations or powdered supplements which were added to food. Nutritional supplements such as sip feeds were also mentioned in their responses. Fiber supplements were the least popular (0.9%, n=2).

**Table 4: The use of nutritional supplements in children with ASD**

Nutritional supplement (number of parents/ caregivers)	No	Yes
Omega 3 fatty acids (n=265)	71.7% (n=190)	28.3% (n=75)
Vitamins (n=249)	78.7% (n=196)	21.3% (n=53)
Minerals (n=234)	88% (n=206)	12% (n=28)
Combined vitamin and mineral preparations (n=251)	75.7% (n=190)	24.3% (n=61)
Fibre (n=219)	99.1% (n=217)	0.9% (n=2)
Probiotics (n=229)	90.4% (n=207)	9.6% (n=22)
Digestive enzymes (n=223)	96.9% (n=216)	3.1% (n=7)

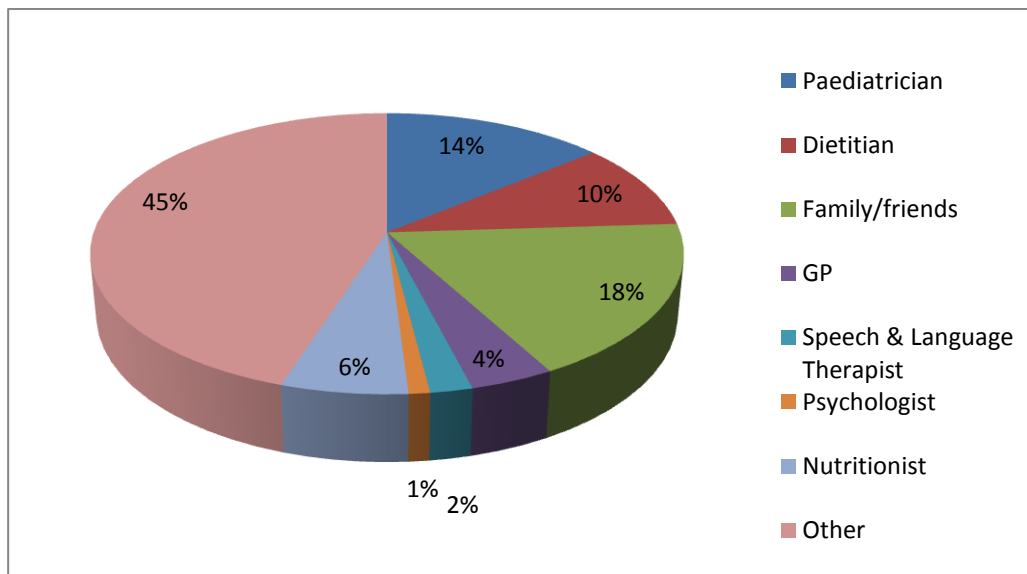
The use of fatty acid supplementation was significantly higher (61.2%, n=30) in children who were also on exclusion diets (gluten and/or casein free) than in the children who were not on exclusion diets ( $p < 0.001$ ) (Figure 22).



**Figure 22: The use of fatty acid supplementation in children with ASD where exclusion diets were used compared to those who did not use exclusion diets.**

### Source of recommendations for the use of supplements

Parents/ caregivers (n=141) were asked who primarily recommended the use of these supplements. Parents/ caregivers' family or friends (17.7%, n=25) were identified as the most frequent source information, followed by paediatrician (14%, n=20) and then by dietitians (9.9%, n=14) and nutritionists (6.4%, n=9). Interestingly, most parents/ caregivers (45.4%, n=64) chose the option 'other' for this section but unfortunately they did not specify (Figure 23).



**Figure 23: Who recommended the use of nutritional supplements? (n=141)**

### 3.5. PREVALENCE OF EXCLUSION DIETS ON AND THE USE OF NUTRITIONAL SUPPLEMENTS

The use of nutritional and dietary supplements were significantly higher ( $p < 0.05$ ) in the group where exclusion diets were already in use, particularly for fatty acids, vitamins, minerals, probiotics and digestive enzymes (Table 5).



**Table 5: Use of nutritional supplements by children with ASD following exclusion or non-exclusion diets (NED).**

<b>Nutritional supplement</b>	<b>Use of nutritional supplement while on Exclusion Diet</b>	<b>Use of nutritional supplement with No Exclusion Diet (NED)</b>	<b>p-value*</b>
Fatty acids	61.22% (n=30/ 49)	20.95% (n=44/ 210)	<b>p&lt;0.001*</b>
Vitamins	39.5% (n=15/ 38)	17.1% (n=35/ 205)	<b>p = 0.003*</b>
Minerals	37.1% (n=13/ 35)	7.8% (n=15/ 193)	<b>p&lt;0.001*</b>
Combined vitamin and mineral supplement	42.5% (n=17/ 40)	21.5% (n=44/ 205)	<b>p = 0.007*</b>
Fibre supplementation	3.5% (n=1/ 29)	0.5% (n=1/ 184)	<b>p = 0.216</b>
Probiotics	36.1% (n=13/ 36)	4.8% (n=9/ 187)	<b>p&lt;0.001*</b>
Digestive enzymes	18.8% (n=6/ 32)	0.5% (n=1/ 185)	<b>p&lt;0.001*</b>

\* Statistically significant  $p<0.05$

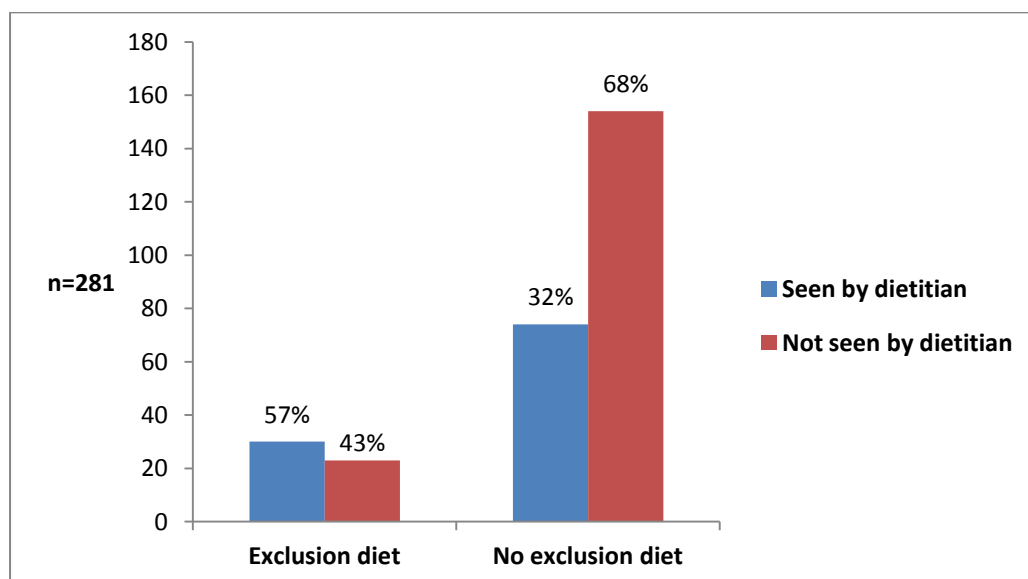
### 3.6 DIETETIC SUPPORT

Another objective of this study was to make recommendations regarding appropriate advice and support to meet ASD patients' needs. Parents/ caregivers reported on their experience of the service given by dietitians.

Over a third (37.6%, n=108) of parents indicated that their child was seen by a dietitian. The main reasons for consulting a dietitian were: concerns regarding the provision of a balanced diet/ not eating a varied diet (15.3%), advice on exclusion diets for ASD (7.6%), general dietary assessment (6.6%), constipation/ gut related problems (6.3%), refusal or difficulty accepting new foods (4.9%), underweight (4.5%), overweight (4.2%), unacceptable behaviour during mealtimes (2.1%), iron deficiency anaemia (1%) and dietary supplementation (0.7%).

When parents/ caregivers were asked if a dietitian supported their decision to trial or continue exclusion diets and / or nutritional supplements, 13.5% (n=39) said *yes*, 4.9% (n=17) said *no* and for 80.6% this question was not applicable.

Using Chi-square analysis, comparisons were made between children who were seen by a dietitian who were on exclusion diets and those who were not on exclusion diets (NED). Dietitians had seen a significantly higher percentage ( $p=0.001$ ) of children who were on exclusion diets (56.6%, n=30) than those who did not follow exclusion diets (32.5%, n=74) (Figure 24).



**Figure24: Children with ASD on exclusion diets compared to those not on exclusion diets, seen by dietitians (n=281)**

Parents/ caregivers were asked who recommended the use of nutritional supplementation for their children. Results show that interestingly, dietitians appeared to play a larger role in advising on the use of nutritional supplements

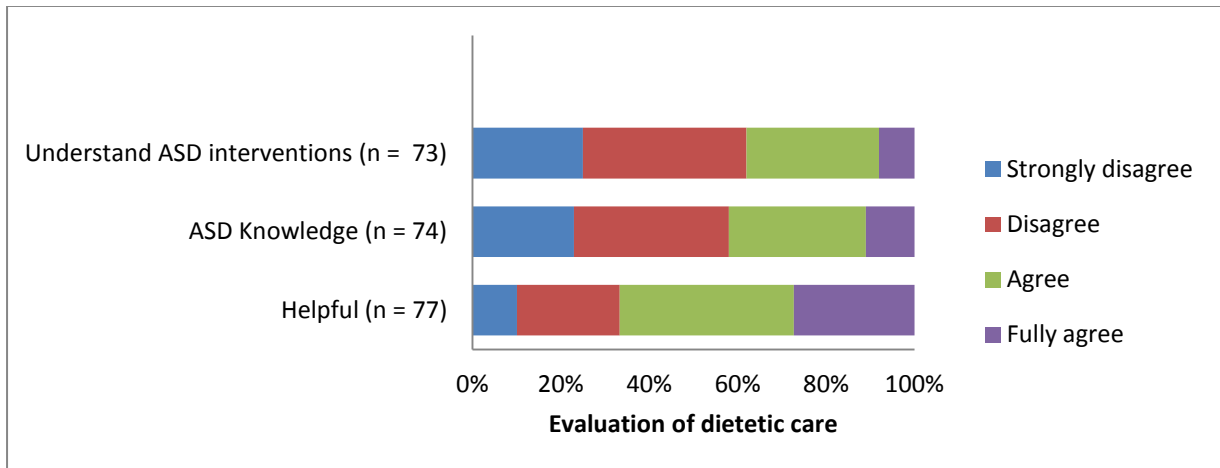
where children were not on exclusion diets (12.4%, n=11) in comparison to children who were following exclusion diets (6%, n=3) (Table 6). However, nearly half of the respondents (45.3%, n=139) were following recommendations made by other, yet unspecified, sources.

**Table 6: Comparison of persons who recommended the use of nutritional supplements in children with ASD on exclusion diets, and those not using exclusion diets (n=139)**

WHO RECOMMENDED THE USE OF NUTRITIONAL SUPPLEMENTS								
DIETS	Other	Paediatrician	Dietitian	Family/friends	GP	SLT	Psychologist	Nutritionist
Children on Exclusion diets (n=50)	54% (n=27)	14% (n=7)	6% (n=3)	16% (n=8)	0	0	0	10% (n=5)
Children on normal diets (n=89)	40.5% (n=36)	14.6% (n=13)	12.4% (n=11)	17.9% (n=16)	6.7% (n=6)	2.3% (n=2)	1.1% (n=1)	4.5% (n=4)

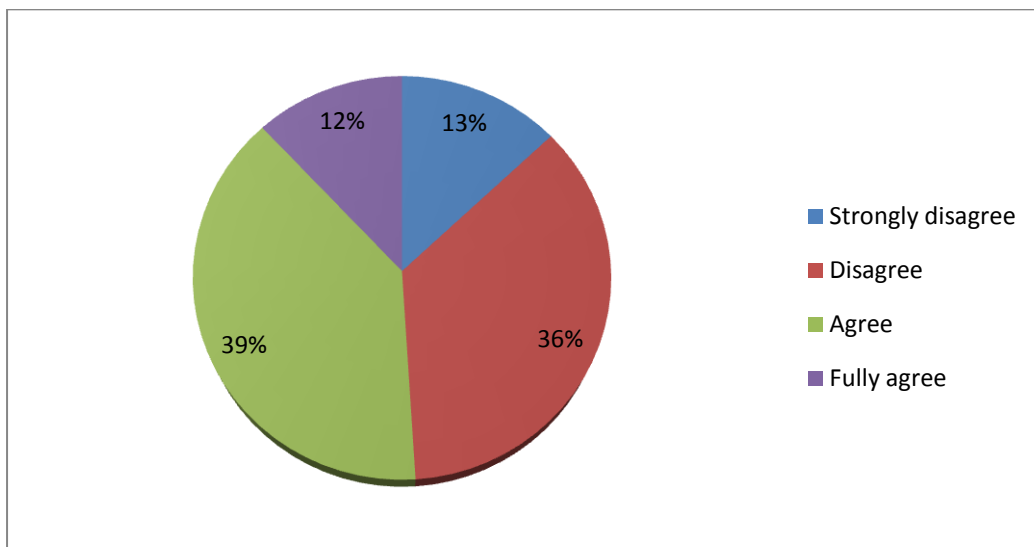
Parents/ caregivers were asked about their experience when seen by a dietitian by responding to certain statements. The first statement was: *'The dietitian had a good understanding of current dietary interventions available for children with ASD'*, showed that the majority (61.7%, n=73) of parents/ caregivers felt that dietitians did not have sufficient knowledge or understanding of current dietary interventions for children with ASD. A Mann-Whitney test indicated that there is no significant difference between the respondents' perception of dietitians' knowledge to dietary interventions for children with ASD who were on exclusion diets compared to those who were not on exclusion diets.

Similar responses were received on the following statement: *'The dietitian had good knowledge of ASD and associated eating patterns and behaviour.'* More than half (58.1%, n= 43) of parents/ caregivers felt that the dietitian they consulted did not have good knowledge of ASD in relation to dietary intake. However, when parents/ caregivers were asked if *'it was helpful to see a dietitian'*, the majority agreed (66.3%, n=51) (Figure 25).



**Figure 25: Perceptions of parents/ caregivers of children with ASD about the competency of the dietitian they consulted**

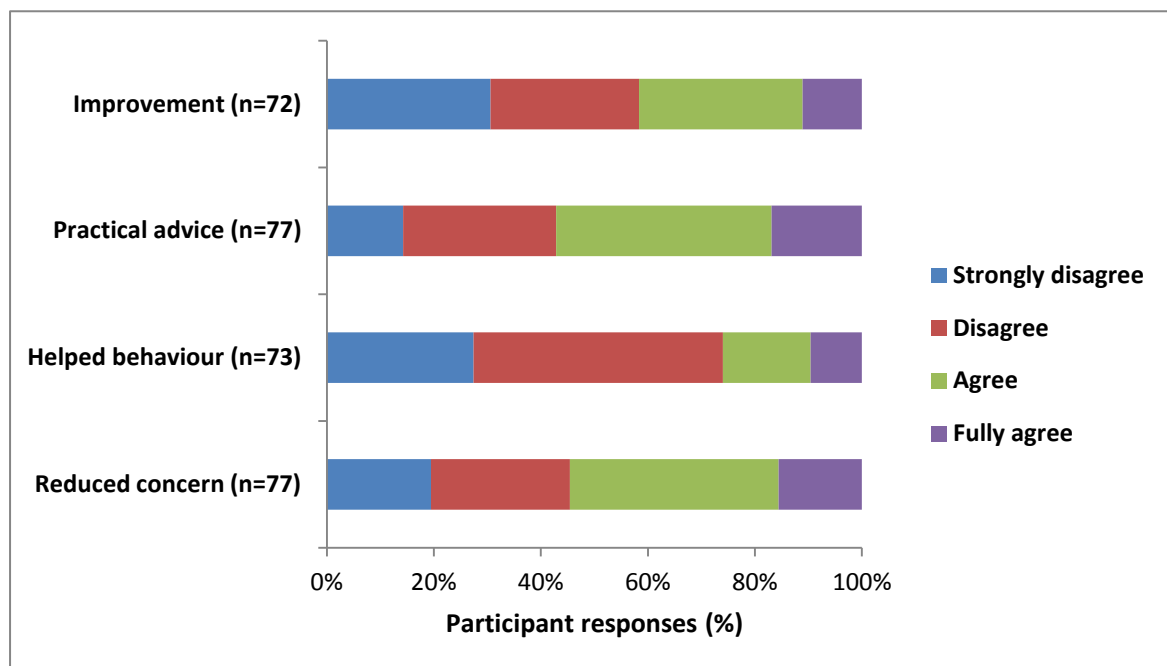
Responses to the statement *‘the clinic setting in which my child was seen was appropriate for his/ her condition’* were divided as nearly the same number of respondents reacted positively or negatively (Figure 26).



**Figure 26: Appropriate clinic setting to see children with ASD (n=75)**

Parents/ caregivers were asked to choose the most appropriate response to the following statement: *‘Seeing a dietitian has reduced my concern/ stress relating to my child’s diet’* and 54.6% (n=42) responded positively. A similar trend was observed in the next question when parents were asked if *‘the dietitian who they consulted with gave practical advice on improving their child’s diet’* and 57.2% (n=44) agreed.

However when asked if *'the dietitian gave useful advice about managing their child's behaviour around food and mealtimes'* nearly two thirds of respondents (62.4%, n=54) felt that the dietitian they had consulted did not give useful advice about behaviour during mealtimes. Parents' (n=72) responded to the question whether *'the situation for which their child was referred, had improved since consulting with a dietitian'*. Responses indicated that more parents (58.4%, n=42) felt it did not improve (Figure 27).



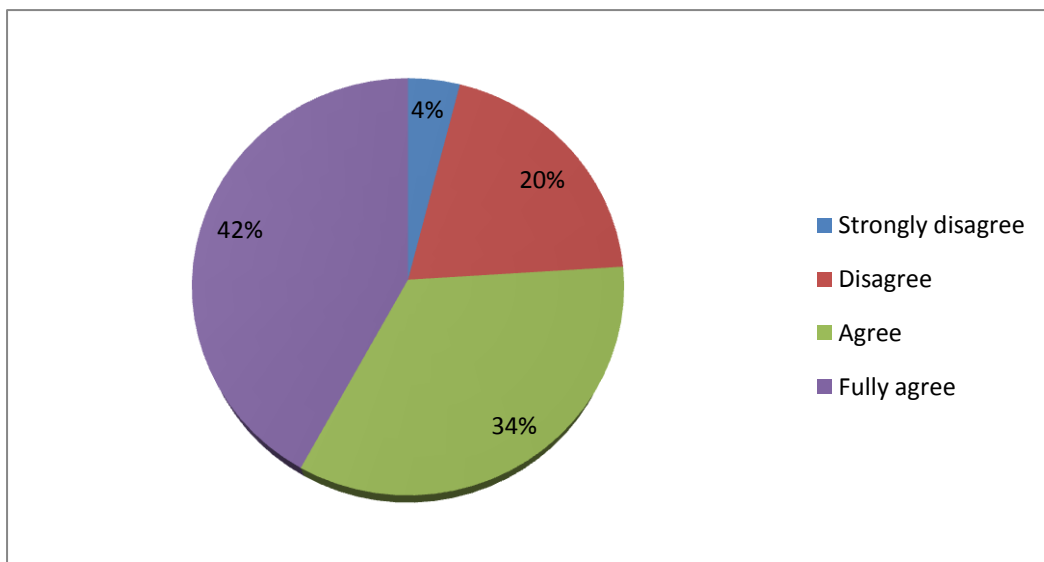
**Figure 27: Perceptions of parents/ caregivers of children with ASD about of dietary advice offered by dietitians**

Parents/ caregivers (n=108) were then asked to make suggestions of how dietitians (both working in the National Health Service in the UK (NHS) as well as in private practice) could improve their service for children and families living with ASD:

- Better knowledge of ASD and dietary related problems (48.6%, n=140)
- Better understanding of current dietary interventions and research for children with ASD (41.3%, n=87).
- Provide more practical guidelines (30.2%, n=87).

- Provide more written information (such as diet sheets) and other resources (such as star charts and social stories) (28.1%, n=81).
- More frequent consultations (23.6%, n=68).
- Improved clinic environment and consultation rooms (13.2%, n=38)
- Longer clinic appointments (7.3%, n=21).

The last question of the questionnaire asked parents/ caregivers: *'If your child has not seen a dietitian, do you feel that he/she would benefit from seeing a dietitian for nutritional advice?'* Even though the previous questions portrayed some negative responses to the competency of dietitians, the majority of responses (76.4%, n=143) *agreed/ fully agreed* that parents would value help from dietitians and only 4% (n=7) *strongly disagreed* (Figure 28).



**Figure 28: Perceptions of parents/ caregivers whether a child with ASD may benefit from seeing a dietitian (n=187)**

# CHAPTER 4

## DISCUSSION

## 4. DISCUSSION

A descriptive, cross sectional study was performed to improve understanding of parents/ caregivers' experiences related to children with ASD and subsequent feeding behaviour. This study investigated many aspects of ASD and responses were dependent on parents/ caregivers' perceptions. The aim of this study was to investigate factors which may play a role in food selection and nutritional intake in children with ASD such as early feeding history and feeding experiences, assessment of the mealtime environment and trends in current food selection. The primary objective of the study included that dietary intake of children with ASD would be assessed. According to literature, poor dietary intake may negatively affect nutritional status. Nutritional status however requires a complex assessment including anthropometric indicators (such as weight and height), biomarkers (such as individual's blood results), and clinical assessment.<sup>50</sup> Guidelines for assessing nutritional status are also outlined in UNICEF's conceptual framework and include other factors such as dietary intake, presence of infectious diseases, maternal nutrition, and environmental and social factors.<sup>51</sup>

Therefore the study did not directly determine nutritional status of children with ASD, but may highlight possible nutritional concerns that may have an effect on nutritional status.

The use of exclusion diets, special diets and nutritional supplements were also investigated, as well as views on current dietetic input for children with ASD. The results are discussed in the order of the study objectives.

### 4.1. Demographic information

The response rate of 2.7% yielded a study population of 325 parents/ caregivers and was statistically significant ( $n \geq 248$ ). The composition of the study population differs from the current ASD population in the United Kingdom in terms of gender as it indicates a higher relationship (7:1) of males to females than current data in the UK, where the male to female ratio of children diagnosed with ASD is approximately 4:1.<sup>52</sup>

The results showed that the age when most children were diagnosed with ASD was between the ages of two and six years (69.5%). According to the Autism Education



Trust this may be attributed to improved diagnostic techniques and criteria that have been developed in recent years which enable professionals to identify children with ASD earlier.<sup>53</sup>

Parents and caregivers reported that most information regarding ASD was obtained from health professionals, followed by the NAS, UK. Other independent organizations such as Autism File, Autism Trust and ANDI were less popular. It was not specified which alternative sources were consulted for information, thus the influence of Internet sources cannot be assessed, and the impact of unscientific information cannot be commented upon.

## **4.2. Common feeding problems in children with ASD**

A number of factors were investigated including early feeding history such as breastfeeding practices, and the presence of any feeding problems during breast or bottle feeding. Weaning practices and the acceptance and progression of weaning foods were also investigated, as well as current food intake, mealtime environment and factors that may influence current food selection such as sensory problems.

### **4.2.1 Breastfeeding**

Results for this study correlates well with the incidence of breastfeeding in the general population in England. Early feeding history of children with ASD in this study suggests that where possible, breastfeeding was an important part of feeding during infancy. The study showed that 75.7% (n=246) of this population group (n=325) were able to breastfeed their children. Similarly results from the 2005 Infant Feeding Survey (UK) showed that 78% of mothers initially breastfed their children.<sup>4</sup> This study indicated a much higher prevalence of breastfeeding among children who were later diagnosed with ASD than the American study by Williams et al. (2000) where only 44% (n=83) of respondents reported their child was breast-fed for some period of time.<sup>54</sup>

This study specifically asked parents about the duration of exclusive breastfeeding. For parents who chose to breastfeed, 30.9% (n=76) managed to do so exclusively for up to one month. As expected, the incidence dropped after 2 months. It appears

that if parents managed to exclusively breastfeed, they were able to continue this for longer with an increased incidence of 17.1% up to 4 months, 19.1% for 4 to 6 months and surprisingly the same percentage of 19.1% for more than 6 months. The incidence of breastfeeding up to 6 months in this study is slightly lower than for those in the general UK population, where 26% of mothers still breastfeed their babies exclusively up to 6 months.<sup>4</sup>

Problems experienced with breastfeeding could not be analyzed due to the qualitative nature of the research. It was not possible from this study to identify whether other factors, such as latching problems were more prevalent in children with ASD and if there is any relation to this and sensory problems often associated with the disorder.

#### **4.2.2 Feeding problems during breast or formula feeding**

The questions regarding feeding problems included both breastfed and formula fed infants. The main feeding problem, identified by parents/ caregivers was that their children did not settle down after their feeds. This suggests that nearly half of infants (45.9%) who were later diagnosed with ASD were unsettled during or after feeds of either breast milk or formula. Current data on the prevalence of food intolerance in the UK, Europe and North America, suggest that up to 8% of children under the age of 3 years, have food intolerance.<sup>55</sup> It is debatable as to whether there may be a higher rate of food intolerance in this group which may have contributed to infants feeling uncomfortable after feeds.

The second most prevalent feeding problem identified in this group suggests that children (32.7%) also experienced problems consuming the full volume of their feeds. This corresponds with the reported results that at least 14% of infants were not interested in the feeds offered and 15.9% did not cry to indicate hunger. However, it is important to note that many parents (regardless if the child has ASD or not) may feel that their infants did not consume adequate volumes of feeds at an early age. Comments from parents in this section suggest that tolerance of feeds (breast or formula) was not ideal and that infants had problems with wind, colic, gastroesophageal reflux and for some infants, cow's milk protein intolerance was identified at this stage. When gastrointestinal discomfort causes a chronic reduced

intake of feeds for an extended period of time, it may impact negatively on nutritional intake and inhibit normal growth and development.

#### **4.2.3 Introduction of complementary foods**

Guidelines proposed by the UK government, recommend mothers to delay weaning until the age of 6 months. However, results from the Infant feeding survey (UK) 2005 showed that most parents started the weaning process earlier and only 2% delayed weaning as recommended.<sup>4</sup> In the current study, the majority of children (72.5%) were weaned between the ages of 4 to 6 months, and delayed weaning (>7 months age) was present in 20% of children. Delayed weaning may have an impact on speech development as the same oral muscles required for eating are used for speech.<sup>56</sup> Early weaning (before 4 months)<sup>56</sup> was present in 7.2% of children which is similar to the Infant Feeding survey results in 2005 that indicated that less than 10% of children were weaned early.<sup>4</sup> Valid reasons exist for not weaning infants early: infants have immature kidneys that are not able to cope with the renal solute load of food, the potential for allergic reactions due to the immature gut and an underdeveloped immune system<sup>57</sup>, breastmilk and infant formulae meet nutritional requirements up to 6 months of age<sup>58</sup>, solid food reduces the availability of nutrients (in particular from breast milk), neuromuscular co-ordination may not be developed properly for eating<sup>57</sup> and there may be an increased risk of obesity with early weaning.<sup>59</sup> Therefore weaning practices may have particular importance for children with ASD who may present with problems such as delayed speech and language development, sensory problems, food intolerance and gut related problems.

Considering that children with ASD may have sensory problems, the transition to more textured food during the stages of weaning, may be more difficult than in the general population. This seems to be true for this study population as well. Only a small percentage of parents indicated that their children would struggle to accept or had problems to tolerate smooth pureed food. However, when asked about the acceptance of stage 2 and 3 weaning foods, the results were very different. Sixteen percent of children always found it difficult to accept food with soft lumps and 24% of children always struggled with food with textured lumps and chunks. Therefore it seems as if the transition from smooth pureed food to more textured food proved to be the most problematic for this group. These results are similar to those of Cornish

(1998) and Nadon et al (2011) where parents indicated that problems with food acceptance increased when progressing from baby to family foods or mashed food to solid food.<sup>23,26</sup> Acceptance of finger foods though posed less problems as only 12.8% of children in this study would always refuse these. It is important for infants to progress to age-appropriate textures during the weaning period, to encourage chewing and development of oro-motor muscles. A delay in the progression from pureed to more textured food may therefore have a detrimental effect on later speech development.<sup>57</sup>

#### 4.2.4 Food texture

The most common feeding problem in children with ASD is food selectivity and this is the main contributor to the low rate of overall food acceptance.<sup>60</sup> Food texture remains a key theme in the literature related to food selectivity as oral defensiveness could cause overreaction to the feel of certain foods in the mouth.<sup>54,61</sup> A study by Sharon et al (2010) suggested that children with ASD who have sensory sensitivity may restrict their food intake to food textures that are tolerable and more manageable, and therefore food intake becomes limited in range and nutritional composition.<sup>61</sup>

The study aimed to gain more insight into the characteristics of food which most affect food acceptance or refusal in this group of British children. Questions were asked regarding food texture as well as food temperature. **Crunchy** and **dry** food was by far the most popular, 79% of children accepted these. It may be worthwhile encouraging crunchy and dry foods in children where dietary intake and food acceptance seems poor. **Smooth pureed** food including foods such as smooth yogurt and custard was also popular as nearly 70% of children would normally eat smooth pureed food without problems. Therefore it is not surprising that **soft and easy to chew** foods were also very popular in this group, 72.5% of children would normally eat these well. Other more chewy foods such as meat may be refused as the child may prefer softer foods that are easier to manage. Moist foods such as cooked food with sauce, proved to be rather unpopular, more than half of children (54.2%) would normally refuse these. This information is invaluable for menu planning, food preparation and making necessary consistency adaptations to encourage consumption of essential nutrients for instance protein sources. Cornish

concluded that reassurance and advice during these early years and support around the progression to more solid food textures would be a valuable use of dietetic human resources.<sup>26</sup>

When considering the temperature of food, results indicate that cold and lukewarm foods were equally popular as responses for both were over 60%. The nutritional implication of these results are that certain important meals such as cooked family meals may be refused if there is a preference to cold foods. Creative recipe adaptations may be necessary and parents may need guidance from the dietitian in this aspect.

#### **4.2.5 Mealtime environment**

Nearly 25% of children would only eat in a specific environment or place. However, other factors such as eating in a specific chair, with music playing, or even with the same person present during meals, did not play a large role. Results differ from the study by Williams et al (2000) where over a third of children's eating patterns were influenced mainly by situations and people.<sup>54</sup> Comments from parents in this study suggest that the set mealtime routine and meal times have important implications. Any change to the routine may cause anxiety and undesired behaviour, especially when meals are taken outside of the normal environment, such as in restaurants or other similar social settings.<sup>54</sup> Challenging behaviour during mealtime increases family stress and is disruptive to the family climate.<sup>61</sup>

#### **4.2.6 Sensory problems**

Research and clinical observations suggest that food selectivity is the main problem that affects food intake in children with ASD and that these children may present with very strong preferences to certain foods according to type, texture, colour or packaging.<sup>60</sup> Sensory sensitivity could also be defined as sensory defensiveness where certain experiences relating to the feel of textures could cause a negative behavioural response.<sup>61</sup>

The presence of particular sensory problems that may have a negative effect on food acceptance and total dietary intake were investigated. This study found that more than half (59.9%) of children dislike getting their hands or face dirty. Mealtimes can be a messy exercise for children, especially during the weaning period. Children may

choose not to have specific foods, not because they do not like the way it looks or tastes, but possibly due to how it feels and the effect it has on their hands afterwards. Furthermore, finger foods comprise an important part of children's diet and include nutritious foods such as fruit. If the sensory defensiveness prevents children from consuming nutrient dense finger foods it could have a negative impact on children's micronutrient status causing a lower intake of certain vitamins and antioxidants.

This study concludes that children differ significantly according to sensory issues. Some children may experience hyper- or hyposensitivity to taste, texture and smells and their dietary intake and food selectivity may reflect this. For children with selective eating habits, a dietitian's input is essential to assess if they need additional nutritional supplementation or creative menu adaptations.<sup>61</sup> Children under the age of 5 years tend to have a more restricted dietary intake and limited range of food textures and thus input from dietitians is important to provide advice and reassurance during these critical stages of growth and development. The study reiterates the fact that children with ASD often has selective eating habits that go beyond the usual 'fussy eating' behaviour as seen in children throughout specific developmental ages.<sup>18</sup> These findings are similar to those as reported by the BDA Dietary Management of ASD.<sup>18</sup> A holistic approach is recommended by the BDA for the management of children with ASD who have severely limited eating habits. Services should include assessments from a dietitian, speech and language therapist, occupational therapist and a clinical psychologist.<sup>18,26</sup>

The presence of oral defensiveness appears to be common in children with ASD which could cause avoidance of certain activities in the mouth, such as tooth brushing. Results from this study indicate that half of the children dislike physical touch (13.7% *always dislike* and 41.3% *sometimes dislike*). This may be dependent on the situation or environment but could influence food intake negatively. Interestingly, this study indicates that most children did not have a specific preference for eating utensils, cutlery and cups.

The results also indicate that the majority (71.7%) of children with ASD in this study dislike strong odors possibly due to hyper-sensitivity to smell. These findings

correlate well with data from the NAS where children and people with ASD may experience over- or under-sensitivity to smells, sounds, light or colours.<sup>2</sup>

Current literature indicates that children with ASD are particularly specific regarding food colour and presentation. Williams et al reported that the main factors that influence food selection were texture, appearance and presentation, smell and temperature.<sup>54</sup> In this study, half of the children's food intake was not influenced by food colour. However, food presentation plays a major role as the majority (64.8%) of children was particular about the appearance of their food, including specific brands of food and food packaging. Children with ASD often do not appear to accept any change well, which may explain why most of them in this study struggled with changes to the food presentation and appearance which they were used to. This is supported by other studies where rituals surrounding eating and problems adapting to change were present.<sup>54</sup>

#### **4.2.7 Food choice**

Specific food preferences were also investigated and it was found that a considerable number of children (75.6%) would repeatedly choose the same foods for meals. Sharp et al (2009) also reported that children with ASD generally consume a smaller range and quantity of food, and would also present with disruptive behaviour when non-preferred foods are offered.<sup>60</sup> Raiten and Massaro (1986) has similar findings and also found that these children show more food preferences than children with typical development.<sup>62</sup>

It is crucial to keep in mind that feeding problems and food selectivity is complex and multi-factorial and associated behaviour may cause additional stress and disruption to family life.<sup>61</sup> Careful assessment by health care professionals and assisting parents with concerns about their child's eating is important in helping the family cope with difficult behaviour. The dietitian might consider consulting other health care professionals.<sup>54</sup>

Selectivity by food group is often reported in studies, and suggests that children have a strong preference for carbohydrate rich foods rather than fruit and vegetables.<sup>60</sup>

In this study, there were statistically significant ( $p < 0.05$ ) differences in food selectivity of children with ASD according to food groups, apart from vegetables and refined

carbohydrates. Findings of the study are discussed according to each food group and the nutrients that may be affected:

- **Fruit** seemed to be more popular than anticipated where at least 41.6% of children would readily eat fruit and 45.7% of children would consume **fruit juice**. However, this still indicates that more than 50% of children would not normally eat fruit. Fruit is an important source of certain vitamins and antioxidants that help to maintain a healthy immune system. Vitamin C, present in citrus fruits, is also necessary for the absorption of iron.<sup>13</sup> Fruit is also rich in dietary fibre, which helps to maintain a healthy gut. Fruit intake was affected by texture and temperature.
- Half of the children would not eat **vegetables** implying that they miss the opportunity to consume a range of important nutrients. This is also true for children who are not diagnosed with ASD as found by Williams *et al* in 2005 when a retrospective study was conducted comparing selective feeding of children with typical development, and those with ASD. Williams found that 58% of 3.5 year old children (n=178) had no vegetables in their diets.<sup>63</sup> Important nutrients will be lacking in the diet when vegetables are not eaten. For example green leafy vegetables are good sources of Vitamin C, Vitamin A, folate and iron. Fruit and vegetables contain mainly water, and contribute several essential vitamins and minerals when consumed in recommended amounts. People who eat less than the recommended amount of fruit and vegetables are at risk of nutrient deficiencies, and higher rates of cardiovascular disease and cancer.<sup>64</sup>
- Half of the children would refuse to eat **unrefined starchy foods**. Unrefined carbohydrates such as cereal, grains, wheat, oats, rye, barley, rice and maize contain substantial amounts of protein, dietary fiber and B vitamins. B vitamins are particularly important for a healthy nervous system and the release of energy from the blood and deficiency causes loss of appetite, slow growth and development and impaired health.<sup>65</sup>
- **Starchy vegetables** such as potatoes were very popular (62.6%). Potatoes are energy dense and are a good source of Vitamin C.



- **Refined carbohydrates** were acceptable to at least 64.4% of children and these findings correspond with findings by Sharp et al.<sup>60</sup> These types of foods would normally be popular in children due to the sweet taste and the texture, but refined carbohydrates are normally energy dense and have a high glucose load thus frequent consumption may lead to excessive weight gain. Refined carbohydrates and sweet tasting food may be preferred by most children. However this study confirmed that theory that children with ASD may have a predisposition for sweet foods. Children with autism may also have habituated to the sweet taste of food.<sup>66</sup> All forms of **egg** were likely to be refused (59.3%). Eggs are an important source of protein of high biological value and iron; it also supplies good amounts of phosphorus, fat, Vitamin A, calcium as well as some Vitamin D, riboflavin, thiamin and biotin<sup>67</sup> Nutrient deficiencies may develop if alternative sources of these nutrients are not provided, especially if the intake of other protein rich foods such as meat is also limited.
- **Unprocessed meat and fish** was less acceptable as only 35.9% of children would *always* consume these. This may play a role in the high prevalence of iron deficiency (low serum ferritin levels) commonly found in children with ASD as red meat is the best source of haem iron.<sup>32</sup> Iron deficiency in infancy and childhood could have adverse effects and has been associated with poorer communication, cognitive-, motor-, social- and emotional functioning in later childhood and adolescence.<sup>32</sup> Similar problems are frequently associated with ASD. Studies suggest that supplementation with iron may improve sleep, verbal learning and memory. Researchers suggest that children with ASD should be routinely screened for iron deficiency.<sup>32</sup> Dietitians may play an important role by assessing dietary adequacy and aim to prevent or correct dietary iron deficiency. Iron supplementation could also be monitored carefully and different varieties of supplementation could be advised to minimize adverse effects such as constipation or loose stools.
- **Processed meat** was preferred, 52.4% of children would *always* choose to eat this. Most processed meats have a high fat and sodium content and also contain food additives and preservatives. A high fat intake can lead to

excessive weight gain and high sodium consumption is a factor in the development of hypertension leading to heart disease.

- A positive finding was that the majority of children would *always* take **dairy products and alternatives**. A relatively small proportion of children (15%) would refuse dairy products. This may lead to low intakes of calcium having a negative impact on bone health during this important time of growth. These results seem to be contradictory to a cross-sectional study by Witwer; in which food diaries of children with ASD (n=46) were assessed and it was reported that they appeared to have lower dairy and therefore calcium intake compared to children with typical development.<sup>68</sup>

Practical and creative ideas to encourage the intake of fruit, vegetables, meat, and / or dairy products were formulated by Cornish (1998), following the analysis of food diaries of autistic children. These guidelines are called *the balance of good health in autism*, and may be useful in some children with ASD where the dietary intake is limited.<sup>26</sup>

#### **4.2.8 Fluid intake**

Current guidelines suggest that 6-8 cups/ glasses of fluids should be consumed by for children aged 3-16 years for healthy children.<sup>14</sup> The majority of children in this study had a slightly lower fluid intake, 3-5 cups daily. Low fluid intake may cause constipation, which has been reported in this study. Constipation may cause poor appetite and negatively affect dietary intake thus exacerbating existing problems in children with ASD.<sup>63</sup> Furthermore, it was found that nearly a third (31%) of children in this study had suboptimal fluid intake, by taking only 1-3 cups of fluid per day. Fluid requirements for children are dependent on age and weight<sup>14</sup>; however, even for a 3 year old child (minimum inclusion age for this study) 1-3 cups of fluid would not be sufficient.

#### **4.3. Exclusion diets and dietary supplements**

One of the secondary objectives of this study was to investigate the extent to which exclusion diets and dietary supplements were used for children with ASD and the

observed outcome of the dietary interventions. To date it is still accepted that there is insufficient evidence to use exclusion diets for the treatment of autism, although this is an important area for future research as parents are known to try every possible method of treatment. The following exclusion diets and dietary supplements were assessed: Gluten free-, casein free (GF/CF)- and yeast free diets; fatty acid supplements, other special diets and supplements.

#### **4.3.1 Exclusion diets**

Researchers reported that 15.5% and 33.3% of parents/ respondents with children diagnosed with ASD have tried modified diets.<sup>31,69</sup> These findings suggest that parents see dietary intervention as a significant complementary therapy.

Results from this study showed the majority of parents who have children with ASD; do not use exclusion diets related to the ASD, but rather due to unrelated food allergies and intolerances. The combined use of wheat/gluten and/ or casein free diets in this study was 19.1% (n=55) from a total of 288 parents/ caregivers who answered the question relating to exclusion diets. Other exclusion diets such as yeast free or specific carbohydrate diets (SCD) were less popular as only 9.5% (n=27) of parents/ caregivers used these. The use of the gluten and/ or casein diet in this study was therefore similar to that reported by the small study (n=37) by Cornish<sup>31</sup> where 21.6% of children were on a gluten and/ or casein free diet. This may indicate that the perceived benefits of these exclusion diets are not yet widely accepted and that parents are not convinced of their use.

Children in this study followed the gluten and/or casein free diet for more than a year indicating that the parents/ caregivers observed definite benefits from following the diet. Yet it is important to ensure dietary adequacy while using exclusion diets, as the GF/CF diet is usually associated with lower calcium intake.<sup>32</sup> Cornish reported that children who followed a gluten and/ or casein free diet for more than 6 months, were less likely to follow repetitive and selective food patterns than children who followed the diet for shorter periods of time, which enhances dietary diversity.<sup>31</sup>

Reporting on their experiences and observations of their children, parents/ caregivers observed that bowel habits improved (for both constipation and diarrhoea), as well as general health, sleeplessness, disruptive behaviour,

concentration and social communication. It appears that children either responded positively to gluten/ wheat, casein or GFCF diets, or that there was little improvement, however, it is very unlikely for symptoms to worsen. These findings are in line with a recent randomized, controlled, single blind study of a gluten- and casein free diet in children with ASD, showing that there were improvements in the social interaction abilities and stereotypical behaviour, as well as attention and concentration, after 24 months on the diet.<sup>45</sup> Following on this information it appears that bowel habits are likely to improve following the exclusion of gluten and / or casein thus it may be worth considering these exclusions with more children with ASD where plausible. A retrospective study of 150 children with ASD found a three-fold higher prevalence of Coeliac Disease than in the general paediatric population. As the treatment for Coeliac disease is the complete avoidance of gluten, this would further merit the possible use of a gluten free diet in children with ASD.<sup>69</sup> It is important that if such dietary exclusions are considered, it should be discussed with a registered dietitian to ensure that the child's dietary intake is sufficient and that appropriate alternatives are recommended. This is especially important if the child is already a selective eater.

In contrast to the GFCF diet, only a small percentage of respondents used a yeast free diet (5.3%, n=15) or the Specific carbohydrate diet (SCD) (4.2%, n=12), however, 61-65 parents/ caregivers responded to the questions that followed on the effects of these diets. Therefore data for the use of the SCD and yeast free diet should be interpreted with caution. Most parents/ caregivers reported that there was little improvement in bowel habits, general health, sleep, behaviour, concentration and social communication. Unfortunately there are currently no research studies on the use of the SCD and this study found that only a very small number of parents/ caregivers had trialed them.

#### **4.3.2 Use of nutritional supplements**

If used correctly nutritional supplements can be valuable to ensure optimal nutrient intake for children with feeding problems. The use of nutritional supplements in this study was much lower than anticipated, where the majority of parents/ caregivers (71.7% - 99.1%) did not use vitamins, minerals, fatty acid or fibre supplements for their children. Similarly the study by Witwer that was conducted in the USA

concluded that a mere 17.3% of children and adolescents with autism had taken special formulated vitamin supplements.<sup>68</sup>

Comparisons between the group of parents/ caregivers who used exclusion diets, and those who did not use exclusion diets showed that the use of nutritional supplements were significantly higher in the group who were using exclusion diets. In particular, the use of fatty acids, vitamins, minerals, probiotics and digestive enzyme use was significantly higher ( $p < 0.05$ ) in children who were on exclusion diets vs. children who were not on exclusion diets. There are many possible explanations for this. Firstly, they may feel the need to supplement their child's diet due to the fact that they are excluding certain food groups. Secondly, parents/ caregivers who use exclusion diets may be more health conscious or more aware of the benefits of nutritional supplementation in general, or specifically for ASD. It was surprising that few parents/ caregivers used these supplements for their children where dietary intake may be limited by other factors relating to ASD. A systematic review by Daniel (2009) found that multivitamin and mineral supplementation may be beneficial in children with ASD to help ensure nutritional adequacy.<sup>32</sup> Parents/ caregivers may need further advice on the importance of these for their children by consulting dietitians to assess the adequacy of their children's diets.

Results showed that supplementation was specifically higher for fatty acids, separate vitamins or minerals, as well as combined vitamin and mineral preparations, probiotics, and digestive enzymes. Seventy five (28.3%) of children in this study were supplemented with polyunsaturated fatty acids (PUFAs) such as *n3* and *n6* fatty acids. PUFA deficiency in children has been associated with poor reading, spelling, and auditory working memory, and has implications in neuro-developmental disorders such as ASD.<sup>32</sup> A recent systematic review investigated the role of *n3* fatty acids in ASD as some studies suggest that lower plasma levels of *n3* fatty acids were found in children with ASD compared to other children with typical development.<sup>32</sup> Schultz (2006) compared children with autism ( $n=861$ ) and children with typical development ( $n=861$ ) and observed a significantly higher risk of developing autism in children who did not receive essential fatty acids through breastmilk or infant formula.<sup>70</sup> Current research concludes that PUFA supplementation may improve symptoms of ASD; however the systematic review

concluded that there is still insufficient evidence to determine if *n*-3 fatty acids should be used as a treatment for ASD.<sup>32</sup>

The supplements least used were fiber, digestive enzymes and probiotics, despite constipation being a frequently reported symptom by parents/caregivers. It is thought that the use of digestive enzymes and probiotics may be beneficial in some children with ASD who have decreased production of digestive enzymes and gut related problems.<sup>71</sup> A case report found improvements in autistic behaviours using digestive enzyme supplementation<sup>32</sup>. Brudnak *et al* (2002) supplemented diets for 12 weeks which led to significant improvements ( $p < 0.5$ ) in multiple autistic behaviours<sup>72</sup>. Munasinghe conducted a double-blind randomized controlled trial and found small improvements in food variety with digestive enzyme supplementation<sup>73</sup>. However, the study concluded that there was no clinically significant improvement in gastrointestinal symptoms, sleep quality or behaviour in children with ASD following digestive enzyme supplementation.<sup>73</sup>

Chronic constipation as well as other gastrointestinal problems such as gastroesophageal reflux (GOR), diarrhoea, bloating, abdominal pain and faecal impaction appear to be common in children with ASD.<sup>32</sup> A study by Horvath (2004) found that 80% of children with autism had at least one gastrointestinal related problem.<sup>71</sup> It is thought that children who have underlying gastrointestinal problems such as GOR may develop a conditioned aversion to eating some foods due to the pain and discomfort associated with eating.<sup>63</sup>

Responses from parents in this study indicated at least 6.3% of children suffered from constipation and therefore fiber supplementation may be an important part of the treatment, in addition to other dietary and fluid recommendations. As mentioned previously, constipation may also be a contributing factor in food selectivity and refusal, due to reduced appetite as a result. Children may therefore become adapted to eating and drinking small amounts of food across the day.<sup>63</sup>

Interestingly, when parents who used supplements were asked who recommended its use, only 10% responded that it was recommended by dietitians, and recommendations from family and friends appeared to play a larger role. Most parents (45.4%) chose the option 'other' but did not specify the impact or the scientific quality of these sources (e.g. Internet). When further comparisons were

made, dietitians played a larger role in advising children to use nutritional supplements where they were not following exclusion diets, in comparison to children who were on exclusion diets. Reasons for this are unknown.

As above studies suggest, some nutritional supplements may be beneficial. However, before embarking on the use of nutritional supplements, consultation with a registered dietitian is strongly recommended as vitamins and supplements can be toxic in high doses. Registered dietitians will assess the use of supplements by reviewing the safe upper levels of supplementation for children according to age.<sup>74</sup>

#### **4.4. Dietetic support**

The final objective of the study was to make recommendations regarding appropriate advice and support to meet ASD patients' needs based on parents/ caregivers previous experience of the service they received from dietitians.

More than half of parents/ caregivers (58.1%) felt that the dietitian who they consulted did not have good knowledge about children with ASD and associated feeding problems. Similarly most parents/ caregivers (61.7%) felt that the dietitian did not have good knowledge and understanding of current dietary interventions for children with ASD. They also felt that dietitians could not give adequate advice regarding their children's behaviour around food and during mealtimes (62.4%). When parents were asked if their child's condition for which they were referred improved, most of them (58.4%) disagreed. Although some of these experiences were negative, most parents reported that they found it helpful to see a dietitian (66.3%) for their child with ASD; the dietitian gave practical advice on improving the diet (57.2%) and helped to reduce their concerns about their child's diet (54.6%). There is little published data on current dietetic practice for children with ASD.<sup>75</sup> Bowers (2002) conducted an audit of children with ASD referred to their dietetic department and concluded that the majority of referrals were for advice on gluten- and casein free diets, management of food selectivity and dysfunctional feeding behaviour. The short audit suggested that ASD is a particularly complex area due to the complexity of the disorder, other conditions associated with ASD (such as gut related problems), and behavioural aspects.<sup>75</sup> It is possible that the perceived lack

of knowledge and support that some parents have experienced from dietitians is a consequence of the complexity of the individual child and their condition, and not specifically related to the dietitian's apparent lack of knowledge of ASD. To what extent parents' knowledge of the disorder is scientifically sound may also influence their response to the dietitian who needs to convey education and counseling in an evidence based manner.

Another audit by Cornish (1998) assessed the dietary intakes of children with ASD referred to the dietetic department and highlights the fact that children who generally ate less than 20 types of foods and children under the age of 5 were more vulnerable and would benefit more from individual dietetic assessment.<sup>26</sup> In this study it was positive that the majority of parents (76.4%) whose children have not yet seen a dietitian responded that they would value the input of a dietitian. Dietitians should continue to carry out weight and growth monitoring in children with ASD, as well as detailed dietary assessments as is common practice for children of typical development.

A matter of concern was that where children were on specific exclusion diets (n=53), 43.4% were not seen or assessed by a dietitian. This is potentially detrimental to these children's nutritional status and health as their daily diets may be lacking in important nutrients. A case report by Fox *et al* (2004) warns of the dangers of unsupervised dietary exclusions. In this case report, a child with confirmed cow's milk protein allergy was put on a milk protein free diet, whereas his mother excluded dairy products from her diet while he was breastfed. He remained on a very limited diet when solids were introduced and throughout his toddler years. There was no encounter with a dietitian to assess the adequacy of his diet and he subsequently developed rickets due to Vitamin D deficiency. The report concludes that adequate supervision by qualified dietitians, and appropriate dietary supplementation is essential to ensure nutritional adequacy in children.<sup>6</sup>

Dietitians play a role in reassuring parents and providing support through evaluation of the child's dietary intake and associated feeding behaviour. Where parents/caregivers would like to trial different dietary approaches, careful evaluation of the individual child's diet should take place, with justification of any interventions and critical evaluation of current research for the intervention. Certain interventions such



as a gluten-and casein free diet may be plausible, however, dietitians should supervise and monitor the use of this carefully and ensure that appropriate alternatives are taken where food groups are excluded, and to advise on appropriate dietary supplementation as necessary.

# CHAPTER 5

## SUMMARY

## 5. SUMMARY

### 5.1. Conclusions:

The study gathered information about a range of factors that may influence dietary intake of 325 children with ASD, including the presence of early feeding problems, food selectivity, limited dietary intake, difficulty accepting new foods, progressing to different textures, mealtime environment and behaviour, sensory problems, and the presence of gut related problems.

The study concludes that children with ASD present with early feeding problems which may or may not relate to their diagnosis of ASD. The most difficult stage of weaning was the progression from smooth pureed foods to more textured food. However, each child needs to be assessed on an individual basis taking into consideration other medical conditions as well as preferences according to the type of autism and associated behaviour. Food selectivity remains a prominent part of ASD and may relate more to the specific textures of different foods due to hyper- or hyposensitivity. Dry and crunchy foods were preferred by most children. Product branding and food presentation also played a large role in food acceptance. Food selectivity was significant according to food groups, and preferred food groups were starchy vegetables such as potatoes and refined carbohydrates. The lack of dietary diversity raises concern. The fluid intake of this group appeared to be suboptimal which may contribute to gut related problems such as constipation.

Special and exclusion diets, especially gluten and casein free diets are used by some parents and the longer term (>1 year) observations appear positive with improved bowel function, general health, sleep, behaviour, concentration and social interaction. Dietitians do not currently advise parents to use the GFCF diet, in view of limited conclusive studies. However, from this study, it is clear that this diet may work for some children, and that there are significant improvements to these children related to their ASD. The study also highlighted that there were no reported side-effects to the use of these diets, if used under supervision of dietitians, to ensure nutritional adequacy. However, a large number of children who were on exclusion diets were not seen or assessed for nutritional adequacy by dietitians.

The use of nutritional supplements were lower than anticipated, however, the use of nutritional supplements were significantly higher where exclusion diets were used, compared to the group where no exclusion diets were used.

Parents who participated in this study had varied perceptions regarding the knowledge and understanding of dietitians about children with ASD. However, they felt that dietitians provided reassurance and support in relation to their children's dietary intake and behaviour. The study highlights the complexity of treating children with ASD and that it is crucial to enhance the competence of dietitians regarding this important group of disorders.

## **5.2. Recommendations:**

Further training is necessary for dietitians who work with children in ASD to enable them to fully understand the complexity of the disorder, as well as to update knowledge about current dietary interventions and related research. Continued professional education opportunities run by dietitians who frequently work with children with ASD should be arranged. Dietitians should also access training opportunities through national organizations such as the NAS as well as local autism support groups.

The study should be repeated in other countries to establish the situation of children with ASD and in specific ethnicity groups.

Referrers (such as general practitioners, paediatricians and other healthcare professionals) should be aware of the potential for children with ASD to develop nutritional deficiencies. This is particularly true for children who have very limited diets and for those who are following exclusion diets. Parents/ caregivers with children with ASD should be made aware that they are eligible to be referred to a dietitian to assess the nutritional adequacy of their child's diet.

This study was based on qualitative data and therefore there is a need to repeat the study on a specific quantified population, and ideally do case-control studies to comparing children with ASD to children with typical development. It would be useful to directly observe the study population and have in-depth interviews with parents and caregivers to clarify some of the perceptions expressed in these findings.

Comprehensive guidelines for dietitians can be formulated, containing the following principles: summary of practical aspects that dietitians need to consider.

1. Assess weight, growth, dietary intake against recommendations for age and gender.
2. Gather information about early feeding history and feeding skills, progression with weaning and other textures. Identify any history of feeding problems.
3. Establish any feeding behaviour/ preferences that may influence food intake.
4. Assess for the presence of sensory problems and the effect it may have on dietary intake and food acceptance. Try to find trends in food preferences according to specific textures and sensory attributes. Consult with other health professionals if necessary.
5. Assess selectivity according to food groups and note which food groups and nutrients may be lacking as a result.
6. Give practical ideas for incorporating essential nutrients into the diet where lacking. The *Balance of good health in autism* by Cornish could be used as a reference where appropriate.
7. Assess for presence of gastrointestinal problems and ensure that medical advice has been sought if symptoms persist.
8. Assess for presence or potential to develop nutrient deficiency. If necessary refer to GP for a blood test.
9. If nutrient deficiency is identified or the diet lacking in specific micronutrients, advise on appropriate supplements and monitor the use of these.
10. Advise on the benefits of particular nutrients such as omega 3 fatty acids, probiotics and dietary fiber, especially in the presence of constipation. Identify dietary sources of these, and if not able to consume from the diet, recommend on appropriate dietary supplements.
11. If parents ask about the use of exclusion diets, explain the pros and cons in relation to current research. Support parents who would like to trial certain

exclusion diets, providing that dietary intake would be monitored and the child should be reviewed in the dietetic clinic.

### **5.3. Limitations of the study:**

This study was based on experiences and observations of parents/ caregivers with children with ASD. Therefore, responses were based on each parent's/ caregiver's experience with their specific child and are not meant to be generalized to all children with ASD. Some of the data was retrospective, parents/ caregivers relying on memory to answer questions related to early feeding history, depending on the child's current age.

This study may only be appropriate for a population within the UK.

The researcher did not ask participants to specify ethnicity. England has a multicultural population and therefore dietary intake and preferences may be influenced by ethnicity, cultural and religious beliefs.

Improvements noted with exclusion diets may have been due to a placebo effect as there was no specific measurement for this and the results relied on parents/ caregivers' perceptions.

The researcher did not ask parents on the use of any medications for behaviour, gut related problems, or sleep. Therefore any changes noted with exclusion diets and other interventions may be confounded by the use of medication.

Food preferences of the family and the presence of food selectivity within the household may have affected food choices of the child, and this was not directly addressed in this study.

The presence of anxiety and other mental health conditions that may affect appetite and food intake was not addressed.

Due to the study design, comparisons could not be made between cases and developmentally normal controls.

This study investigated a wide range of feeding aspects that may be encountered in children with ASD. It may be more beneficial to focus on specific aspects of feeding and to do more in depth study of sub-categories.

The presence of other functional disabilities such as dysphagia and other physical problems that may inhibit normal eating patterns were not specified, nor were other medical conditions that may affect muscle tone and therefore ability to eat (e.g. Down's Syndrome, Cerebral Palsy) or other associated developmental delays).

Unfortunately some of the respondents misread the question about location and instead of completing the county in which they live in England; many participants said 'England', and 'United Kingdom'. Therefore a clear distribution of the participation in specific counties of England could not be assessed.

Other questions relating to the use of exclusion diets may have been misinterpreted as a certain number of parents identified that they used exclusion diets, however, when asked on the effect of these they did not respond to these questions.

#### **5.4. Further areas of research:**

The prevalence of gastrointestinal problems in children with ASD needs further investigation with large case-control studies. It would also be interesting to investigate whether children with ASD have a higher incidence of food allergy/intolerance than in the general population. Assessment of nutritional status in children with ASD should be assessed using anthropometric parameters, biomarkers and clinical parameters. Further investigation of the training needs of dietitians who work with this client group would be beneficial. Investigations of exclusion diets are necessary, especially double blind case-control studies of a larger study population to evaluate the effects of special diets, dietary exclusions and dietary supplementation, are necessary.

## 6. ADDENDA

### 6.1. Informed consent form – Addendum 1

#### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: **Feeding problems and current dietary practices in children with autism spectrum disorder (ASD) in England.**

**REFERENCE NUMBER:** N10/05/153

**PRINCIPAL INVESTIGATOR:** Leanie Huxham

**ADDRESS:** 23 Jacklin Green, Woodford Green, Essex, United Kingdom, IG8 0TY

**CONTACT NUMBER:** 0044 (0)7976906566

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

**This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University (South Africa) and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.**

What is this research study all about?

*(Where will the study be conducted; are there other sites; total number of participants to be recruited at your site and altogether.)*



The study will be conducted at any location suitable to the participants where they can access the National Autistic Society's website to complete a questionnaire online or to request a questionnaire to be sent via email/ post.

Explain in participant friendly language what your project aims to do and why you are doing it?

There are currently relatively limited dietetic services available to patients with ASD and the study aims to establish what role a paediatric dietitian plays in ASD and how dietitians can improve on the current service provided. The study will be conducted by a dietitian with a special interest in paediatric nutrition. The researcher would like to gather information about eating habits, feeding history, feeding problems experienced, and exclusion and special diets used in children with autism spectrum disorder (ASD) in England. The study aims to highlight common problems associated with eating in this group and to gain insight to what parents/carers are experiencing at home. The information will provide more insight to dietitians and other healthcare professionals and should help parents/carers/ families living with ASD.

Explain all procedures.

Participants will access the study from the NAS website ([www.nas.org.uk](http://www.nas.org.uk)) and will then choose the option to 'Surveys and research, participate'. By clicking this link, the browser will open the next page, 'Surveys, your views are sought'. The title: 'Feeding problems and current dietary practices in children with ASD in England' will show. Participants can then click on the title of the study and will then be able to provide informed consent and start the online questionnaire. If participants do not wish to complete the questionnaire online, they can contact the researcher by email ([leaniebreitenbach@yahoo.co.uk](mailto:leaniebreitenbach@yahoo.co.uk)) to request the questionnaire to be sent as an MS-Word document via email or to request a paper copy in the post. The link to the study will be available on the NAS website for two months.

The questionnaire consists of 33 questions and is divided in 5 sections: Information about your child and diagnosis, Early feeding experiences, Food preferences, Dietary interventions and supplements, and Dietetic support.

The questionnaire is self-explanatory and each multiple choice question will have an instruction as to how many answers are required. Some questions have additional comment boxes in order to share views/experiences with the researcher.

Explain any randomization process that may occur.

No randomization will take place; all participants who would like to contribute to the study can take part. Participants must live in England and must have/care for a child with ASD between the ages of 3-16 years. The researcher will need at least 248 participants up to a maximum of 300. The link to the study will be removed from the NAS website when 300 completed questionnaires have been submitted.

Explain the use of any medication, if applicable.

Not applicable to the current study

Why have you been invited to participate?

You have been invited to participate in this study to share your views and experiences of your child's diet with ASD.

What will your responsibilities be?

Your responsibilities will be to fill out the informed consent form and to complete the questionnaire as honest and comprehensive as possible in order to contribute to the study.

Will you benefit from taking part in this research?

There are no personal benefits in taking part in this study. However, your participation will contribute to autism research and therefore to improve services for children with ASD.

Are there in risks involved in your taking part in this research?

There are no risks involved by taking part in the study.

If you do not agree to take part, what alternatives do you have?

Not applicable to the current study

Who will have access to your medical records?

No medical records will be used for this study.

Only the researcher will have access to the completed questionnaires, whether submitted by email, post or online.

All questionnaires will be treated confidentially and any personal information will be discarded. Each completed questionnaire will have a unique number allocated for data capturing and will therefore be completely anonymous.

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

There is no risk of any injury to occur as no pharmaceutical agents will be used for the purpose of this study.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part. If you request a paper copy of the questionnaire to be sent to you in the post, the researcher will carry the cost of envelopes and stamps.

Is there anything else that you should know or do?

You should inform your family practitioner or usual doctor that you are taking part in a research study. *(Include if applicable)*

Not applicable to the current study

You should also inform your medical insurance company that you are participating in a research study. *(Include if applicable)*

Not applicable to the current study

You can contact Leanie Breitenbach, at telephone number 07967906566 or email: [leaniebreitenbach@yahoo.co.uk](mailto:leaniebreitenbach@yahoo.co.uk), if you have any further queries or encounter any problems.

**You can contact the Health Research Ethics Committee (Stellenbosch University) at 0027(0)21-938 9207 (Cape Town, South Africa) if you have any concerns or complaints that have not been adequately addressed by your study doctor.**

**You will receive a copy of this information and consent form for your own records.**

Declaration by participant

By signing below, I ..... agree to take part in a research study entitled *(insert title of study)*.

**I declare that:**

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.

I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) .....  
2010.

Signature of participant      Signature of witness

Declaration by investigator

I (*name*) ..... declare that:

I explained the information in this document to .....

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... On (*date*) .....  
2010.

Signature of investigator      Signature of witness

**6.2 Questionnaire – Addendum 2**

**Participant number.....**

**Feeding problems and current dietary practices in children with autistic spectrum disorder (ASD) in England**

**Questionnaire for parents and carers**

**1. What is your child’s current age? .....years**

**(Please note; only proceed if your child is between the ages of 3-16 years)**

**2. Which county of England do you live in?**

.....

**(Please note, only proceed with the survey if you reside in England)**

<b>Section 1: Information about your child and diagnosis</b>
--

**1. Is your child:**

Male

Female

**2. What is your child’s diagnosis? (Please choose ONE)**

Classical Autism	
Autistic Spectrum Disorder (ASD)	
Pervasive Developmental Disorder not otherwise specified (PDDNOS) / atypical autism	
Asperger Syndrome (AS)	
Other	

**For the remainder of the questionnaire, the term Autistic Spectrum Disorder (ASD) will be used to include the following diagnoses: Autism, Asperger Syndrome, and Pervasive Developmental Disorder (PPDNOS)**

**3. At what age was your child diagnosed with Autistic Spectrum Disorder (ASD)?**

.....years

**4. When your child was diagnosed with ASD, where did you find the MOST supporting information about the condition:**

**(Please choose ONE)**

Healthcare Professionals (E.g. Paediatrician, Speech & Language Therapist, Dietitian or other)	
The National Autistic Society	
Autism Research Unit	
Other organisations (E.g. Autism File, ANDI, The Autism Trust etc)	
Books related to autism	
Internet	
Other parents	
Other- please specify	

## Section 2: Early feeding experiences

1. How long was your child exclusively breastfed (if at all)? (E.g. only breastmilk offered, no formula or solids given at the time)

- Not applicable
- Less than 1 month
- 1 to 2 months
- 2 to 3 months
- 3 to 4 months
- 4 to 6 months
- More than 6 months



**2. Were there any significant feeding problems when your child was taking breast or formula milk? Please indicate all options if more than one option is applicable.**

	Yes	No	Comment
Not taking full volume of feeds			
Not interested in feeds			
Not crying when hungry for a feed			
Distressed while feeding			
Unsettled after feed			
Other – please explain:			

**3. At what age did you first give your child solid food (e.g. baby rice, baby rusks, and puree from a spoon)? (I.e. when did weaning start?)**

- 0-1 months
- 1-2 months
- 2-3 months
- 3-4 months
- 4-5 months
- 5-6 months
- 6-7 months
- 7-8 months
- 8-9 months
- 9-10 months
- Older

4. Did your child struggle to take smooth pureed food when solids were introduced during the first stages of weaning? Please indicate the most applicable option for each phrase.

	Always	Sometimes	Seldom	Never
Not wanting to take food from the spoon				
Getting upset when food offered				
Not interested in the food offered				
Vomiting/ 'gagging' when food offered				
Other, please explain:				

5. Did your child have difficulty accepting stage 2 weaning foods (suitable for children 7-9 months) or stage 3 weaning foods (suitable for children 9 to 12 months)? Please indicate the most applicable option for each phrase.

	Always	Sometimes	Seldom	Never
Food with soft lumps				
Food with textured chunks and lumps				
Finger foods				
Other, please explain:				

**Section 3: Food Preferences:**

a. Is your child particular/ fussy about food colour and/ or food presentation? Please indicate the most applicable option for each phrase.

	Always fussy	Sometimes fussy	Seldom fussy	Never fussy
Food colour				
Food presentation (E.g. will only eat food from a specific brand or known packaging?)				
Other, please explain:				

b. **Is your child particular about food texture or temperature?** Please indicate the most applicable option for each phrase.

	Will eat readily	Will eat with encouragement	Sometimes refuses	Always refuses
Crunchy food (e.g. apple, corn flakes, toast etc)				
Smooth food (E.g. smooth puree, yogurt, custard etc)				
Dry food (E.g. cooked food without any sauce or dry crackers/ bread etc)				
Wet/ moist food (E.g. cooked food with sauce etc)				
Soft/ easy chew food				
Hot food or drinks (E.g. very warm cooked food, tea/coffee/ hot chocolate etc)				
Warm/ lukewarm food				
Cold food (E.g. yogurt, cheese, cold cooked food etc)				
Other, please explain:				

**c. Is your child particular about his/her mealtime environment?**

- No (If no, please continue to the next question)
- Yes – **Please choose all options that apply to your child**
  - My child will only eat meals at a certain place in the house
  - My child will only eat in a specific chair
  - My child will only eat when certain music is playing
  - My child will only eat when a certain person is present
  - Other, Please explain:

.....  
 .....

4. Does your child have any of the following sensory issues? Please indicate the most applicable option for each phrase.

	Always dislikes	Sometimes dislikes	Seldom dislikes	Never dislikes
Getting hands or face dirty				
Touch (E.g. around face, or general such as giving a hug)				
Licking food and objects				
Washing or brushing hair				
Smell (E.g. strong perfume, pets, smell of food etc)				

**d. Is your child particular about utensils/ cutlery or plates used when eating?**

No (If no, please continue to the next question)

Yes - **Please choose all options that apply to your child**

Only accepts food from a certain spoon

Only accepts food from a certain plate or

Only takes drinks from a specific cup/ glass

Other, please explain:

.....  
.....

**e. Does your child repeatedly demand the same type of foods for meals?**

No

Yes

▪ Please specify the types of foods preferred:

.....  
.....

f. The following question pertains to your child’s current food preferences and their habitual behaviour. Please indicate the most applicable option for each phrase

	Will always eat	Will eat with encouragement	Sometimes refuses	Always refuses
Fruit (Fresh, tinned, dried, and frozen fruit)				
Fruit juice/ fruit smoothies				
Vegetables* (including carrots, tomatoes, sweetcorn, green beans, peas, spinach, green/red peppers etc) – not including potatoes  <i>(*All forms of vegetables apply: fresh, tinned, frozen, raw/cooked etc.)</i>				
Starchy vegetables (potatoes, sweet potatoes, yams, cassava, chips etc)				
Unrefined starchy/ high fibre carbohydrate based foods and grains (wholemeal/ brown/ rye/ oat/ seed bread, oats porridge, high fibre cereal – bran flakes/ muesli/ shredded wheat, white/ wholemeal pasta, brown rice, rye/ wholemeal crackers,				
Refined Starchy/ carbohydrate based foods and grains (white bread, cake, biscuits, pastries, , ‘white’ cereals -such as rice crispies, corn flakes, sugar puffs etc)				
Eggs (Boiled, scrambled, fried, poached, omelette etc)				

Unprocessed meat (including chicken, beef, lamb, pork, minced beef/lamb, fish etc)				
Processed meat (including breaded chicken, chicken nuggets, beef burgers, fish cakes/ fish fingers, Frankfurters/ pork sausage, sandwich meat –ham/turkey etc)				
Meat alternatives (soya protein, beans, peas, lentils, tofu, quorn etc)				
Dairy products (milk, yogurt, cheese, calcium enriched soya milk/yogurt/cheese etc)				

**g. On average, how many glasses/cups of fluid does your child drink daily? (E.g. water, fruit juice, squash, fizzy drinks, tea, milk, etc) Please choose one option.**

- 1-2 glasses
- 2-3 glasses
- 3-4 glasses
- 4-5 glasses
- 5-6 glasses
- 6-7 glasses
- 7-8 glasses
- More than 8 glasses



**Section 4: Dietary interventions and supplements:**

1. **Are you currently excluding the following from your child's diet?** Please choose one option

Wheat only	
Gluten (wheat, rye barley and oat products)	
Casein (cow's milk protein = milk free diet)	
Both gluten and casein (gluten and milk free diet)	
I have not excluded gluten and/or casein from my child's diet	

2. **If you have used, or are currently using a gluten and/or casein/milk free diet for your child, how long have you used this diet?** Please choose one option

Less than a month	
1-3 months	
4-6 months	
7-12 months	
More than 1 year	
Not applicable	

3. **Have you noticed any significant improvement in your child when following a gluten and/or milk free diet?** Please indicate the most applicable option for each phrase.

	Yes: significant	Yes: slight improvement	No: little improvement	Worsened
Bowel habits				
General health				
Sleep				
Undesired behaviour				
Concentration				
Social communication (E.g. speech, eye contact, smiling etc)				
Other (please explain):				

4. **Have you tried any other types of exclusion diets in the past or currently?** Please choose all options that apply to your child

	Yes	No
Specific carbohydrate diet		
Yeast free diet		
Other	– please explain:	
.....		
.....		
.....		

5 **Have you noticed any significant improvements in your child on the other types of exclusion diet/s?** Please indicate the most applicable option for each phrase.

	Yes significant	Yes (slight improvement)	No little improvement	Worsened
Bowel habits				
General health				
Sleep				
Undesired behaviour				
Concentration				
Social communication (E.g. speech, eye contact, smiling etc)				

**6. Is your child currently taking any nutritional supplements?** Please choose all options that apply to your child

	Yes	No
Fatty acid supplement (omega 3 or 6 fatty acid/ fish oil supplements)		
Vitamin supplement/s (E.g. Vitamins A, B, C,, D, E etc)		
Mineral supplement/s (E.g. iron, calcium etc)		
Complete multivitamin and mineral supplement		
Fibre supplement		
Probiotic supplement/s		
Digestive enzymes		
Other – please specify		

**7. Who primarily recommended the use of exclusion diets and/or nutritional supplements for your child? (Please choose ONE):**

Not applicable	
Dietitian	
Nutritionist/ nutritional therapist	
General practitioner (GP)	
Paediatrician	
Psychologist	
Speech & Language therapist	
Family or friends	

Other: please specify	
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**Section 5: Dietetic support**

**1. Has your child been referred to see a dietitian or is currently seeing a dietitian?**

No

Yes

**2. What was the MAIN purpose of being referred to the dietitian? Please choose ONE option:**

Not applicable	
General dietary assessment	
Concerns regarding the balance of the diet/ not eating a varied diet	
Constipation or other gut related problems	
Advice on an exclusion diets for autistic spectrum disorder (ASD)	
Dietary supplementation (E.g. vitamin/ mineral supplementation)	
Iron deficiency anaemia	
Underweight	
Overweight	
Difficult behaviour during mealtimes	
Refusing / difficulty accepting new foods	
Other	

**3. Did a dietitian support your decision to trial or continue exclusion diets and/ or supplements?**

- Not applicable (Please continue to Question 5)
- No (Please continue to Question 4)
- Yes (Please continue to Question 4)

Please explain :

.....

.....

.....

**4. If applicable, please describe your experience with seeing a dietitian to provide dietary advice for your child with ASD.** Please indicate the most applicable option for each phrase.

	Fully agree	Agree	Disagree	Strongly disagree
It was helpful to see a dietitian for my child with autistic spectrum disorder (ASD)				
The dietitian had a good knowledge of ASD and associated eating patterns/behaviour				
The dietitian had a good understanding of current dietary interventions available for children with ASD				
The clinic setting in which my child was seen was appropriate for his/her condition				
Reduced my concern/ stress about my child's diet				
The dietitian gave practical advice on improving my child's diet				
The dietitian gave useful advice on managing my child's behaviour around				

food and mealtimes				
Since my child has seen a dietitian, the situation (for which he/she was referred for) has improved.				
Comment:				



**5. In general, how can dietitians (NHS and private) improve their service for children and families with ASD?**

Please choose all options that apply:

Not applicable	
Longer/ Extended clinic appointments	
To be seen by a dietitian more frequently	
Better clinic environment/ consultation rooms	
Provide more written information such as diet sheets and other resources (E.g. star charts/ social stories etc)	
Provide more practical guidelines and tips	
Better knowledge of ASD and dietary related problems	
Better understanding of current dietary interventions and research for children with ASD	
Other – please comment:	

**6. If your child has not seen a dietitian, do you feel that he/ she would benefit from seeing a dietitian for nutritional advice?** Please choose the option that apply to your child

- Fully agree
- Agree
- Disagree
- Strongly disagree

**Thank you for taking the time to complete this questionnaire. We sincerely value your willingness to share your experience with us.**

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